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CAREGIVER GOALS FOR CHILDREN WITH AND WITHOUT ASTHMA

A QUALITATIVE ANALYSIS OF CAREGIVER GOALS FOR URBAN CHILDREN WITH  
AND WITHOUT ASTHMA

A dissertation submitted in partial fulfillment of the requirements for the degree of  
Doctor of Philosophy at Virginia Commonwealth University

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### Acknowledgment

I have so many people to whom I am most indebted for helping me reach this milestone. First, I would not be writing this section if it weren't for the help of many mentors and friends at the University of Iowa. Specifically, I would like to thank Dr. Katy Bruchmann for hiring me as a research assistant when I was a first-semester sophomore who just thought research was cool. I would also like to thank the members of Grazyna's Child Lab for teaching me invaluable skills and introducing me to the world of Indian food buffets. I would not have made it through graduate school without either of these things. I'm so very grateful for Dr. Terri Sullivan's mentorship and guidance over the years; thank you. Dr. Marcia Winter supported me from the outset and has helped me realize my passion for pediatric psychology along the way; I am forever grateful. To my committee members-- Dr. Heather Jones, Dr. Rose Corona, and Dr. Maria Thomson: thank you for your wisdom and support; I am so very fortunate to be surrounded by such knowledgeable, passionate, and successful women and to have benefitted so much from your collective strength. Similarly, I would like to extend a special note of thanks to my graduate school cohort. The 2014 cohort have changed my life in so many ways, and I could not even begin to describe how much I have grown with them over the last six years. Nour, Allie, Liza, Jessie, Sydney, Sarah, Sage, Zoe, Erin, Annie-- cohos forever.

To my parents and siblings-- thank you for your patience. Thanks for the late night phone calls and understanding when work got in the way of holidays and vacations. I love you all.

And to my husband, Billy--words are not enough. You've been there since the beginning, and you've stayed by my side through it all-- applications, rejections, reports, and crazy schedules. The last eight years have not always been easy, but we finally made it. I love you with all of my heart.

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**Abstract****A QUALITATIVE ANALYSIS OF CAREGIVER GOALS FOR CHILDREN WITH AND WITHOUT ASTHMA**

By Megan Carlson, M.S.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

Virginia Commonwealth University, 2020

Major Co-Directors: Terri Sullivan, Ph.D., Professor, Department of Psychology & Marcia Winter, Ph.D., Assistant Professor, Department of Psychology

Pediatric asthma is a major public health concern that disproportionately affects children of color and youth living in low-income, urban areas. The implications for public health, child health, and family functioning necessitates our understanding and addressing experiences by families who are facing barriers within their socio-demographic context *in addition* to the stressors associated with managing pediatric asthma. The current study applied qualitative methods to interviews with caregivers of children with and without asthma in an effort to more deeply connect with caregivers' experiences and yield richer information about the intersection of identities as Black caregivers living in an urban setting while managing a pediatric chronic illness. Eighty-five caregivers who self-identified as Black or African American participated in semi-structured interviews to explore their parenting beliefs and practices, as well as their goals for their children and perceived barriers and supports to these goals. Two questions were selected for analysis from the broader Everyday Parenting Interview (EPI). Interviews were transcribed and coded for emergent themes. A total of eight themes emerged for the first question and related questions/prompts (i.e., What are your goals for your child?), while a total of five themes emerged for the second question and associated questions/prompts (i.e., What do you think

children in general need in order to reach those kinds of goals?). Emergent themes spanned several domains, yet health generally and asthma specifically, were rarely mentioned as goals for children. Instead, caregivers highlighted several goals related to achievement, individual responsibility, and social connection. Heavily discussed were caregiver concerns about neighborhood safety and perceived barriers to future success. Findings inform clinical recommendations for systematic screening efforts and intervention to address environmental stressors and competing priorities for Black caregivers of children with asthma.



## Introduction

Pediatric asthma is a major public health concern that disproportionately affects racial/ethnic minority children and children living in low-income, urban areas. Recent estimates showed that approximately 7 million, or one in every 11, children across the U.S. have asthma (Center for Disease Control and Prevention, 2014). While pediatric asthma affects millions of children across racial/ethnic backgrounds and socio-economic statuses, Black children are two times more likely to have asthma than white children (CDC, 2012). A great deal of work has highlighted racial/ethnic disparity in asthma treatment and outcomes, with researchers noting that racial and ethnic minority children living in urban settings experience some of the highest rates of asthma morbidity (Akinbami & Schoendorf, 2002). Reasons postulated for these differences include environmental factors (e.g., positive reaction to cockroaches, exposure to second-hand smoke), lack of access to care, and differences in adherence to treatment (Kattan et al., 1997; Mitchell et al., 1997). The disparity in mortality rates between Black and white children has also increased in recent years, with Black children experiencing four times as many hospitalizations and five times as many deaths, as compared to white children (CDC, 2006). Despite significant emphasis on the use of inhaled corticosteroids as an effective means to mitigate asthma morbidity, well-defined national guidelines for asthma management, and a large number of interventions targeting asthma outcomes in urban settings, disparities in outcomes continue to impact Black and Latinx youth (Wu, Smith, Bokhour, Hohman, & Lieu, 2008). Apart from the emotional toll it takes on children and families (Fiese, Winter, Anbar, Howell, & Poltrock, 2008), poorly-controlled asthma in children of all ages contributes to increased healthcare costs, more missed days of school, and overall poorer quality of life (QOL) for patients and their families (Asthma and Allergy Foundation of America, 2018).

Because of the myriad implications for public health, child health, and family functioning it is important to further our understanding of the reality of life for this population of children and families of children with asthma. To do so meaningfully involves working to understand and address experiences of families who are facing barriers within their socio-demographic context *in addition* to the stressors associated with managing pediatric asthma. Thus, applying a qualitative approach to research with families – both children with asthma and not – offers an opportunity to more deeply connect with caregivers' experiences and will yield richer information about the intersection of their identities as caregivers and as caregivers managing a pediatric chronic illness. In addition, the current study serves to highlight family strengths and protective factors to extend the research to date that has focused on elucidating caregiver and family risk factors, as well as maladaptive outcomes.

There are several studies examining and emphasizing caregiver and family risk factors, as well as maladaptive contributors to asthma outcomes (Wamboldt & Wamboldt, 2000; Wood et al., 2007). This population is burdened with significant stressors related to the disease and its management (Fiese et al., 2008; McQuaid, Walders, Kopel, Fritz, & Klinnert, 2005; O'Connell, 2004). Specifically, family members work to ensure medication adherence, attend doctors' appointments, refill prescriptions, monitor the child's asthma symptoms, navigate school attendance and absences, as well as maintaining a balance between family obligations and responsibilities related to the child's illness. Because of the increased burden of managing a chronic illness, and the subsequent stress it places on families, caregivers, and developing children, it is also important to understand key protective factors and strengths that may be bolstered to improve outcomes. Examining family strengths and caregiver goals for their children with and without asthma may provide researchers and medical providers insight into

some of these factors. Thus, the current study focuses on caregivers' goals for their children, as well as their perceptions of barriers and supports to their children accomplishing those goals, considering both inter- and intra-personal factors (e.g., personality characteristics, relationships) and system-level factors (e.g., neighborhood safety, education). By analyzing interviews using a strengths-based approach, rather than simply highlighting family, parent, or child-level risk factors, we can elucidate important differences and commonalities in caregiver socialization and developmental goals for their children in low-resourced, underserved communities, regardless of health status.

Given the unique burden pediatric asthma places on families and caregivers, however, it is likely that caregivers of children with asthma have different goals for their chronically-ill children, as well as potentially different perceived barriers or supports to their children reaching those goals. Understanding the role of both shared and different experiences of caregivers with asthma in low-resourced, underserved communities across diagnosis is important in understanding how researchers and medical providers might better navigate intervention development and provider-patient relationships. Thus, the overarching aim of this project is to elucidate caregiver goals and associated barriers and supports to those goals within the context of urban families who may or may not have a child with a chronic illness (i.e., asthma).

Acknowledging the increased risk for poorer asthma outcomes among urban, racial/ethnic minority children, the current study included a predominately low-income, sample of Black families from the urban Richmond, Virginia area, approximately half of which have a child with asthma. With the Asthma and Allergy Foundation of America (AAFA) recently ranking Richmond the second-most challenging city to live with asthma in the United States, this setting is ideal for understanding the ways in which pediatric asthma affects the larger

community (AAFA Asthma Capitals Report, 2018). This study uses qualitative methods based in grounded theory (Glaser & Strauss, 1967) to elucidate caregiver goals for their children--with and without asthma-- as well as perceived barriers and supports to their children attaining those goals in a low-resourced, urban setting. The analysis was conducted using a portion of semi-structured interviews in which parents and caregivers provided in-depth descriptions of their experiences raising children with and without asthma.

### **Review of the Literature**

This literature review begins with a general discussion of ecological systems theory, as well as family systems theory, followed by an overview of the literature on parenting children in urban, underserved settings. Theoretical and empirical background research regarding parenting practices and beliefs in families with and without asthma is provided, and the concept of parental goals is then introduced along with relevant theory. Particular emphasis is placed on theory and research pertaining to Black families, with the review highlighting an intersectional relation among Black, urban families living with or without pediatric chronic illness. Information about qualitative data analysis and techniques is also presented.

**Socio-ecological model of development.** Bronfenbrenner (1979; 1994) theorized that development must be understood within and across expanding ecological contexts, with developmental-contextual theories suggesting that childhood experiences and relationships are shaped by transactions between the individual and his or her environment. For example, peers and parents are a part of an individual's microsystem, or the component of one's ecology that has immediate and ongoing influences on developmental processes. Caregivers and families are crucial influences on children's development and provide models for relationships, as well as expectations for behavior in and out of the home.

With regards to development in the context of pediatric chronic illness, conceptualizations have begun to explore reciprocal influences between psychological factors and asthma morbidity (Wade et al., 1997). A bidirectional relationship between psychological functioning in caregivers and children's physical disorders (i.e., asthma) likely exist with family psychological factors contributing to poorly-managed pediatric asthma. There is also a large evidence base to suggest that having a child with asthma is challenging for families and thereby increases psychological stress and negatively influences psychological functioning (Kazak, 1989).

Despite the growing number of studies examining aspects of psychosocial functioning related to asthma, the literature is mixed when considering the psychological effect of having asthma on children, with some research indicating that children with asthma are at greater risk for problems in psychological functioning, especially for internalizing disorders, than children without asthma (Mcquaid et al., 2001; Gillaspay et al., 2002). Other research indicates that children who have mild to moderate asthma do not tend to experience increased psychological difficulties (Bender, Annett, et al., 2000). However, researchers concur that children with asthma combined with poor psychological functioning do, in fact, have worse health outcomes (Creer & Bender, 1995), and that psychopathology, family dysfunction, and medication noncompliance have been found to be associated with increased risk of severe, poorly controlled asthma (Bender & Klinnert, 1998). In order to understand how psychological and family variables affect asthma outcomes, and thus be able to intervene with affected families, researchers must consider relations among multiple aspects of family functioning and parent-child relationships. Incorporating a socio-ecological model to better understand interactions of the child, family, and environment in the context of childhood illness better reflects the ways in which family and

system functioning are linked to children's adaptation to illness and its treatment (Kazak, Segal-Andrews, & Johnson, 1995).

*Social Disorganization Theory.* Both for children with and without chronic illness, when thinking about various levels of influence on children's socioemotional development, it is important to consider the environment in which more proximal systems (e.g., the family) are situated. Social Disorganization Theory considers the role of neighborhood environment on socioemotional development. It suggests that neighborhood structural characteristics of economic disadvantage can reduce the ability of residents to establish social cohesion and maintain informal social control (i.e., neighborhood social processes), resulting in maladaptive outcomes such as high rates of criminal activity and delinquency (Sampson, Morenoff, & Gannon-Rowley, 2002; Sampson, Raudenbush, & Earls, 1997). For families living in less-resourced, urban settings, it is particularly important to understand the ways in which these types of systemic contributions may affect children's development. While families within this "risk" group are heterogeneous and have multiple protective factors that buffer the negative effects of poverty, there are shared risks associated with poverty that are well-documented in the literature.

There has been a shift in the levels of "chaos" present in American families' lives over the last several decades (Bronfenbrenner, McClelland, Wethington, Moen, & Ceci, 1996; Evans, Gonnella, Marcynyszyn, Gentile, & Salpekar, 2005). Parents in general have less time that they can spend with their children, with more hours being spent away from home, working, commuting, and delivering children to and from child care, school, and other activities; families are also increasingly less likely to share meals and other rituals together as shared time becomes compressed (Evans et al., 2005). Additionally, greater numbers of children live in crowded, noisy, and substandard urban housing, with families describing home life as hectic (Evans,

2004). Although this pattern is seen across demographic groups, this level of dysregulation is not evenly distributed in the population. Low-income families are more likely to face chaotic living conditions than are their middle- and upper-income counterparts (Evans et al., 2005).

Sporadic levels of activity, lack of structure, and unpredictability - combined with high levels of environmental stimulation and noise - can negatively impact developing children by creating barriers to the kinds of well-structured, predictable, and sustained exchanges with people, objects, and symbols in the immediate environment that are critical to fostering and sustaining healthy development (Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 1998). Thus, poor children who reside in more crowded, noisier, and poorer-quality housing (Evans, 2004; Saegert & Evans, 2003) and live with less structure, routine, and predictability in their daily home life (Brody & Flor, 1997; Jensen, James, Boyce, & Hartnett, 1983; Matheny, Wachs, Ludwig, & Phillips, 1995) - are at greater risk than their more affluent counterparts for negative socioemotional outcomes. There is also research to suggest that these stressors are associated with children's psychological distress (Evans, 2001; Evans, Wells, & Moch, 2003), as well as lower parental competency ratings, satisfaction with family, and school achievement (Fiese et al., 2002; Repetti, Taylor, & Seeman, 2002). The context in which low SES families live has a strong influence on parental, child, and family functioning. Understanding how various families function and thrive within these settings is essential to understanding caregivers' goals for children living in poor, urban environments.

The same holds true for families managing pediatric chronic health issues. Although numerous contributing factors to child health outcomes have been identified, the family home environment is a central context of influence that requires deeper understanding.

Bronfenbrenner's ecological model of development (1986) states that children are most affected

(for better or for worse) by their primary environment—the family—and that the family is simultaneously affected by surrounding contexts. Specifically, the family represents a microsystem-level influence on children, and it interacts via the mesosystem with other microsystem influences (e.g., school, neighborhood, community), as well as broader surrounding influences from the exosystem (e.g., social services, health care system) and macrosystem (e.g., culture). According to this model, individual child characteristics—including child health outcomes—cannot be effectively explained without considering the interactive contexts within which they are embedded (Bronfenbrenner & Morris, 1988).

Using an adaptation of ecological systems theory, Davison and Birch's Family Ecological Model (FEM; 2001) highlights complex contextual influences on families' abilities to engage in healthy lifestyles (Davison & Birch, 2001). Following this model, a qualitative study identified several characteristics of disorganized home environments, including variation in daily schedules and residential instability, that were not adequately captured in the original model but presented challenges to maintaining healthy habits (Davison et al., 2012). Similarly, Bates and colleagues (2018), postulated that high levels of “family entropy” --a novel term that borrows from thermodynamics to capture the organization/disorganization across the family home environment-- occurs in homes that are disorganized and unstructured and are associated with greater likelihood of pediatric overweight/obesity.

The level of organization or disorganization in the home environment has already demonstrated relevance to a variety of child health outcomes. Children residing in organized households that engage in regular family routines—including family mealtimes, bedtimes, and chores—demonstrate positive health outcomes, including better sleep and shorter duration of illness (Fiese et al., 2002). By contrast, disorganized households (i.e. characterized by chaos and



instability) have been shown to negatively impact child health via contributions to developmental delays, internalizing and externalizing disorders, and poor physical health (Coley, Lynch, & Kull, 2015; Weisner, 2010). Organization and disorganization are conceptualized to be moderately and complexly related constructs, such that it is possible for families to demonstrate organized behaviors even in the presence of a disorganized environment (Miller et al., 2015). This responsibility, of course, falls on caregivers to manage and adapt parenting practices in pursuit of maintaining organization in the family.

*Family Systems Theory.* A vast majority of early theoretical models aim to demonstrate that parenting practices and outcomes--positive or negative-- are causally linked (e.g., Reid & Patterson, 1989; Snyder & Patterson, 1987), such that parental effects have been seen as the primary influence on child and adolescent outcomes. Even theories more focused on parent-child interactions (e.g., attachment; Bowlby 1969) were still often operationalized in ways that emphasize how caregivers' behaviors directly influence child outcomes. Since then, however, there has been a shift towards examining the parent-child relationship from an interactional and transactional perspective, with Family Systems Theory (Bowen, 1974) adding the importance of intra-familial transactions. Family Systems Theory serves to explain reciprocal interactions (e.g., parent-child, child-parent) while describing the interactive nature of each family member's influence on the others (Gavazzi, 2011; Minuchin, 1985). Thus, within this framework, it becomes clearer that children influence their caregivers' behaviors just as much as caregivers' parenting practices or other behaviors influence children's actions.

Further, environmental stressors and individual development influence family dynamics, highlighting the importance of understanding the role of the broader environment when examining parental beliefs, goals, and interactions with children (Feldman, 2008). Bowen (1974)

described the family system as having a circular relationship-- rather than linear-- with the reciprocal effects of parent-child interactions marking important influences on child outcomes (Hughes & Gullone, 2010). This theoretical perspective is particularly useful in examining pediatric illness, as pediatric health conditions by their very nature require individual, relational, and group processes (i.e., family processes) that promote the preservation of family functioning, management of treatment demands, and adjustment to diagnoses (Winter, Al Ghriwati, & Devine, 2019). These demands likely become even more difficult to manage in the context of families who face financial hardship and lack of access to resources in their neighborhoods.

**Parenting with chronic illness.** Generally speaking, stress has been linked to asthma outcomes; higher levels of stress are associated with greater asthma morbidity (e.g., more symptoms, quick-relief medication use, ED visits; Asthma and Allergy Foundation of America, 2018). In particular, socioeconomic and neighborhood stressors such as low socioeconomic status (SES) and exposure to community violence have been associated with greater asthma morbidity (e.g., hospitalizations, symptoms, severe episodes; Chen & Schreier, 2008). Factors that may be more amenable to intervention, such as family stressors (e.g., poor family functioning, poor relationship quality, caregiver stress, and caregiver mental health) have also been associated with increased asthma morbidity (Chen & Schreier, 2008).

Children with asthma from urban families living in poverty are more likely to experience higher levels of toxic stress, which can further compound a child's risk for poor asthma outcomes (Miadich, Everhart, Borschuk, Winter, & Fiese, 2015). Toxic stress is described as a continual activation of the stress response (multiple stressors) without a sufficient buffer against stress (e.g., caregiver support) in children (Johnson et al., 2013). Families living in low-income,

urban areas are subject to higher levels of poverty, family violence, community violence, and single parent homes that may contribute to a toxic stress environment for children (American Academy of Pediatrics; Johnson et al., 2013). An accumulation of stressors across multiple domains more robustly predict asthma outcomes (asthma control and quality of life) than any one individual stressor (Miadich, Everhart, Greenlee, & Winter, 2020). These chronic stressors may make it difficult for caregivers to dedicate time and support for their child's asthma and its daily management (Bellin et al., 2014). Given that pediatric asthma is managed within families, it is important to understand caregivers' perceptions of barriers and supports in daily life that their family and child with asthma encounter. Traditional parenting literature may aid in conceptualizing different approaches to communication, discipline, and monitoring used amongst families with and without pediatric chronic illness.

*Parenting styles.* A great deal of research has examined parent-child relationships within the framework of Diana Baumrind's Parenting Styles theory (1972), which outlined authoritative, authoritarian, permissive, and--later-- neglectful parenting styles. This theory posited that children who are raised by authoritative parents (i.e., representing a combination of high levels of both parental responsiveness and demandingness) tend to have adaptive outcomes, including being more socially skilled and independent, as well as doing better in school and having more positive social relationships (Baumrind, 1991a, 1991b; Fugligni & Eccles, 1993; Lamborn et al., 1991). In contrast, the other types of parenting styles have traditionally been associated with fewer positive and more negative outcomes, depending on the specific style. For example, Steinberg (2008) noted that African American, Latinx, and Asian American parents tend to be more often classified as using authoritarian versus authoritative parenting. However, unlike in white samples, among these racial/ethnic groups some studies show that authoritarian

parenting is not associated with negative outcomes (Garcia Coll, Meyer, & Brillon, 1995). For example, Baumrind (1991) found that while authoritarian parenting was associated with more fearful behavior among European American children, this type of parenting was linked with more assertive behaviors and independence in African American children. Other studies have found that authoritative parenting is not associated as strongly with academic achievement in Asian American and African American children as compared to European American children (e.g., Steinberg, Mounts, Lamborn, & Dornbusch, 1991). Thus, the differences among racial/ethnic groups in terms of the effectiveness of specific parenting styles suggest that race/ethnicity is an important consideration when examining parent-child relationships and specific parenting behaviors. It is also important to note that a traditional parenting style may more accurately capture the nuances of parenting among racial/ethnic minority families.

Additionally, research supporting parenting styles theories was primarily derived from white, middle class samples, and may not be applicable to the same degree for racial/ethnic minority families (Darling & Steinberg, 1993). Because these families frequently face racism, prejudice, and discrimination, Holden (2010) suggested that racial/ethnic minority families may maintain traditional cultural beliefs, fostering different parenting styles and behaviors. For example, it may be that families from minority racial and ethnic groups fit the “traditional” parenting style that Baumrind (1987) proposed; such families place strong value on parental authority, respect, loyalty, and obedience, and acceptance of parental rules and decisions (Julian, McKenry & McKelvey, 1994; Mulvaney & Morrissey, 2011; Reis, 1993). Traditional parenting style reflects a combination of high responsiveness and high demandingness; however, the aspects of demandingness represented are not synonymous to those found within the authoritative parenting style, as described by Baumrind and colleagues.

*Parenting in African American families.* Researchers have examined the “traditional” parenting style within African American families, with results indicating that this is a relevant parenting style within Black families (Lamborn, Mounts, Steinberg, & Dornbush, 1991; McWayne, Owsianik, Green, & Fantuzzo, 2008; Randolph, 1995). Parents and caregivers may use more direct forms of discipline and control, be stricter, and emphasize obedience, compared to non-Black caregivers (Brody & Flor, 1997; Garcia Coll et al., 1995). Additionally, Nobles (2007) noted that African American families generally place a strong value on family, community, belongingness, and respect. Cauce, Hiraga, Graves, and Gonzales (1996) theorized that African American parents use traditional parenting behaviors with hopes that their children will grow up self-reliant and independent, while still maintaining their loyalty and respect to their family and their culture. Thus, African American caregivers employ traditional parenting behaviors in service of their larger goals for their children. In some studies, African American mothers reported that fostering high expectations for obedience and respect would increase school achievement and promote positive child and adolescent outcomes (Lamborn et al., 1991; McWayne et al., 2008; Randolph, 1995).

In thinking about Black or African American caregivers and children, Lerner’s (2004) developmental systems perspective highlights that context has an important influence on children’s development. Apart from larger environmental contexts, such as a neighborhood, school, or general community, the family context can also greatly impact child and parent behaviors. Specifically, the relationship dynamics and interactions within the family and the way in which family members reciprocally influence each other affects development. These dynamic interactions make up the developmental systems perspective (Lerner, 2004), and point to the need to consider the importance of examining the contextual influences.

Another theory that addresses the ways in which individuals and contexts interact to influence outcomes is the phenomenological variant of ecological systems theory (PVEST) (Spencer & Tinsley, 2008). PVEST is a variation of Bronfenbrenner's socio-ecological model (Bronfenbrenner, 1979) that addresses individual-context interactions that are both unique for an individual and those that reflect the role of maturation. This model differs from others in that it considers the unique and cumulative individual-context interactions a person may have. Within this model, social inequalities (e.g., economic disadvantage) have an impact on contextual experiences and can function as both potential risk processes, as well as sources of daily stressors (i.e., managing stereotypes around skin color, racial categorization, economic status) (Spencer & Tinsley, 2008). Thus, while youth may share a particular context (e.g., under-resourced neighborhood), they have unique individual-context interactions (e.g., at family and neighborhood-levels) that can be associated with different developmental trajectories (Spencer & Tinsley, 2008). For example, individual-context interactions can lead to adaptive and maladaptive coping, and pathways to negative as well as positive outcomes (Spencer & Tinsley, 2008). This likely applies to the development of underlying socialization goals and decisions around parenting behaviors, as well.

Within the current sample, for example, it is important to consider that living in a neighborhood context with higher levels of crime and violence may influence caregiver actions and parenting decisions. African American families are disproportionately represented in low-income neighborhoods, and it has been suggested that parents living in these contexts may be seen as more strict, largely stemming from their own appraisal of a neighborhood's relative safety and the desire to protect their children (Lindstrom Johnson, Finigan, Bradshaw, Haynie, & Cheng, 2011). Parents of color face the same developmental tasks that all parents face; however,

they are also presented with additional tasks to ensure that their children are safe and will grow and thrive, secure both within their own group and in relation to other groups (McAdoo, 2002). Specifically, African American families may face the challenges of discrimination and racism (Holden, 2010; McAdoo, 2002), and teach their children how to deal with these experiences (Coll & Pachter, 2002).

There is not, of course, a monolithic African American experience (Boykin and Toms, 1985). Coll and Pachter (2002), expand on the work by García Coll and colleagues (1996) that states African American families and children can be fully understood only in relation to the interaction of their race, social class, culture, and ethnicity. They use an integrative model of ethnic minority child development to put forth the idea that racial socialization—via parental emotion socialization—is a key mechanism by which ethnic minority families aim to protect their children from discrimination and other damaging experiences. Thus, one goal for caregivers of children of color is racial and emotion socialization. According to McAdoo (2002), central issues that face some African American parents are: (1) lack of financial resources, (2) roles of education, (3) high rates of single parents, (4) grandparents as primary caregivers, and (5) racial socialization of children. Per McAdoo, these concerns are in addition to the tasks that all parents must perform but require special effort and parenting approaches that most other caregivers may not need to consider (McAdoo, 2002). Thus, the current study is focused on the goals and perceived barriers and supports for Black caregivers, specifically. There is significant literature to show that Black families have unique experiences—historical and modern—that affect their cognitions, beliefs, and goals around parenting and children’s development (Wilkinson, 1997). **Caregiver goals.** Parental beliefs, values, and socialization goals for their children are critical influences on children’s development (e.g., Baumrind 1968; Goodnow 1988; Miller 1988).

Specific socialization goals span a range of specific skills and behaviors (e.g., good manners and academic ability) to more general qualities (e.g., independence, spirituality, critical thinking) (Darling and Steinberg, 1993). Generally speaking, parental goals serve to organize and guide caregivers' cognition and behavior when interacting with their children (Dix, 2002; Hastings & Grusec, 1998; Kuczynski, 1984).

There is some research detailing specific parenting goals, such as (1) safety and health of a child, (2) working to promote a child's self-management, and (3) enhancing the development of a child's values—particularly within the domains of cultural, religious, family, or intellectual/scholastic achievement (Dix & Branca, 2003). More general parenting goals discussed by Dix and Branca (2003) included being loyal to one's family, engaging in and adhering to family routines, respecting cultural traditions, as well as being social, achieving at school, and being happy. There is literature to suggest that these are common goals endorsed by parents across cultures (Dix, 2002; Dix & Branca, 2003). These goals have been shown to directly influence caregivers' behavior and affect parent-child communication, parenting strategies, as well as child behavior (McPherson, 2009). This is largely because parental goals serve to organize caregivers' thoughts and actions, with caregivers implementing different strategies to promote long- or short-term goals for their children. Previous work has highlighted the idea that caregivers use different strategies with their children to promote long-term goals (e.g., health and safety) versus short-term goals; that is, for long-term goals, caregivers tend to be more conscious and deliberate in their socialization strategies (Dawber & Kuczynski, 1999; Kuczynski, 1984).

Most models of parenting suggest that parental values and goals are transmitted to children both explicitly, via parental practices and styles, and implicitly, via tone of voice and



body language (e.g., Darling and Steinberg 1993; Murphey 1992; Simons et al. 1992). Reese and colleagues (2016), reporting on educational and socioeconomic differences in parental goals and aspirations, noted that the transmission of parental values and goals and their internalization by children may be conceptualized as a self-fulfilling prophecy, in which the holder of a set of aspirations interacts with the child in ways that cause those aspirations to become realized (Good and Nichols 2001). Tazouti et al. (2010) showed that parents' educational beliefs were both directly and indirectly related to their children's subsequent educational achievement. That is, parents with higher levels of education tend to have higher expectations for their children's educational achievement, are more involved in their children's education, and their children achieve at higher levels (e.g., Davis-Kean 2005). Studies including parents living in lower-income households note high expectations of their children's educational achievements, and were linked to adolescents having higher aspirations themselves (Kirk et al. 2011).

Thus, while caregiver goals are important aspects of parenting and research suggests that some goals are more universally endorsed, it is likely that SES contributes to caregivers' socialization and development goals for their children. Due to parenting responsibilities required for African American parents (e.g., McAdoo, 2002), it follows that racial/ethnic identity may also influence caregivers' goals.

*Socialization goals in African American families.* A burgeoning area of research has begun to shed light on socialization goals and strategies among African American caregivers. For example, Dunbar and colleagues (2015) examined caregivers' racial and emotion socialization practices via young Black adults' emotional adaptation. They found that variation in caregivers' levels of cultural socialization, bias preparation, and support varied as a function of family income and child's gender. Caregivers in families with higher incomes engaged in high rates of

cultural socialization as well as providing support in response to children's negative emotions. The authors noted that previous research (e.g., Boykin & Toms, 1985) highlighted the idea that African American families value and foster the open expression of emotions—positive and negative. However, Kang and Chasteen (2009) stated that negative emotional expression by African American children is more likely to be seen by society as threatening or as aggressive, compared to similar expressions by white youth. Thus, African American caregivers must balance both their value of emotional expressivity and society's racial biases when setting and enacting socialization goals in their ethnic minority children.

In a review of mothers' goals for children in African American, Dominican, and Mexican families by Ng and colleagues (2012), the authors note that while African American families may have a longer history of residence in the United States than Latinx immigrants, their history is one characterized by slavery and segregation. The socialization goals of African American parents are likely to reflect values that originated from their traditional community, those of the mainstream American culture, as well as those that have arisen from the unique challenges they faced as an oppressed group (García Coll, Meyer, & Brillon, 1995; McAdoo, 2002). Studies have found that, traditionally, there is significant importance placed on being obedient and respectful of elders in the family and the community (García Coll et al., 1995). In a study by Suizzo (2007), parents of African American and Mexican backgrounds did not differ in their emphasis on tradition and conformity in their socialization goals.

Ng et al. (2012) found that another important socialization goal of African American parents involved promoting children's self-esteem, especially given the ubiquitous emphasis placed on confidence and self-promotion in the mainstream culture (Heine, Lehman, Markus, & Kitayama, 1999; Miller, Wang, Sandel, & Cho, 2002). African American parents of young

children have been found to place greater emphasis on self-maximization goals than European caregivers (Suizzo, 2007). Specifically, promoting self-esteem among children is deemed important in African American culture as one way of buffering children from the negative effects of racism and minority status (García Coll et al., 1995; Spencer & Markstrom-Adams, 1990).

While the current study's focus is not on racial nor emotional socialization, specifically, due to the open-ended nature of the caregivers' interview, it is important to keep in mind caregivers' goals, as well as possible underlying motivation, when considering the broader goals for this population. The current study, then, aimed to ask more general questions about Black caregivers' goals for their children, to contribute to the extant literature, especially with respect to goals for children with asthma. This is especially important, given that little is known about specific parenting goals for children with asthma.

*Goals in pediatric chronic illness.* The primary goal in asthma management is increased adherence, as adherence to inhaled corticosteroids (ICS) in pediatric asthma is consistently suboptimal (McQuaid, Kopel, Klein, & Fritz, 2003; Bender, 2016). Many studies have focused on contributing factors to non-adherence within this population, primarily via identifying factors at the individual- and family- level (e.g., child age, familial division of responsibility), while other studies look more broadly at features of the community or health care system (Bartlett, Lukk, Butz, et al., 2002; Bender, Cvietusa, Goodrich, et al., 2015; McQuaid, et al., 2003; McQuaid, Penza-Clyve, Nassau, et al., 2001; Walders, Drotar, Kercksmar, 2000;). By middle-to-late childhood, children with asthma share responsibility for asthma management with their caregivers (Duncan, Hogan, Tien, Graves, Chorney, Zettler, & Portnoy, 2013). Thus, parental goals for their children with asthma could include goals that are specific to issues around asthma management; however, asthma-specific parenting goals (e.g., having child remember to take

daily medication) may be in conflict with typical child development goals, like having their child experience a “normal” childhood (Robinson et al., 2011). Like much of the literature on pediatric chronic illness (e.g., diabetes mellitus, obesity), most studies of families with children with asthma focus on asthma management, not necessarily on general development of the child with a chronic illness (Robinson et al., 2011). We know little about general parenting goals of caregivers for children with asthma. While it is reasonable to assume that caregivers of a child with asthma share many of the general goals listed above, they also must consider asthma management goals with or above general goals potentially affecting children’s social, emotional, or cognitive development (Grusec et al., 2000). This tension between general and asthma priorities may be key to understanding parenting goals within the context of pediatric asthma, though it has yet to be explored either qualitatively or quantitatively.

Of note, there is a paucity of research on caregivers’ perceived barriers to their goals for children outside of treatment adherence (e.g., obesity intervention, medication adherence). Mansour and colleagues conducted a focus group with parents of children with asthma and identified four types of barriers to treatment adherence: patient/family characteristics, environmental barriers, difficulties with health care providers, and the health care system generally (Mansour, Lanphear, & DeWitt, 2000). Wu and colleagues (2008) found that caregivers of Black and Latinx youth with asthma experience more competing family priorities that are common barriers to the use of preventative health care services, as compared to white families. Their study built on work by Gurmankin and Baron (2004) that posits families have a finite “worry budget” to allocate amongst various stressors in everyday living (e.g., housing, neighborhood safety, employment, relationships, finances, family members’ health statuses). Wu et al. found that parents of Black children were more likely to have competing family priorities

“all of the time” or “most of the time” in relation to their children’s asthma management. These caregivers were more likely to report that they worried all or most of the time about housing, safety, employment, finances, and health (Wu et al., 2008). These areas of worry compete with cognitive or emotional resources that could be allotted to health management and are likely to become barriers to treatment adherence, while implicating difficulties with broader goal achievement.

While a handful of studies directly address parents’ perceived barriers to socialization and values transmission (i.e., Hughes, Rodriguez, Smith, Johnson, Stevenson, & Spicer, 2006; Tamis-LeMonda, Way, Hughes, Yoshikawa, Kalman, & Niwa, 2007), to our knowledge there are no studies that specifically examine caregivers’ perceptions of barriers to their general parenting goals. Thus, the current study adds to the extant literature by presenting caregivers’ descriptions of barriers and supports to their goals for their children.

**Qualitative data analysis.** The literature surrounding pediatric asthma and parenting is a limited one in which the primary focus is often (non-)adherence or caregiver/family characteristics that influence pediatric asthma outcomes. While there is some research examining the role of broader environment on caregiver characteristics and asthma outcomes (e.g., Miadich, Everhart, Borschuk, Winter, & Fiese, 2015), additional research is needed to better understand caregivers’ daily experiences and aspirations for their children while managing a pediatric chronic illness. Additionally, because asthma disproportionately affects Black families, especially in densely-populated, urban areas (Akinbami & Schoendorf, 2002), it is imperative to move toward a more inclusive theory of coping with chronic illness, rather than relying on traditional theory that has leaned heavily on research with white, middle-class samples. Past research has not relied on racial-theory guided perspectives, but rather has utilized traditional parenting and coping

frameworks that may or may not be sensitive to cultural differences in parenting, family interactions, and coping/resilience.

Understanding potential differences between asthma and non-asthma families, their goals, as well as perceived barriers and supports to these goals has important implications for asthma-related public health initiatives, improved medical provider-patient relationships, as well as Quality of Life (QOL) interventions. To expand on this nascent literature and begin to advance our understanding of parents' goals for their children with asthma in low income, urban settings, we conducted semi-structured interviews with Black caregivers of children with and without a pediatric asthma diagnosis. A qualitative approach was employed to identify parenting goals as well as perception of barriers and supports to achieving those goals.

Qualitative methods are particularly well suited to bolster past research. Grounded theory techniques allow for the development of new ideas and theories to emerge from under-represented samples' own stories and perspectives. Rather than rely on established theories that may not account for differences in experience (e.g., experiences with racism), research using grounded theory instead reveals aspects of participants' lives that may have otherwise been overlooked or misattributed to inaccurate assumptions or stereotypes. The current study's interview questions were drawn from two previous studies aimed at better understanding parents' cognitions about their children. One study used a sample of 51 parents from a "broad cross-section of social and family backgrounds" recruited from an outpatient clinic at a large, urban pediatric hospital (Newberger, 1980), and the other used sample of middle and low-SES white mothers and low-SES Puerto Rican mothers, as an attempt to formulate a culturally sensitive definition of normative attachment (Harwood, 1992). Both used a semi-structured reflective interview that simultaneously allowed both a standard set of questions to be asked, as well as

elaboration and expansion by the respondent, using their own words and logic (Newberger, 1980). The current study aimed to expand on that work, specifically highlighting caregivers' goals for their children's growth and development, while looking toward potential differences between families managing a pediatric chronic illness and those who are not.

The goal of the current study is to capture what is unique for families' experiences, considering the intersectionality of their identities and experiences (i.e., Black, living in urban, under-resourced contexts, managing or not managing pediatric asthma). Quantitative measures that are intended to elucidate these experiences tend to lack depth and explanatory power, and often reduce complex experiences to simple pieces of comparative models (e.g., these families are at risk for poor outcomes, compared to...). Rather than reduce these experiences to a comparative model that likely fails to capture the nuance and heterogeneity of families' goals, beliefs, and strengths, the current study relies on participants' narrative accounts coming through the data via inductive and iterative strategies.

Qualitative methods are particularly well-suited to elucidate caregivers' experiences and beliefs, especially toward developing an initial understanding in a less-studied area and/or within an under-studied population. These methods allow for the analysis of data via identifying patterns connected to a phenomenon, then developing a sense of that phenomenon based on those same patterns (Levitt, Bamberg, Creswell, Frost, Josselson, & Suarez-Orozco, 2018). These methods can be used to examine the development of a particular social construct (e.g., Neimeyer, Hogan, & Laurie, 2008), highlight the way communication flows (e.g., Parker, 2015), as well as address societal injustices (e.g., Fine, 2013). Levitt and colleagues (2018) note that qualitative methods are most useful when applied to research questions in literature that may be contradictory, problematic, or ill-fitting for a specific population (Chang & Yoon, 2011), or if the

author is working to give voice to historically disenfranchised populations whose experiences are not well-represented in the extant literature. Within the realm of pediatric psychology and public health interventions, the perspectives and priorities of parents-- as well as the enormous toll that the stress of adversity takes on parents, and in turn, their children -- are rarely given adequate attention or are incorporated into intervention work (Knowles, Rabinowich, Ettinger de Cuba, Becker Cutts, and Chilton, 2016).

There are several types of qualitative methods (e.g., narrative, phenomenological, discursive). Generally regarded as one of the “first methodologically systematic approaches to qualitative inquiry,” grounded theory is one of the most rigorous of qualitative techniques (Saldana, 2009, p. 55). Grounded theory is a systematic, inductive, iterative, and comparative method of data analysis for the purpose of sociological theory construction (Corbin & Strauss, 2015; Glaser & Strauss, 1967) and serves to move qualitative analysis into explicit theoretical statements. This technique is used to develop a theoretical understanding of a phenomenon directly from the data from which it comes, rather than from pre-formulated ideas (Corbin & Strauss, 2015). Classic grounded theory and its associated coding methods (see Figure 1) are generally recommended for research questions that aim to develop a new theory about a phenomenon or process (Corbin & Strauss, 2015). While using another qualitative method may be useful to generate a list or a description of what is talked about in a given data set, it does not offer insightful *meanings* about the participants and their experiences, relying on topic-based nouns that do not capture anything beyond the surface of what it said (Saldana, p. 78). If, however, grounded theory works as it is intended, it will explain variations in behavior with respect to the processing of the main concerns of the subjects involved (Glaser, 1992, p. 15). In



other words, grounded theory research is the study of abstract problems and their processes- not the units from which those problems or processes arise (Glaser, 1992).

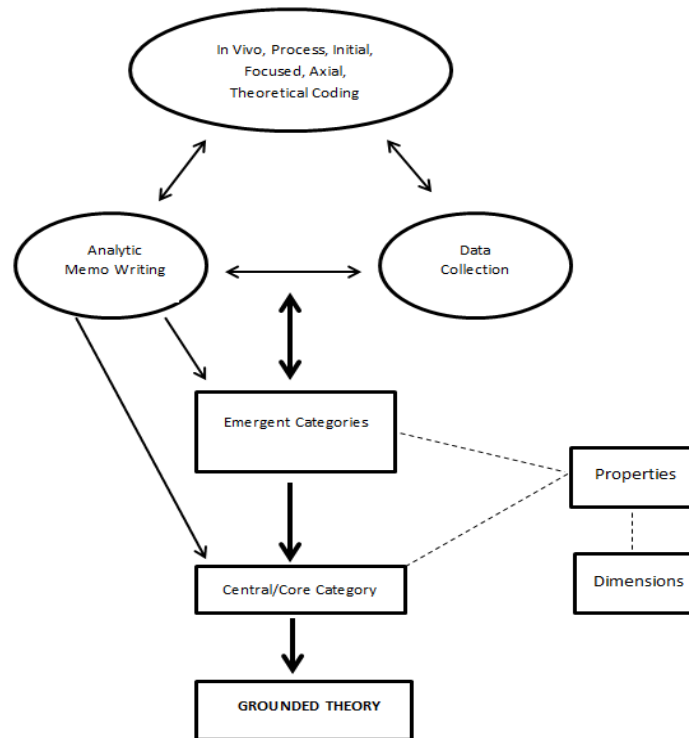


Figure 1: *Model of "classic" grounded theory (Saldana, 2009)*

Grounded theory techniques can be used to gain new insights into existing problems, in addition to studying new areas that may benefit from investigation (Corbin & Strauss, p.11). In addition to this methodology's flexibility and explanatory power, this form of qualitative research has been found to be culturally sensitive and applicable both to individuals, as well as to larger groups (pg. 11). Thus, because the current study's data is drawn from a sample of ethnic minority families--Black families in Richmond that represent an historically disenfranchised population whose experiences are not well-represented-- and because the extant literature on parental goals for children with asthma is so young, grounded theory is a useful tool by which we

can better understand and develop theory around Black caregivers' parenting experiences with children who have a chronic illness.

### **Statement of the Problem**

The present study sought to better understand caregiver goals for their children, as well as caregiver perceptions of barriers and supports for those goals. While there is literature describing both 1) role of parenting behaviors and goals in managing pediatric asthma and 2) parenting and socialization goals in low-income, urban children, there is a paucity of work addressing the role of context over and above the stress of parenting a child with a chronic illness, particularly in Black families. Thus, using a grounded theory approach to analyzing caregiver interviews, the current study sought to add to the literature on pediatric asthma in low-income, urban settings. Through a qualitative approach, caregiver goals for their children, as well as barriers and supports to their children accomplishing those goals, were examined, with attention paid to endorsement of both inter- and intra-personal factors (e.g., personality characteristics, relationships) and system-level factors (e.g., neighborhood safety, education). Differences between asthma and non-asthma caregiver goals were elucidated and serve to demonstrate the role of context and environment over and above pediatric chronic illness.

Thus, the aims of the current study were: (1) to conduct a qualitative analysis of caregiver goals for their children, using grounded theory techniques to elucidate themes across goals for child socialization and development, and (2) better understand differences and commonalities among caregivers of similar backgrounds who may or may not be raising a child with asthma. It was hypothesized that caregivers would report a wide range of experiences and goals, including significant burdens and positive influences attributed to raising a child, and including the role of neighborhood or community context, as well as to caring for a child with a chronic illness.

## Method

### Participants

Data were collected as part of a larger study examining contextual risk and protective factors for child emotional and physical health outcomes. Participants included 96 caregiver-child dyads recruited from the greater Richmond, Virginia area. The research team obtained a list of children ages 5-12 who had been seen at the children's hospital for well-child or asthma-focused visits during the last year. From that list, families living in low-income zip codes, as determined by the Richmond, VA Mayor's Report on Poverty (2014) were chosen to be recruited by phone. These zip codes included four areas of the city in which more than 20% of residents meet federal guidelines for poverty. The poverty rates within these targeted zip codes range from 21% to 53%, with populations between 2,400 and 32,000 residents. In addition to recruitment phone calls, flyers were posted in schools and community centers within targeted zip codes. Inclusion criteria included having a child aged 5-12 who does or does not have asthma, as well as having no diagnosed developmental disabilities that would preclude meaningful participation. Caregivers and children also needed to speak and understand English. Demographic characteristics of the full study sample are presented in Table 2 listed in Appendix A.

The current study participants were children ( $n=85$ ; 49% boys and 51% girls) with an average age of 8.84 ( $SD = 2.03$ ) and their primary caregivers (88% biological mothers) who self-identified as Black or African American and for whom we have completed parenting interviews. Forty-one (48%) of the children had asthma and 44 (52%) did not. Table 3 in Appendix A shows demographic characteristics for participants in the current study.

### Procedure

Families presented to a departmental research building near the university's campus. After obtaining informed parental consent and youth assent, the caregiver and child completed questionnaires, dyadic and individual tasks, interviews, and donated saliva samples in a 3-4 hour visit. Relevant to the present study, the Everyday Parenting Interview (EPI), an in-person interview with caregivers, was administered to adults while children answered questionnaires in another room. While length of interviews varied, caregivers generally spent between 5 and 30 minutes responding to semi-structured interview questions about their experiences, their goals for their children, and their perceptions of parenthood more generally. All study interviewers had prior experience working with families and children from the community and/or had backgrounds in clinical interviewing (e.g., previous research experience administering interviews or were graduate students in Clinical Psychology). Additionally, before data collection, interviewers were trained with a semi-structured protocol to conduct the interviews and to guide use of follow-up prompts. Interviewers included nine women and one man who self-identified as: Caucasian or white (6), Black or African American (1), Asian (1), Middle Eastern (1), and Persian/Iranian (1). Interviews were video recorded and later transcribed for data analysis purposes. Participating families received fifty dollars and a small prize (for the child) for their time. The study was approved by the University's Institutional Review Board.

## Measures

**Demographics.** Parents reported socio-demographic and family characteristics, including age and sex, race and ethnicity, annual income, education level, and family/household composition, as well as whether their child had been diagnosed with asthma by a medical professional.

**Everyday Parenting Interview (EPI).** Prior to data collection, the original study PIs designed and reviewed the content of the semi-structured interview. The EPI was derived from Harwood's (1992) and Newberger's (1980) efforts to understand parental cognitions about children and parenthood via querying socialization goals and parental awareness, respectively. Harwood (1992) was focused particularly on first-time mothers' long-term socialization goals and parenting strategies for their infants (see also Harwood et al., 1999). Harwood and colleagues used open-ended probes with Puerto Rican mothers to examine perceived desirable and undesirable attachment behaviors in young children, developing vignettes and culturally relevant descriptions of children that were later used to elucidate differences in socialization goals between Anglo and Puerto Rican families.

The original EPI in its entirety includes questions related to caregivers' beliefs about parenting, the role of additional caregivers in their lives, and what daily life is like for them. For the current study, caregivers' responses to two domains (a) Caregiver Goals for their Children (i.e., "Caregiver Goals"), and (b) Beliefs About What Children Need in General to Reach Their Goals (i.e., "Caregiver Beliefs") were analyzed (see Table 1). Caregiver Goals included a main question, "What are your goals for your child?" (i.e., Main Goals) (Harwood, 1992) and follow-up questions/prompts that assessed caregivers' perspectives about Personality Goals, Relationship Goals, Education Goals, and Career Goals for their children, also caregivers' perceptions of What Needs to Happen in Order for Goals to be Reached, Parenting Practices Implemented to Reach Goals, perceived Barriers to Goal Attainment, and perceived Supports for Goal Attainment. Caregiver Beliefs included a main question, "What do you feel children in general need the most in order to reach [goals mentioned previously]?" (i.e., General Needs), and questions/prompts addressing Needs from Family and Needs from Society. For each of the

questions, qualitative analyses were completed moving from the data to codes to categories to themes (see Figure 2). The themes were then integrated across questions.

**Table 1**

***EPI Questions and Related Prompts***

Main Question	Associated Questions/Prompts
What are your goals for [your child]?	<ul style="list-style-type: none"> <li>• How about in terms of personality and personal traits?</li> <li>• Relationships? Education? Careers?</li> <li>• What do you think is going to have to happen for [child] to reach those goals?</li> <li>• Do you have certain things you think you do because of these goals? (parenting practices)</li> <li>• Are there things about [child], your family, or your surroundings that might make it easier or harder for him/her to reach those goals?</li> </ul>
What do you feel children <u>in general</u> need <u>the most</u> in order to reach goals like that?	<ul style="list-style-type: none"> <li>• How about from their families?</li> <li>• Other places (like school, community, society)?</li> </ul>

The current study used an abbreviated adaptation of Harwood’s questions. Due to time constraints and in an effort to reduce participant response burden, the two original, separate questions of “*What are your goals for your kids?*” and “*Thinking about [child] in particular, what is one quality you would most like to see in him/her when he/she is older?*” were combined to form one open-ended question (“*What are your GOALS for <child>?*”) that could be followed by prompts as needed (e.g., “*How about in terms of personality and personal traits...?*”). See Appendix A for the full interview.

Video recordings of the EPIs were transcribed in their totality by research assistants. Transcribers were trained to type caregivers’ interviews verbatim, using a standard format.

Transcripts were shared with co-transcribers who checked the transcripts of their peers for accuracy. Sections of interviews that were difficult to hear or lacked clarity were transcribed by consensus between co-transcribers.

### Data Analysis

Following transcription of the EPIs, a qualitative approach based in grounded theory (Glaser & Strauss, 1967) was used to elucidate and compare common themes of caregiver goals. These methods were used to better understand and develop a theory about caregivers' experiences in parenting children who may or may not have a chronic illness while living in high burden neighborhoods in urban settings. Codifying the transcript data into theory involved multiple steps, with each step moving individual datum away from purely descriptive toward the thematic, conceptual, and theoretical content. The steps of the process, shown in Figure 2, included: (1) moving data into codes, (2) grouping common codes into larger categories, (3) combining categories into larger themes or concepts, and (4) building an assertion or theory from themes.

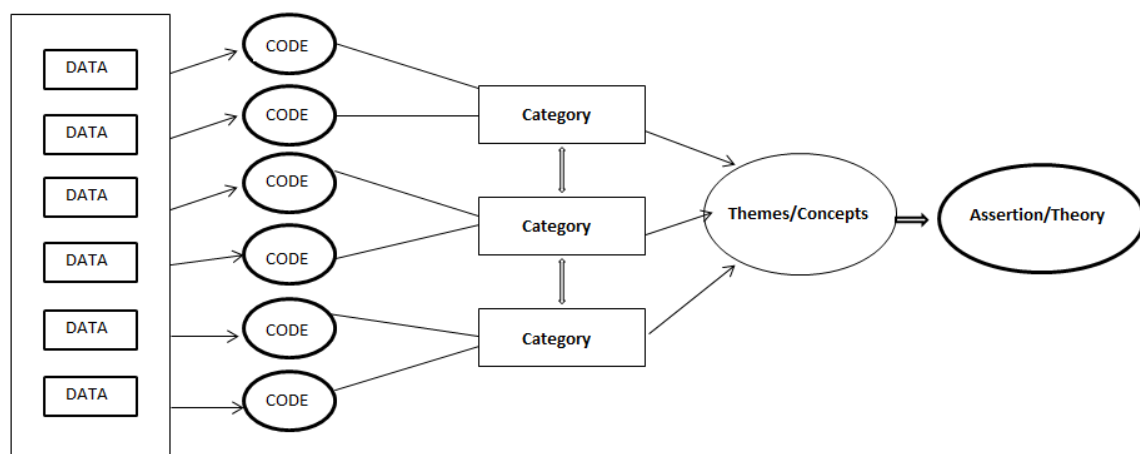


Figure 2: Codes-to-Theory model for qualitative inquiry (Saldana, 2009).

After the research assistants transcribed all EPIs, two levels of coding were used during the theme identification process. Undergraduate and post-baccalaureate research assistants (3) were trained to complete first-level analyses (e.g., open coding and focused coding). This training was comprised of reading and processing didactic materials (i.e., qualitative methods textbooks and readings) and completing coding on practice transcripts that were then reviewed and processed with the first author.

After training was completed, 20% of transcripts (i.e., 18 interviews) were parallel coded between the first author (M.C.), an undergraduate research assistant (M.J.), and a post-baccalaureate research assistant (E.S.) to ensure consensus on the selection of material, and the remaining transcripts were then divided between the first author and two research assistants for further selection of meaningful units from the group sessions (see Haukeland, Fjermestad, Mossige, & Vatne, 2015). The first read of the data involved highlighting text or ‘codable’ units that the coder considered may become a ‘codable’ moment. This required reading the transcripts in detail to identify potential codes (e.g., processes, actions, assumptions, consequences) and marking portions of the transcripts (LaRossa, 2005; Saldana, 2009). Comments were inserted into the margins with initial thoughts and ideas, and short process memos were completed by each member of the team at the end of each work session (per Roberts, Dowell, & Nie, 2019). After codable units were delineated, data were then organized into codes (i.e., short phrases that describe an attribute) and added to a master spreadsheet that would later serve as the basis for the codebook. To elucidate key ideas in the interviews, ensuring that codes, categories, and themes accurately represent the participants’ experiences, initial codes included metaphors, repetitions across informants, and shifts in content that were thought to indicate categories and relevant themes (Strauss & Corbin, 1990).



The second level of coding was an iterative process that began with the development of a codebook and followed with identification of themes. Of note, due to staffing changes (i.e., undergraduate research assistants leaving) and the first author moving out of state, the coding team changed in between initial coding and subsequent levels of analysis. The final coding team was comprised of the first author (M.C.), a post-baccalaureate research assistant who had previously been involved with initial coding (E.S.), and a post-doctoral fellow in developmental psychology who had been involved with the original study as a graduate student and was familiar with the current project (J.G.).

In order to begin to identify themes, the first author and coding team jointly re-examined a subset of first-level codes (i.e., first 20% of transcripts) to identify categories, clearly differentiate separate categories and merge similar categories into subthemes. For each question, (i.e., main goals, relationship goals, personality goals, etc.), a codebook of categories was developed using a spreadsheet of codes that emerged for each specific question. This codebook was refined with feedback from the coding team over the course of weekly coding meetings and served as the basis for a codebook of themes. The codebook listed the categories and each theme and subtheme accompanied by a detailed description, inclusion and exclusion criteria, and exemplars (i.e., typical text examples; Bernard & Ryan, 2010).

Once the initial codebook was complete, the first author and coding team met to review the procedures for marking segments of text that pertain to each theme, and made necessary revisions to the codebook. Then, the finalized codebook was used to analyze the remaining transcripts, which were divided amongst the first author and rest of the coding team. Additionally, approximately 25% (i.e. 20 cases per question) of cases were set aside as consensus cases. Those cases were reviewed and coded over time by the entire team during

weekly consensus meetings (i.e., after team members each coded 5 cases, 5 consensus cases were coded together). Weekly coding team meetings were used to address questions and prevent coding drift over time, and questions about specific cases or codes were addressed.

Once coding was complete, all instances of each theme were tallied via examination of the Excel spreadsheet onto which codes were transferred throughout the coding process. These instances were reviewed by the coding team and the first author, who described the theme by presenting segments of text—paraphrases of cases and verbatim quotes from informants—as typical and atypical examples of concepts. The distribution of the theme across groups (i.e., asthma and non-asthma families) was also examined. There were three types of patterns that were explored: (1) “within-group” thematic similarities and differences (i.e., all interviewed caregivers compared to each other); (2) “cross-group” thematic similarities and differences (asthma caregivers compared to non-asthma caregivers); and (3) relations among themes.

**Maintaining integrity of qualitative methodology.** Of note, special attention was paid to procedural and methodological choices to ensure integrity and establish credibility (Creswell and Miller, 2000). Participant responses guided the emergent coding process, and an audit trail was established through the extensive use of memos post-coding session, summary memos, and a research journal detailing team discussions and decision points (Shaffer, Corona, Sullivan, Fuentes, & McDonald, 2018).

Memos were created by all team members throughout data analysis to maintain transparency and develop an audit trail, the record of analysis for the current project. Analytic memos serve to document reflections on coding processes, emergent patterns, categories and themes, as well as general concepts in the data that may contribute toward theory (Strauss & Corbin, 1998; Saldana, 2009). Ongoing research team meetings were held regularly (in-person

and via telephone/video-conferencing) to discuss emergent coding and clarify relations among constructs, while triangulating emerging themes across researchers and with the relevant literature. Transparency of study materials and procedures were maintained through the detailed descriptions of research team members' methods, data collection, and data analysis plan.

## Results

### Interview Overview

For the current study, sections of the larger qualitative interview were selected that targeted the two domains "Caregiver Goals" and "Caregiver Beliefs". Each domain included a main question and multiple follow-up questions/prompts as described in the Method section. For Caregiver Goals, across the questions/prompts addressing Main Goals, Personality Goals, Relationship Goals, Educational Goals, and Career Goals, What Needs to Happen to Reach Goals, Parenting Practices Implemented to Reach Goals, and Perceived Barriers to Goal Attainment and Perceived Supports for Goal Attainment, a total of eight themes were identified. The percentage of participants who mentioned a specific theme ranged from 4.5% to 25.5%, with 39 to 223 sources per theme (see Table 4). For "Caregiver Beliefs," across the questions addressing General Needs, Needs from Families, and Needs from Society, a total of five themes were identified. The percentage of participants who mentioned a particular theme ranged from 4.2% to 60.8%, with 20 to 287 sources per theme (see Table 5).

The following section presents the themes as they occur within the questions/prompts and across the domain. Themes are generally described in order of largest (i.e., themes that were reported at a relative higher frequency) to smallest (i.e., themes that were cited less often and at a

relative low frequency). Each theme is highlighted by a sample of the thick and rich narratives provided by caregivers.

### **Domain 1: Caregiver Goals**

A total of eight themes emerged when caregivers were asked about their goals for their children that included: Achievement, Actualization, Role of the Individual, Safety and Security, Connection, Family, Environmental Influences, and None or Unknown.

**Achievement.** The theme of Achievement emerged in the coding of four questions/prompts: Main Goals, Personality Goals, Education Goals, and Career Goals. For main goals, caregivers described the desire for their children to be successful in life and do well in school. This theme included 223 sources and was the most common thematic response, representing 25.5% of all sources, including families with a child with ( $n = 140$ ) or without ( $n = 83$ ) asthma. Caregivers noted a strong desire for their children to “*be something*” in life, with one woman stating that she wanted her daughter to “*go out and make something of herself*.” Another caregiver said that all she wanted for her son was “*just want him to be somebody out of life*.” For personality goals, caregivers ( $n = 6$ ) discussed the overarching message of their children achieving independence and seeking out success. Caregivers spoke of their desire for children to stay “*focused*” and maintain focus and drive as an aspect of their personality. One mother said that “*I want her to stay focused...be independent, stand on your own two feet*.”

For educational goals, many caregivers mentioned 91 times that perceived “achievement” as success in academics, with a number of caregivers using the metaphor of education being “the key to success.” A father described that his focus is on supporting his children’s academic endeavors, noting that, “*Whatever you want, you feel that's your to-do in life, hey, go for it. But whatever you do, you definitely need to go to school because school is a big value of life*.” This

educational success and achievement was largely defined by “*finishing school*” and “*going to college*.” Caregivers mentioned 35 times that their specific goal was for their child to graduate high school, with one grandmother saying that her focus was to help her grandchildren “*to graduate, [and] for them to give me high school diplomas.*”

A recurrent sentiment was around caregivers’ dreams for their children to attend college, with one mother saying, “*I want [my children] to go to college because that's something that I wanted to do and I never got a chance to do.*” Caregivers also described specific ways in which their children may demonstrate achievement, noting that earning good grades and graduating high school were top priorities. One mother stated that she wanted her son to “*stay on the A-honor roll,*” and another caregiver sharing that her daughter needs to “*Stay on honor roll ...Go all the way through high school ...Finish within the top ten her class...Maybe go to college.*” These tiered achievements were often described in the context of larger academic goals, such as attending a four-year college or pursuing a prestigious career path. One caregiver said that her daughter’s academic achievement was a priority, and that she as the caregiver had the perspective of “*my goal is to keep pushing her to keep up with her good grades ...to go to Yale University to study as a doc.*” And while several caregivers noted their own role in supporting their children’s educational achievements, a few described their perspective that-- while this is the caregivers’ goal-- it is entirely up to the child to meet these goals. One mother reasoned:

*“I'm not asking you to work, I just want you to go get me a high school diploma...The things that y'all want, as far as phones, tablets, all that y'all [sic] gotta work for that. That's how y'all get that from me, y'all have to earn that. It's like y'all job, you work for it.”*

A number of caregivers agreed that they might exchange rewards and privileges for increased “focus” and good grades. Often this emphasis on academic achievement was also described in the context of additional goals related to professional achievement.

For career goals, caregivers described that “achievement” meant specifically being successful in a child’s chosen profession. Caregivers mentioned 34 times described having a lucrative career as an important marker of success, with a “professional” career mentioned the most frequently ( $n = 18$ ). These careers tended to be in law (e.g., “I want her to be a lawyer”) or medicine (e.g., “I think she wants to be a baby doctor or pediatrician...she has my support”).

Outside of professional occupations requiring additional education, some caregivers emphasized their goal of helping their child achieve as a professional athlete ( $n = 8$  mentions). Football, basketball, and baseball were all mentioned as target careers. One mother acknowledged that her son may have several ideas of what he would like to do when he grows up; however, her goals are for him to play professional baseball:

*“Get that MLB...I’m a make the baseball his number one...he wanna be an astronaut, he wanna travel the world, but that’s one and the baseball is one.”*

Another caregiver emphasized her son’s desire to “go pro” and earn significant income, saying that “he wanna be a football player and get moving in that big old house.” In a similar vein, some caregivers looked toward careers in technology as a path toward success. One caregiver noted that her son was showing an interest in computers and videogames, and she hoped that he would pursue “technology and money and bills, and a better life.”

Yet, other caregivers ( $n = 13$  mentions) declined to provide definitions of what success or achievement might look like for their children’s careers. Several caregivers noted that as long as their child was working and comfortable, they would be seen as successful. One caregiver

suggested that she would be open for her son to have many different ideas about his career, but that she “*would like him to professional anything...doing something that's going to benefit him in the future.*” Thus, some caregivers appeared to suggest that while achievement (e.g., having a career, earning a good income) is a primary goal for them, it is equally important that their child experiences satisfaction and fulfillment in their life.

**Actualization.** A similar theme emerged regarding caregiver goals for children’s personal growth and happiness or self-fulfillment. The theme of Actualization emerging in the coding of three different questions: Main Goals, Personality Goals, and Career Goals. For main goals, this theme was noted 132 times and represents statements reflecting overcoming obstacles, self-improvement and self-esteem, and having a positive outlook on life with good relationships. This was a common thematic response to the interview questions (i.e., 15.1% of sources), with caregivers of a child with asthma making 89 of those responses (compared to non-asthma families’ 43 mentions). In addition to general goals for their children’s happiness and wellbeing, caregivers also spoke about their desires for children to overcome obstacles already present in their lives, with one mother stating that she wants her daughter to “*be able to overcome all of the challenges that I know that a lot of young, Black women experience.*” Another mother agreed, noting that she hopes her daughter can overcome her learning disability and find fulfillment:

*“I want her to run until [she] can't do it no more, versus me-- I can't run no more and I'm tired. For me being thirty-two, I'm tired. But as long as I show [her] sky's the limit, and [she will] never touch that sky, so you might as well keep on going.”*

Other caregivers emphasized that for them, their children’s growth and sense of fulfillment would be measured by the children’s ability to reach their own goals. One caregiver said that she feels her son will be successful when he is in a position to “*tell his story.*” She noted

that while she would like for him to follow in her footsteps and learn from her experiences, it is important for her son to choose his own path and decide how to tell his own story:

*“We [parents] all like to make our kids' decisions...because we could say we had the experiences of life already. But our experience in life makes us who we are today, as far as our strengths...and our role that we play. [In that case]...they don't get that chance or opportunity...in order for that to happen...he's gonna have to experiment [with] things hisself.”*

Similarly, a father shared that a child is better off following their own path and making their own choices as they grow and develop, saying that

*“I believe that if it's something a child is not happy doing, they're not gonna be successful, so you have to allow them to express their selves, find out what they like, what they don't like, and accept it even if you don't like it.”*

For career goals, this reflected some caregivers' views on children's career aspirations, as well. A number of caregivers said that their biggest goal for their child's future career was to simply allow the child to explore and discover what field or job makes them happy. A mother said that *“Whatever [my son] decides to do in life, he can do that and I will be behind him...one hundred percent, no matter what it is.”*

Other caregivers said that they are following their child's lead on the matter while still providing guidance and support. One caregiver noted that she supports her son's dream of playing professional basketball *“All he talks about is how he wants to go to the NBA so 'course I'm gonna encourage him to you know-to-to go to school to go to college ...I know he has to have other plans just in case that don't work out.”* Another caregiver mentioned that, *“His Plan A is...a lawyer...I told him [to] use the basketball to get...what you need for your law...education.”*



Caregivers simultaneously allowed their child to develop their own hopes and goals while providing guidance around the issues at hand.

For personality goals, while “*being happy*” was rarely endorsed as a goal for most caregivers (i.e., 4 sources), the theme of Actualization came through in their discussions of personality traits and goals. Specifically, caregivers described goals related to overall growth and maturity in developing a sense of self, as well as a general preference for positive personal attributes. Several caregivers shared their hopes for their children to maintain a good “attitude” in life, with comments like “[*I want him to*] *keep his good attitude up*” and “[*She’s got to*] *get her attitude under control and [work on] the way she talks to people and the way she makes enemies so quick.*”

Other caregivers focused on their desire for their children to overcome a perceived negative attribute. The idea of being “*tough*” came through often, with one caregiver hoping that her daughter would overcome her social inhibition: “[*child*] *is real timid...if she can just take--uh-- man up a little bit.*” Another caregiver hoped that her child would overcome her *lack* of social inhibition, stating that she needs to accept “[*not always*] *having the last word.*” This aligns with a common sentiment that caregivers hope their children grow and mature. A caregiver said that she wished her son would out-grow his silliness and “*stop playing in school so much.*” Often, these types of goals were also paired with a statement about the desire for a child to overcome one attribute and live up to their potential (e.g., “*be the best man he can be*”). This sometimes came through interviews with goals of a child being “*good.*” One mother repeated over the course of this section of the interview that her priority was helping her daughter to “*be a good girl,*” in hopes that this would allow her daughter to one day become a “*good mother.*”

For other caregivers, personality growth was contingent on their child accepting and being him or herself. Several caregivers stated that they would like for their children to "*be [himself]*" or "*love herself*." One father was particularly concerned that his son would face difficult peer interactions because of his dream of being a vet; his goal was that he "*want[s] him to know it's okay to be different*." Altogether, many caregivers agreed that a main goal of theirs was that their child experience growth and positivity in relation to their personality development. Some of this development was described in terms of traits or behaviors that caregivers could help shape or support, while other aspects of development were strictly confined to the child's own responsibility and choices.

**Role of the Individual.** The theme of the Role of the Individual emerged in the coding of four questions: What Needs to Happen to Reach Goals, Parenting Practices Implemented to Reach Goals, Barriers to Goal Attainment, and Supports for Goal Attainment. This theme emerged from caregivers' descriptions of the perceived importance of an individual contributing to goal attainment (e.g., a child him/herself, a caregiver). Across interviews, this theme was noted 131 times and represents a common thematic response to the interview questions (i.e., 15% of sources), with caregivers of a child with asthma making 76 of those responses (compared to non-asthma families' 55 mentions). Caregivers reported a strong belief that children have an integral part in shaping their own destinies, and that personal attributes play a pivotal role in whether or not someone is successful in reaching their goals or not.

In response to the question, "What needs to happen in the family's life in order for their child to reach the goals that caregiver has for them?" two different response patterns emerged, with regard to the role of an individual. The more prevalent response pattern focused on child-driven efforts (i.e., 71 sources). Caregivers frequently stated that a child must decide whether he

or she will work towards achieving goals. One mother said that *“that's something that [child] is going to have to do for herself...it's [child's] choice.”* There was significant emphasis on children staying on track and being focused, with several caregivers (i.e., 20 sources) making statements like, *“[my daughter] gotta stay focused.”* The idea of children giving respect to elders was also prevalent, with one caregiver saying that in order for her daughter to be successful in life, *“she have to listen to her mom [and] the teacher.”*

The other response pattern-- although less frequent than the above-mentioned-- indicated that caregiver-driven efforts were important contributors (i.e., 26 sources). Some caregivers described the importance of their teaching on the likelihood of their children accomplishing their goals. A mother said that she is *“trying to teach [her daughter] how to...talk to other people,”* with the hope that her daughter will be able to improve interpersonal attributes. One caregiver described that in order for her son to meet the goals she has for him, she must make efforts to set him on the path to success: *“I just keep on guiding him and putting him in the right place hopefully, and leave the rest up to God.”* A similar sentiment revolved around caregivers' monitoring as the primary path to goal attainment. One father said that he was *“Gonna have to stay on them [his children], 'cuz there are a lot of distractions out there.”* However, some caregivers felt that their role was to encourage independence and avoid providing too much interference. A mother said that while she engages in monitoring and has a sense of what her son is or is not capable of, she feels that it is important for her to step back sometimes and *“let him fall and pick himself back up again.”*

For the question about parenting practices implemented to reach goals, several caregivers discussed themselves as individuals and their own personal attributes as helpful in parenting and helping their child to meet the goals they have. Honesty was favored, with one caregiver stating

that “*I don't lie to them about nothing...I tell [the kids] the truth about everything.*” Other caregivers reflected on their own upbringing and used their experiences as a template for or against what they wanted to do as a parent. One mother shared that:

*“So I wasn't very responsive to [own mother's harsh discipline]. I kind of rebelled. So I figured I use what my mom did to me and know what I don't like and use [that] towards raising [my daughter], and it seems to work.”*

Other caregivers described the steps that they take in order to be better parents to their children. Specifically, the topics of self-care (i.e., “*trying to keep myself on track also*”) and sacrifice (i.e., “*I sacrifice a whole lot*”) came through, with caregivers highlighting their contributions as individuals to their children’s success and goal attainment.

For the question addressing barriers to goal attainment, the theme of individual responsibility also came through when caregivers were asked about barriers to their children meeting the goals that they had described. Specifically, discussion around a child’s personal attributes and health (mental and physical) highlighted ways in which caregivers believed a personal problem could prohibit goal attainment. With regards to perceived problematic attributes, several caregivers noted that their child being “*sweet*” or “*trusting*” will cause problems in their future. One father lamented about his son:

*“He's so trusting...when he actually sees how people are, that's gonna break him a little bit...because he has to grow up and defend himself because the world is--they're trippin.”*

A mother shared a similar concern about her son, saying:

*“I think he is too kind-hearted, and you know where we live, I feel like you know, the kids take advantage of that.”*

Other attributes that were perceived as a barrier included difficulties with "attitude," as well as problems with focus or motivation.

Caregivers reported on their children's lack of focus and often disclosed mental health diagnoses. Autism spectrum disorders and Attention-Deficit/Hyperactivity Disorder (ADHD) were mentioned as barriers, specifically to academic achievement (e.g., studying and homework completion, test-taking). One mother described her frustration with her son's attention difficulties, noting that:

*"He have [sic] to learn how to, you know, complete tasks without getting frustrated easy. But that also comes with ADHD. He don't know how to stay still, he's very fugitive [sic]...he is bored real quick...He just cannot sit in one spot for five minutes, so, uh, he sees a psychiatrist and she diagnosed him with ADHD. He supposed [sic] to be on medication, but the medication don't work too well..."*

Caregivers' own health difficulties (mental or physical) was sometimes disclosed as a barrier. For example, one mother disclosed that she had been diagnosed with schizophrenia, and that she had previously lost custody of her older children. She stated that while her mental health presents as a barrier, she is optimistic that she can parent the children she has custody of well.

For the question addressing support for goal attainment, complementing the perceived barriers that an individual might create in relation to goal attainment, caregivers also reported on a handful of supports (i.e., four sources) that an individual may contribute. Specifically, caregivers discussed the role of individual child attributes and caregiver attributes that may support a child's success. Positive, innate qualities such as intelligence (i.e., "[child] is very smart") were reported as important contributors to meeting goals and achieving. Similarly, caregiver empathy was described as an easy way to help children, with one mother noting that

"What makes it easier is that when you try to involve yourself in it and you try to get from [sic] her point of view and her understanding." While individual responsibility comprised a small proportion of responses in this category (i.e., only 4 sources), it is interesting to note that caregivers were more likely to report on barriers related to individuals' contributions to goal attainment (i.e., barriers included 20 sources).

**Safety and Security.** Perhaps in direct contrast with the goals listed as related to children's self-actualization and growth, a theme related to pragmatics-- specifically around safety and sticking to the status quo-- emerged. The theme of Safety and Security emerged in the coding of four different questions: Main Goals, Education Goals, Career Goals, and Parenting Practices Implemented to Reach Goals. While this theme was discussed less frequently than some others (i.e., 119 instances across interviews), for main goals, caregivers described a strong desire for their children to be financially stable, avoid negative peer and neighborhood influences, and be able to meet all of their basic needs (e.g., food, shelter, access to healthcare).

For main goals within this theme, there were also instances in which caregivers alluded to safety within the status quo. Specifically, there were two direct comments made about caregivers wanting their children to follow in their own footsteps (e.g., "*try to lay the foundation so she will follow in what I do but not how I do it;*" "*just do what I did*") and wishing that their children would accept unfairness in their life (e.g., "*get him to understand that life is just sometimes not fair*"). Other caregivers noted that their main goal was for their children to survive into adulthood, particularly their sons. Three different caregivers noted that one of their top goals for their sons was that "*he don't come up...a statistic.*" Another mother shared that her focus was on safety and survival, noting that she wants to prepare her boys "*Cause it's going to be hard out there...as far as being a Black man in general.*"

Along with general safety and stability, several caregivers discussed their hopes that their children will be financially stable and meet their own basic needs. One caregiver said about her children that:

*“If they can have a comfortable life, then--that would be ideal for me. I'm not trying to reach too far...As long as they're comfortable and don't have to worry about too much stuff...is good.”*

Another mother agreed, and also highlighted the importance of her daughters' abilities to be self-sufficient. She emphasized that both she and her grandmother were independent and that she hopes for her girls to *“Be able to make enough money to take care of their own self and not worry about nobody else, no man or like dat.”* Four other mothers said that one of their top goals for their daughters was to wait to have children or avoid becoming pregnant at a young age (e.g., *“no babies until after 21;” “she don't get pregnant like me”*).

Finally, a very small number of caregivers (i.e., 2 sources) described their goals in relation to health maintenance and safety. One mother specifically said that one of her main goals for her son was to *“help him better his asthma.”* Another caregiver said that her main goal was for her son to *“[outgrow] this asthma thing.”* No other health goals for children were shared across interviews.

For education goals, rather than focusing on health and safety, caregivers instead spoke of the practical steps needed to meet educational goals. Specifically, caregivers discussed the importance of children staying motivated in school, their hopes that children will be able to maintain a sense of balance between school and activities (e.g., sports), and their belief that school must stay a top priority, if a child is to succeed. One caregiver said that her *“overall goal is to teach her [daughter] how to balance both [her love of basketball and her education].”*

Another caregiver emphasized her belief that her son needed to toe the line and stay focused and motivated in school to succeed, avoiding negative influences and keeping an eye on the prize, as it were. She said that her goal is for him to "*[finish school] before [he] has kids, before [he tries] and have a life.*" Rather than focusing on the achievement aspect of education, then, some caregivers chose to discuss the nuts and bolts of educational goal-setting.

For career goals, a similar pattern emerged in caregivers' responses to this question. A small subset of caregivers (i.e., 9 sources) focused not on their child's or their own ambitions for a career, but rather on the practical components of having a job and earning a living. These caregivers tended to agree with sentiments like this one presented by one female caregiver:

*"So got to go get you a trade, 'cuz you not gonna make it in this damn life time doing nothing. You got to do something 'cuz depending on somebody else to do it for you will never get it done."*

These caregivers are not so much concerned with specifics, but they are hoping that their children make a living and are safe and secure. One caregiver said that she would be happy with her child doing almost anything because "*working is good...my daddy taught us you gotta always have something.*"

For the questions addressing parenting practices implemented to reach goals, some caregivers also noted that they take a practical approach to parenting in the hopes that their children will meet the goals that they have set for them. A large portion of caregivers (i.e., 55 sources) described some kind of structure as support within their preferred parenting strategies. They also described provision of opportunities and resources as their way of parenting in pursuit of goals.



With regards to structure and support, caregivers discussed pushing and challenging their children, closely monitoring their children's activities, enforcing routine, using discipline (physical and otherwise), and engaging in academic support (e.g., structured reading time, designated homework time). Monitoring was described by several caregivers as a tactic used to protect their children from negative peer influences. For example, one mother said that

*"I monitor who he talks to, he doesn't go over anybody [sic] house. Anybody come to our house, 'I gotta meet your parents, I gotta know what kind of person you are before you come in.'"*

The structure around academics was notable, with 25 sources describing some kind of involvement in extracurricular studying or reading time (i.e., *"I always help him...when he come [sic] home to do his homework"*). Several caregivers mentioned special reading time (i.e., *"we read along together [at night]"*) and one parent noting that they *"get their teacher to send extra work home on the weekends."*

Similarly, caregivers described their role as providers as an important aspect of parenting. Specifically, caregivers mentioned providing resources (e.g., food, shelter), providing access to clubs and activities, and providing opportunities to get out of negative environments (e.g., specific neighborhoods) and protection (i.e., *"I try not to overwhelm her why certain things is the way it is [sic]"*) as key aspects of their parenting strategies to promote success. With regards to providing safety and opportunities to leave negative neighborhood environments, one mother said that

*"I've been trying to get out of this community for the last year...I think the sooner I can get [my son] out of the community, it will help him boost his self-confidence to...want what he wants more."*

The theme of Safety and Security came through in various ways across categories, with some variations more literal than others (e.g., concerns for safety in the neighborhood vs. security in daily routines). While this theme was less frequently discussed than others, it appears to be an important aspect to caregivers' goals for their children's futures.

**Connection.** The theme of Connection emerged in the coding of three questions: Personality Goals, Relationship Goals, and Parenting Practices Implemented to Reach Goals. This theme emerged from caregivers' descriptions of desire for their children to be part of a larger community and maintain positive relationships within and outside of their families. This theme also emerged when caregivers described the specific parenting practices they use in order to help their child reach their goals. Across interviews, this theme was noted 108 times, with caregivers of a child with asthma making 64 of those responses (compared to non-asthma families' 44 mentions). While a less frequently mentioned theme in comparison to others, a number of caregivers reported that it is important for children to have a sense of connection with others and be able to engage socially with siblings, peers, and adults.

For personality goals, the category in which caregivers spoke the most frequently about social connectedness was in discussing goals for their children's personalities. There were 26 sources that described social connection in relation to personality goals, with caregivers describing goals for their children to be kind to others (e.g., "*Keep a good personality towards... others*"), exhibit open and honest communication styles, work well with others, and give and receive respect. The idea of open communication as a path to social connection was described as a general "*openness*," as well as a kind of assertiveness. One caregiver said that she hopes her son will be able to "*speak how he feel instead of don't let nobody guess how he feel or insinuate.*" Other caregivers noted that they hope generosity would lead to greater social connectivity. One

grandmother said that she hopes her grandchild will "*be someone who wants to give back to the community.*"

For relationship goals, caregivers discussed goals related to their hopes for high quality relationships for their children, as well as being socially involved and aware. For some, this involves the giving and receiving of respect from others.

When discussing their hopes for high quality relationships for their children, a few caregivers mentioned that they hoped their children would improve upon their own experiences. One mother said that she hopes her children are able "*to do it better than I've done.*" The most common pattern of response (i.e., 13 sources), however, was caregivers stating a specific relationship that they hoped would improve for their child (e.g., "*I want [child to have] a better relationship with [child's] dad*"). This applied to sibling relationships and relationships with co-parents.

Finally, a small proportion of caregivers described their goal for their child to be socially aware or demonstrate some savviness with respect to their peer relations. One mother was particularly concerned with her son's perceived naïveté, saying, "*I just want him to know that everybody is not his friend.*" In contrast, some caregivers hoped that their child would become more open to social experiences and develop close relationships in which they feel comfortable expressing themselves. For example, one caregiver said that: "*I would like her to be open...you don't have to say okay to everything, everything don't have to be okay.*"

For parenting practices implemented to reach goals, the theme of Connection was prevalent within specific parenting practices that caregivers used to help their children reach the goals that they have set. This theme came through in caregivers' description of encouragement and support, special one-on-one time (e.g., "*play a little game together or get on his...tablet*"),

and role modeling. These parenting practices can generally be described as ones comprised of warmth and support and were described by 51 sources across interviews.

Several caregivers (i.e., 23 mentions) described using encouragement and support to help their children succeed. Occasionally this was a vague description of offering encouragement (e.g., *"Try to be as supportive as I can"*), while other caregivers described specific ways in which they might serve as a role model. One mother shared that she leads by example, noting that:

*"That's another reason why I've stayed in school and did everything myself, it's because I wanna be a good role model for him..."*

A few caregivers (i.e., 7 sources) described how they incorporate warmth into their discipline practices, hoping to maintain that connection between caregiver and child in the context of corrective actions or difficult interactions. One father said that *"When I discipline...or scold...I come back and I share with them why I had to."*

Another mother shared that her daughter with special needs (i.e., developmental delay) struggles with noncompliance. The mother said that she uses discussion to provide corrective feedback to her daughter and avoid damaging their relationship by becoming upset. She said:

*"She doesn't understand no, so sometimes I have to sit down and explain to her. you know, things can happen, there is a lot of bad people out there. "*

The importance of connection to caregivers was evident across multiple categories within this interview. It is clear that high quality, prosocial relationships are a goal many caregivers have for their children, though it was less frequently mentioned than other qualities or goals.

**Family.** In a similar vein, caregivers spoke often of the importance of family in relation to their goals for their children. The theme of Family emerged in the coding of three questions: Relationship Goals, Barriers to Goal Attainment, and Supports for Goal Attainment. This theme

emerged from caregivers' descriptions of desire for their children to experience positive family relationships, and it invokes some of the pitfalls associated with co-parenting difficulties, intergenerational differences in beliefs, and the struggles associated with being a single parent and relying (or not) on extended family for support. Across interviews, this theme was noted 60 times, with caregivers of a child with asthma making 39 of those responses (compared to non-asthma families' 21 mentions). Caregivers reported that family is an important aspect of their children's success in life, for better or for worse.

For relationship goals, caregivers spoke specifically about their goals for their children to stay close to their family (often mothers, specifically), have a partner in life, and have a family of their own one day. These goals were equally distributed, for a total of 12 sources. One mother said that she does not have any goals outside of maintaining the connection she and her son already have: *"I don't really have any goals for him just keep loving me and that's it."* Another caregiver hoped that her children would stay close as they grow and *"look out for each other."*

A small group of caregivers spoke of their goals for their children to find a good partner and build a life together. Similarly, caregivers shared their hopes that their children would experience parenthood one day and have a family of their own.

For barriers to goal attainment, a number of caregivers described specific family members or family units as a whole to be obstacles to their goals for their children (i.e., 24 sources). Specifically, caregivers mentioned the absence of a parent (e.g., father figure) or difficulties with familial interference in their parenting practices to be the biggest barriers. A number of caregivers described the hardships associated with being a single parent. One father noted that his sons have never had a consistent female presence in their lives. More commonly,

mothers shared their sadness or frustration with raising children without a father figure. One mother said:

*“I try to give [child] everything in the world...but it's just one thing I can't give her, and that's a dad...You know, I just can't [give her children their father]. I can't do it...and I feel bad about it because I can't do it.”*

Another mother noted that while her daughter's father lives locally and has some contact with her, he is frequently unavailable and cannot maintain regular contact with the family. The mother lamented that *“There's things [child] want to tell her daddy that she can't tell him because he goes.”*

Some caregivers instead focused not on the absence of a partner in parenting, but rather in a lack of familial support from relatives. One caregiver said that she wears many different hats and serves several different roles in her children's lives, due to lack of family in the area. She said: *“Yeah...we don't have the family structure...my parents are gone... So I have a lot to work on because [the structure] is not there, so I have to build it and make it there.”*

Other caregivers discussed their desire for family members to be *less* involved. A common thread involved the perceived interference of well-meaning family members. One father explained that he and his son's mother are working to co-parent effectively but have faced some inference from a grandmother: *“[Caregiver's] mom and I...have two different parenting styles...And Grandma wants to take over.”* Similarly, one aunt who cares for her niece and nephew described how increased family involvement would derail her plans for the children. She described her hopes that her niece would overcome several adverse experiences from her early childhood and said that the key to success would be to stay away from negative influences within the family: *“Her mother and father are both heroin addicts...as long as she can stay away from*

*family...that will be a big help.*” While family is typically viewed as a support for children’s development and achievement, it was clear from a number of caregivers that this is not always the case.

For supports for goal attainment, the theme of family was the most commonly described support across interviews (i.e., 19 sources, 51% of reported supports). Caregivers discussed ways in which extended family serves as back-up and help children reach their goals. One caregiver noted that *“Everybody, my family supportive, we, we close [sic], we stick together so everybody be [sic] right there together with [her daughter].”* Another caregiver agreed, saying that, *“with my family it will help because when I can't explain something to [child] or get close to him, I can pick up the phone and call my sister.”* Family were seen as providers of encouragement (e.g., *“family...we're going to motivate [daughter] into doing what she has to do”*) as well as additional resources and providers of information. A few caregivers specifically mentioned the role of older siblings or older cousins in supporting their younger children. One mother said that she expects her daughter’s future success to be *“easier because [daughter] has the older two sister, older brother...they help [her] out.”* It was clear, then, that for some caregivers, family is an important support in their pursuit of various goals for their children.

**Environmental Influences.** Many caregivers described their world in terms of what happens within the family and what happens in the world around the family. The theme of Environmental Influences, representing what happens in the surrounding neighborhood or broader context in relation to the family, emerged in the coding of two questions: Barriers to Goal Attainment and Supports for Goal Attainment. This theme emerged from caregivers’ descriptions of outside influences on their children’s lives and on the goals that caregivers have in mind for them. Across interviews, this theme was noted 58 times, with caregivers of a child

with asthma making 33 of those responses (compared to non-asthma families' 25 mentions). Caregivers reported significant effects of the environment on their goals for their children.

For barriers to goal attainment, caregivers spoke the most about outside influences on their goals for their children was when they were asked about barriers to their children succeeding (i.e., 28 sources, 37% of category responses). They specifically described the impact of environmental influences, especially the role of neighborhood, peers, and resources.

A large proportion of caregivers described the main barrier to their goals for the children as being related to living in under-resourced neighborhoods with frequent exposure to violence (i.e., 20 sources). This came through when caregivers described their hopes that their children will “*get out*” of the neighborhood into which they were born and “*be something*.” One caregiver said that “*I want them to do better...be better than most of society think that they in [sic] the neighborhood*.” Apart from anticipating their children needing to overcome negative perceptions based on their background, several caregivers had more immediate concerns with their living situation's effect on their children and the goals that they have for them. One mother explained that she and her daughter both experience symptoms of anxiety, living in a specific housing project in the city. She said:

*“We're one of the worst apartment projects that we live in...Lots of anxiety, depression, and just sleepless nights...Sirens, cops, you know just the cars, the train noise, the bullets. There's screaming, yelling, and fireworks...Unfortunately I cannot move. I'm sure it will traumatize her at some point.”*

Another mother explained that she sees her neighborhood as a barrier and tries to address it with her children. After describing several negative aspects of the family's living situation, she said:



*“I can't control [exposure to neighborhood violence]. I can sit down and talk with him, explain to him, you know, the things that are going on...sometimes we don't have control over in life. We can only control ourselves and what we do.”*

Other concerns revolved around perceptions that the neighborhood schools are not appropriate. One caregiver said that the biggest barrier for her goals is *“the school [child] go [sic] to because I really dislike it... 'Cause that's not where I want my child to be, but...”* and indicated that it was difficult for her to move out of the area to enroll in a different school. Some caregivers indicated that they were most concerned about the potential negative influence peers might have on their children's future successes. Five caregivers specified that negative peer influence was one of their perceived barriers to their children's goals. One caregiver said that the biggest barrier is *“the environment that I'm in, yeah makes it harder cause none of the kids around where I live at is respectful, all of them disrespectful.”* Another mother agreed, noting that the modeling in her neighborhood is not conducive to the plans she has for her children:

*“The public housing is not what it used to be, so you can't really teach your children...what you expect them to do, as far as the good things in life because you got the people in the neighborhood showing them the bad things in life.”*

Another barrier connected to neighborhood difficulties was a lack of resources. Several caregivers noted a lack of safe places for children to play and connect with each other. One mother said that it is difficult for her son to practice basketball due to lack of safe spaces. She said *“our area we live in like he doesn't get to go outside to play basketball and... 'cuz... the area we live in is not that safe.”* Other caregivers describe a lack of financial resources and job opportunities as negative environmental influences on their goals for their children's development. One mother said, *“My daughter sees what I go through, you know, living paycheck*

*to paycheck, and it's not good to live like that.*" While there were several caregivers who described difficult environmental barriers, a number of parents and caregivers also noted positive aspects to their neighborhoods and schools that serve to support their dreams for their children.

For supports for goal attainment, caregivers spoke most about the role of outside influences on their goals for their children when they were asked about supports to their children's success (i.e., 13 sources, 35% of category responses). They specifically described the impact of environmental influences, especially the role of positive people, school, and clubs/activities. Several caregivers reported that they felt having positive people in children's lives increased the likelihood that those children will be able to meet the goals their parents have for them. One caregiver suggested that-- when surrounded by positive, giving people-- you have a higher chance of success. She said, *"the more people you know...somebody might know what you wanna do can also help you go down the right path"* and that she would like to *"try to have [her daughter] interact with more, more of these [successful people]."*

A small group of caregivers said that they feel that there are positive people at school that can help their children (i.e., 4 sources). One caregiver said that *"school is helping [with attitude]-[child] has a little in-school counselor."* Another caregiver said that school is a support because her son *"has like four or five people at school that can help him...interact with him, check in on him."* Similarly, caregivers identified sports, clubs, and activities (e.g., Boys and Girls club, recreational sports) as positive environmental supports for their children. One caregiver acknowledged the negative aspects of where they live but shared her strategy for overcoming that particular barrier: *"where we live might make it harder but that's why I try to keep him as busy as possible."* The same mother who described the *"sleepless nights"* and fears of traumatizing her child because of living in their neighborhood also acknowledged the positive

activities that she has sought out to support her goal of having her daughter experience a “*stable, comfortable living situation;*” that is, she said that her daughter “*has church, [and] she has Girl Scouts.*” Thus, even while many caregivers describe significant environmental barriers and stressors that negatively impact their efforts to help their children succeed, a number of caregivers are also describing profound support within that same community. The theme of environment is a wide-ranging one.

**None, Unknown.** Finally, some caregivers endorsed not having any goals or not being sure of what goals they might have for their child. This occurred across most questions and was noted 39 times, with caregivers of a child with asthma making 17 of those responses (compared to non-asthma families’ 22 mentions). Responses highlighted the caregiver’s reluctance to predict their child’s future: “*He’s so young now and I don’t know what to expect from him,*” as well as their desire for their child to make her own goals: “*I don’t want her to be what I want her to be, I want her to figure out what she wants to be. I want her to set her goals, and I want her to go for it.*”

## **Domain 2: Beliefs About What Children Need in General to Reach Their Goals**

In addition to describing their own personal goals for their children, specifically, caregivers were also asked to describe their beliefs about children’s General Needs, Needs from Families, and Needs from Society to meet their goals. A total of five themes emerged across this domain and included: Positive Attention, Consistency, Internal Motivation, External Supports, and Education.

The theme of Positive Attention emerged in the coding of all three questions: General Needs, Needs From Families, and Needs From Society. This theme emerged from caregivers' perceptions that children thrive on warmth, encouragement, and positive regard, and that in some cases, this is sufficient for success (e.g., "*all you need is love*"). Across interviews, this theme was noted 287 times and represents the most common thematic response to any of the interview questions (i.e., 60.8% of sources), with caregivers of a child with asthma making 173 of those responses (compared to non-asthma families' 114 mentions). Caregivers reported a high value on the demonstration of warmth and encouragement, as well as verbal support and affection.

In response to the question about general needs, (i.e., what do children need in general to reach the kinds of goals the caregivers had described for their own children), caregivers overwhelmingly endorsed the theme of Positive Attention. Responses involving warmth or encouragement, positive relationships or love totaled 153 sources (i.e., 64% of responses to general needs). These responses largely centered on the ideas of support/encouragement, love, positive and open communication, positive relationships with others, affection and interest, as well as patience and understanding.

For many caregivers, the idea that love is sufficient for a child's relative success was a popular one (i.e., 45 sources). One caregiver said that all children need is "*love from their mamas and daddies.*" Another caregiver agreed that love was important but added that the role of attention also plays a large part in determining a child's success, saying that "*with love and attention, everything else will follow.*" Similarly, one mother said that love is the foundation for other positive interactions that will ultimately support a child's development. To her, "*Love, that's first...caring for them, respecting them, paying attention to them, helping them.*"

Other caregivers noted that love and warmth may be conveyed by different people in different ways. One grandmother said that love is not sufficient, one must demonstrate love through behaviors:

*“TLC, that's the biggest thing. If you give that to your child...a lot of issues wouldn't be there, because they feel they have attention...Not you verbally telling them, you have to show them that you love them.”*

Several other caregivers agreed, saying that the biggest way someone may show love rather than saying words of affection is via demonstration of respect. “*Respect*” was often a vague term used throughout the interviews, but one caregiver gave a specific example of what giving respect to a child might look like. She explained:

*“I think parents need to communicate with their children...hear both sides, hear [the child's] side, give them a piece of their side and come to some type of understanding together.”*

While the majority of caregivers’ responses to this general need actually focused on what parents may offer their children, rather than encompassing a broader sense of what children might need across domains, it is interesting to note that caregivers tended to gravitate towards family-based contributions, rather than environmental supports. Of course, caregivers who spoke more generally were also asked about their beliefs regarding what families specifically can offer children.

In a pattern similar to that of the General Needs category, the theme of Positive Attention represented the most common response within the category of what children need from families in order to reach goals (i.e., 65 sources, 62.5% of category responses). Caregiver responses were similar in their highlighting of the role of love, communication, and understanding/acceptance of

a child. Additionally, several caregivers discussed the role of one-on-one time that families can spend with children in order to support their growth, development, and success. The majority of the focus, again, was on the warmth that parents and primary caregivers can provide, with a number of caregivers sharing the opinion that parents simply do not spend enough time with their children. One statement from a caregiver highlighted a common refrain; that is, children today exhibit greater behavioral and emotional dysregulation because they do not have the positive attention from their parents. She said:

*“Y'know lot of parents don't sit down with their kids and conversate or watch a movie, spend time with their kids. And I think that's why a lot of kids are the way they are these days.”*

In that statement, the caregiver simultaneously highlights the importance of positive attention on children's development, as well as offers an example of one-on-one time that provides an opportunity for caregivers to connect with their child and intervene on their development.

Another caregiver offered that, while outside entities (e.g., school) can certainly provide positive attention and support, she feels that without a family to provide that at home, children will not succeed. She shared:

*“[Children need] love. 'Cuz a lot of children don't get love or affection that they need at home, 'cuz I feel like it all starts at home before they go to school; they need to know that they are loved, cared about.”*

In a similar vein, some caregivers alluded to the protective effect that positive attention can have on youth. A few caregivers noted that if a family cannot provide encouragement and affirmation, children will seek it out from peers or within other environments, some of which may be detrimental to the goals that they may have. One caregiver said that *“I show my kids love*

*everyday 'cuz if they don't get it at home, they gonna get--they gonna try and get it somewhere else.*” Another specifically shared her concerns that without positive attention at home, her children would turn to the relative comfort and support of a gang:

*“No matter what, you have to show your child that you love them because then they'll turn into gangs or in jail because they don't feel like they have that love at home.”*

The easiest way --according to several caregivers-- to show children that they are loved is to *“just be there for them.”* While this is a broad statement, it does highlight the relative importance of this theme for families; that is, no specifics are needed, love and support from families are both necessary and sufficient for children’s success.

For needs from society, outside of the family, places like school, the neighborhood, and the broader environment (i.e., society) may also offer positive attention to youth. Once again, the theme of Positive Attention represented the most common response within this category; that is, what children need from society in order to reach goals (i.e., 69 sources, 54.8% of category responses). As within their responses to what kinds of positive attention families might offer children, caregivers highlighted the importance of society offering youth encouragement and support, love and understanding, opportunities to connect with others and work together, as well as access to positive influences. The majority of caregivers spoke directly about what school or their neighborhood might offer children; there were no responses about the broader environment or society as a whole.

For some caregivers, the demonstration of respect and offering of encouragement is integral to children’s abilities to meet goals and succeed. One caregiver offered that members of the community might pay greater attention to children’s thoughts and ideas. Specifically, *“when [children] say they wanna do different things, [you] don't have to close 'em out so much.”* For

other caregivers, simply having a cheerleader or trusted adult may be enough for children to feel supported. One caregiver said that she believes kids “*just need someone to care about them [at school],*” while another agreed that the most valuable source of support for children are “*people in their corner--other teacher, or principal, or tutor, or counselor.*”

The role of teachers as positive influences was often discussed, with caregivers noting teachers’ unique ability to serve as a positive role model and be able to offer support and guidance outside of the home or direct neighborhood. Caregivers reasoned that “*at the school there's always someone to talk to.*” Specifically, caregivers pointed to teachers going the extra mile and supporting children’s goals and dreams with their encouragement and support. One mother said that in order for school to effectively support children’s goals, “*teachers...need to really care about [the kids] and really help them,*” and another caregiver agreed that a powerful component of school providing positive attention to youth is when “*[teachers] find that extra time and pull [the struggling child] aside and at least try to help them.*”

Regardless of where the support or encouragement is coming from, a large proportion of caregivers acknowledge the idea that children benefit the most from being surrounded by positive influences and people who can provide attention and the opportunity for connection. Older caregivers (e.g., grandmothers, great-aunts) reflected on the ways parenting and neighborhoods are changing, speculating that these changes may be reducing the amount of support children receive. One grandmother noted:

*“I was raised where it took a village to raise me...But now since I've gotten older and grown...[people] are not around...everybody has their own stuff going on...That's why, in my eyes, we are having issues we are having here, because we don't care about other people anymore.”*



Other caregivers agreed with the importance of community as providers of support and encouragement to children, as well as havens for connection and positive influences. Caregivers agreed that "everyone should stick together [in the community]" and that adults should open their homes to neighborhood youth in order to support healthy choices and relationships with peers. For example, one mother said that what children in her neighborhood would most benefit from would be "more people who allowed the children [in the neighborhood] to come in your house [instead of being on the streets]." Whether within the home or coming from the community around them, for many caregivers, the importance of positive attention for children's development and success was evident.

**Consistency.** Perhaps in contrast, or as a complement the above theme, caregivers very often described a need for children to experience structure, routine, and discipline in order for them to succeed in meeting their goals. The theme of Consistency was present across all three questions: General Needs, Needs From Families, and Needs From Society. This theme emerged from caregivers' perceptions that children cannot be successful without the structure and routine in place to support them. Across interviews, this theme was noted 108 times and represents a fairly common thematic response to any of the interview questions (i.e., 22.9% of sources), with caregivers of a child with asthma making 66 of those responses (compared to non-asthma families' 42 mentions). Caregivers reported that things like stability, structure, and mentorship/guidance were particularly important in supporting children's development and success.

When asked generally about children's needs in order to be successful, the theme of Consistency came through via discussion of stability, with 55 sources mentioning things related to guidance or teaching, discipline, boundaries and expectations, co-parenting, and family

support (e.g., child care). Generally, several statements about parenting practices and co-parenting were made, highlight the perceived importance of consistency and stability in rules and expectations between parents and children. One mother said that to her, it is of the utmost importance for *“both parents on the same page and [parents] to be a little strict,”* in order to ensure children’s proper development and future success. Another mother agreed, noting that:

*“I ain't trying to be hard or the mean mama, but at some point you have to be firm with your kids and say whatcha mean and mean whatcha say. Otherwise...they just gonna run on top of you...that's not gonna happen. I can't let that happen. I can't.”*

The idea of setting boundaries and expectations came through, with several parents discussing the role of discipline, physical or otherwise (e.g., *“correct and discipline in love”*) and consequences, positive or negative (e.g., *“parents maybe rewarding them when they do good, be hard on them when they do bad”*).

Other general needs related to Consistency included the idea of children receiving *“leadership,”* which was often described as *“somebody to set goals for them”* or *“somebody to...push them and steer them in the right direction.”* Caregivers also described the importance of a *“good support system”* and the role that routine and consistency might play in mitigating negative effects from a disorganized or chaotic environment (e.g., neighborhood with high levels of violence). One caregiver highlighted the role of evening routines and expectations in managing children’s behavior, saying:

*“We can't control what goes on in the external part of whatever's going on in the outside. But in the inside I can control [things] to an extent.”*

In response to the general needs question, several caregivers differentiated between the role of Consistency within families (e.g., parenting practices, family support) and within the environment, society as a whole.

With regards to specific aspects of Consistency that families may provide to children in order to help them meet their goals (i.e., Needs from Families), the idea of structure was one that several caregivers gravitated towards (i.e., 32 sources). Things like discipline, security or stability, and safety/protection were mentioned as specific components of family-based structure that were perceived as most helpful. Most caregivers agreed that children need to be able to find a family member to “*be the backbone to help them...get there, reach their goals.*” A common aspect of security or stability was the perceived importance of dual-parent households. Several mothers noted that children need their fathers in their lives (e.g., “*to see their father be around*”) in order to be successful. Another mother agreed, noting her own stress around being a single parent and the effect she perceives this to have on children:

*“It's all on me basically...All kids really need their daddy, 'cuz you can't teach them much as a daddy can...And I feel sorry for my son 'cuz he don't have that.”*

Another female caregiver agreed that a male influence is important for families but said that it “*doesn't have to be a dad, but some type of guy [at the home].*”

Other caregivers described different aspects of home life (e.g., “*helpin' a child out with their homework*”) in which consistency is most helpful. For example, several caregivers noted that discipline and routine are key to children’s development. One mother said that she imagines other households rely on routines as much as her children do:

*“Routine is really big. We're really big on routine at the house, and if routine gets messed up, it seems like the kids just fall apart.”*

Outside of routine, a common refrain centered on the role of discipline and the parent as an authority figure. One mother said that it is important for children to understand that “*We can still have fun together...where they understand that I'm still mom, I'm not their friend.*” Another mother agreed that children need a leader and authority figure in their lives in order to be successful, though she emphasized a no-nonsense approach to parenting that few other parents shared:

*“When people hear the word “love,” they attach “unconditional” to that. No, love is a condition. If you want me to love you, these are the conditions, okay? I'm the mother, I lay down the rules, and we abide by them so I can raise you to be a productive citizen in the world.”*

For many caregivers, the idea of discipline and structure were intertwined with safety and protection. They felt that children need families specifically because they “*need you to protect them*” from negative influences and experiences. Families, then, can serve as powerful protectors, guardians, and authority figures.

For needs from society, with respect to what children’s neighborhoods or schools might provide by way of Consistency, caregivers specifically highlighted the idea of mentorship. For many of them, this comes from positive adult influences that provide discipline and guidance or teaching, within neighborhoods, schools, and faith communities (i.e., 21 sources). One caregiver highlighted the multiple ways in which children may be shaped by consistent monitoring and guidance from their environment: “*Church, people at church...take a part of molding a child...people at school...[take a part of molding a child]...neighbors...[take a part of molding a child].*”

Other caregivers specifically pointed to schools' roles in providing consistent discipline and structure to children. Several caregivers felt that schools do not do enough to support children via discipline and routine. One woman believed that *"school need [sic] to be more strict on the kids...[school] need to be more discipline [sic] on the kids that are acting up so it won't affect the other kids."* Another caregiver agreed, noting that children benefit from strong involvement from adults, specifically from *"[leadership] from school teachers...and [neighbors] stepping in and telling [child]...you don't need to play with those kids...they're...not the kinda kids you need to play with."* For many caregivers, the structure and routine present at school also serves as a measure of safety and protection. One father said that *"even when [children are at school] they need to feel safe."*

For other caregivers, the role of neighborhood structure and discipline was a prominent point of discussion. Several caregivers discussed the need for community involvement in *"keeping kids off the streets"* and monitoring their activities via opening up their homes to host children. This monitoring is seen as a way to enforce safety and encourage routine. One mother said that she is saddened by what she perceives as a loss of structure and routine in her neighborhood, and that she feels this has a negative impact on the children living there. She shared:

*"In my neighborhood...I'm not judging anyone because I understand there's a lot of single mothers...constantly working...trying to provide for their household. ...I see parents that work all day long and their children roaming the neighborhood, and sometimes [parents] have no idea what's going on...Some structure and discipline with children can honestly make you a lot closer with your children...it will make them straighten up and make them love you more."*

Of note, very few caregivers described specific discipline strategies that they endorse. There were some instances of caregivers describing the use of physical discipline, but most declined to talk about what they or the broader community believe are best practices. A handful of caregivers, however, did share their opinions that not only are today's children suffering from lack of structure or discipline, but that they are specifically losing out on character-building via corporal punishment. One grandmother shared that "*But children now don't get whoopings...I think some of the old ways is the best ways [for punishment]...But you know what, it's children raising children that's the problem.*"

Among caregivers weighing in on the role of families, schools, neighborhoods, and the broader community, the theme of Consistency emerged with some regularity. Caregivers appeared to recognize the importance of children receiving support via routine and consequences, in order for them to be successful in reaching their goals.

**Internal Motivation.** The theme of Internal Motivation emerged in the coding of responses only for the question asking about general needs; however, it accounted for nearly 5% of total responses across interviews and hearkened back to the previous question's theme of the Role of the Individual. This theme emerged from caregivers' perceptions that children cannot be successful if they lack the drive and motivation to achieve. Across interviews, this theme was noted 22 times, with caregivers of a child with asthma making 16 of those responses (compared to non-asthma families' 6 mentions). Caregivers reported that things like children's motivation and focus, self-esteem, personal attributes or skills, and faith (i.e., "*gotta believe in God*") are important to their achievement and growth.

For general needs, while caregivers tended to note specific attributes or skills that children may need in order to achieve goals (e.g., *intelligence*, "*a strong mind*," problem solving

skills), some described the importance of children developing self-esteem and internal motivation. For example, one caregiver said that children need to be able to “*just to say [to themselves]... 'I'm gonna be somethin.' I'm gonna be somebody out of life.*” One mother said that she thinks that if children can develop a strong sense of self, they can accomplish anything. She said:

*“And so I think as long as he knows that I'm in his corner, and I love him and that...my husband loves him, and we make him feel good about himself, and he has that self-respect that he'll just do fine.”*

Other caregivers noted that part of developing internal motivation and drive was to mature emotionally. One caregiver said specifically that before children can work towards any of the goals she described, they must have basic socio-emotional skills on board. She said that “*social and emotional part need to be developed before we focus on anything...[children must] be able to describe their emotions.*” Other areas of development mentioned included being able to plan ahead for goals (i.e., “*think how [their] actions will...affect [their] future*”) and become independent thinkers and doers. One mother described how the latter is very difficult for children to achieve these days, due to constant distraction and digital entertainment. She noted that “*This is really hard to achieve today...to really give kids time where...they can be autonomous. So moments of boredom are not bad.*”

Still other caregivers described the ways in which learning and children’s internal drive to succeed might develop from outside influences. For example, one mother discussed how children in her community might learn from adults in their lives and set different goals than the generation before them. She said specifically that

*"...just because I didn't finish college doesn't mean that [my daughter] won't finish college...You watch what your parents go through, most of the time, you don't want to go through that."*

Thus, while a number of caregivers agreed that internal motivation and drive is a key contributor to children's success and goal attainment, it became clear that they also acknowledged the importance of external or environmental supports in facilitating children's growth.

**External Supports.** Similar to the previously described theme of Environmental Influences, this theme alludes to forces outside of the child-caregiver dyad or immediate (i.e., nuclear) family structure that contribute to a child's successes. The theme of External Supports was present across all questions addressing General Needs, Needs From Families, and Needs From Society. This theme emerged from caregivers' perceptions that children cannot succeed in a vacuum; that is, goal attainment almost certainly requires outside support. Across interviews, this theme was noted 21 times, with caregivers of a child with asthma making 12 of those responses (compared to non-asthma families' 9 mentions). Caregivers reported that resources, educational opportunities and supports, as well as extended family and neighborhood contributions serve to impact children's potential and goal attainment.

For a small proportion of caregivers, what came to mind when asked about things that children generally need in order to be successful was having their basic needs met. One caregiver explained that she thought the most important thing for children was the "*more physical kind of support you can give a child.*" Another mother expanded on this, saying that the things most children need in order to accomplish anything is "*healthy food and a sturdy home.*"



Other caregivers mentioned the idea that all children really need in order to succeed is a good education. A common sentiment was “*Education is the key.*” However, some caregivers acknowledged that, while education is an important resource, many children do not receive adequate support academically, due to decreased funding or perceived disinterest on the part of teachers and administrators. One caregiver discussed ways in which different community groups (e.g., recreation centers, Boys and Girls club) might support children outside of the school day. She noted that while education is a highly important external contributor to children’s success and goal attainment, it is difficult:

*“Cuz a lot of these places don't have too much resources for half the kids out here and for them to get the support that they need.”*

For some caregivers, then, it was clear that the majority of external support for children might have to come from additional sources: extended and chosen family.

In response to the question addressing needs from families, seven unique sources described the role of extended family in providing external support to children and primary caregivers. For the majority of them, children are indirectly supported by these adults via parenting support (i.e., extended family providing helping caregivers perform day-to-day activities). One mother said that it is helpful for children when “*our other kin folk [do] the other stuff I can't do.*” Another caregiver agreed, saying that it is optimal for there to be “*someone else [that the child can go to] if there's something the parent don't [sic] know.*” And while the majority of these respondents specifically pointed to extended family as sources of parenting support, one caregiver disagreed, saying that a child could benefit from co-parenting by “*anybody that's a good leader, it don't have to be your mom or dad; parents, aunts, uncles, even if it's not family, just some kind of support.*”

While a sub-section of caregivers highlighted the role of extended family providing external support for children, caregivers more often discussed ways in which the larger community (e.g., neighborhood) fulfill the same role.

For needs from society, it was more common for the theme of External Supports to arise within the category of what society can offer children in support of goal attainment. Twenty-one sources described the types of resources and supports the broader community can provide, including clubs and activities, safety and protection, as well as parenting support/co-parenting. Caregivers generally agreed that “*everyone should stick together [in the community].*” Across interviews, there was a general sense of the importance of community on children’s development, with some caregivers directly connecting children’s development of a sense of self with a sense of belonging in their environment. One caregiver emphasized that children ought to receive “*support in the community, by the community,*” and that this is what is best for their continuing growth and future goal attainment.

Specific sectors of the community that were mentioned as particularly helpful in supporting children’s development were faith communities and peer relationships. One caregiver extolled the helpfulness of the family’s church in supporting youth’s positive development, noting that children “*get support as well from our church...our pastor is good...he [takes] time to listen.*” Another described how it is important for children to find peers in their schools or neighborhoods who are also motivated to succeed, saying that children need “*peers that’s also trying to reach their goals, not just lollygagging...[Personally,] I’m not going to let [my daughter] have those type of friends [who run in the streets].*”

Many caregivers agreed that a major component of environmental support for children involves keeping them safe and busy with productive activities. When asked about what kinds of

supports she thinks children need from their community, one mother said that all kids could benefit from “*after school program [and] extra tutoring.*” Other caregivers specifically mentioned the boys and girls club or Scouts, and a few said that community centers are helpful for children looking to keep busy; for example: “*the recreation center...doors are always open for the kids.*”

Another group of caregivers de-emphasized the importance of formal community supports and highlighted the idea of “*community support by the community.*” As was noted in the Consistency theme, some caregivers expressed a desire for community members to open up their homes to youth in hopes of keeping them occupied and accounted for. This idea re-emerged with a greater emphasis on community members providing parenting support to busy primary caregivers. One aunt said that:

*“[My niece] comes to my house with her group of friends--there's like six or seven of them-- and I let them sit in my living room and all they wanna do is listen to they music and eat up my snacks...It keeps them out the street. They all right here, I'm looking at everybody, everybody is accounted for.”*

The takeaway message from the majority of these caregivers is that children benefit the most when “*the community and school...they do the stuff I [as a parent] can't do.*” Specific attention was also placed on the role of schools providing that support, either from formal instruction or things like, “*after school tutoring...[kids at tutoring] get help with...things that they need.*” Education again emerged as a major theme for caregivers describing what children need the most in order to reach goals.

**Education.** Finally, while it is an external support (or barrier), Education was widely discussed as a singular influence on children’s relative success or failure in goal attainment. The

theme of Education emerged in the coding to two questions: General Needs and Needs From Society. This theme emerged from caregivers' perceptions that children's early success or lack of success in academic pursuits often sets the stage for whether or not they will be able to achieve their goals later in life. Across interviews, this theme was noted 20 times, with caregivers of a child with asthma making 13 of those responses (compared to non-asthma families' 7 mentions).

In response to the initial question about what kids generally need in order to reach the goals caregivers have for them, a small number of caregivers emphasized the importance of children *"to stay in school."* (i.e., 5 sources). The focus appeared to be on children having teachers that would be able to support them academically and emotionally. One caregiver said that kids at school need *"concern...someone to pay attention to them, to try to understand...a child."* Another caregiver agreed, saying that *"teachers...need to really care about [the kids] and really help them...[teachers] find that extra time and pull [the struggling child] aside and at least try to help them."* One mother reasoned that *"[Parents] don't have...time to teach [kids] a lot of things, so [teachers] can pick up where we slack. We need them."* The consensus appeared to be that, in order for children to stay in school and thus be able to meet the goals that caregivers have for them, schools need to provide a solid education via engaged and supportive teachers. This idea persisted when caregivers were asked specifically about ways in which society can contribute to children's success.

A total of 15 sources described the importance of society (e.g., neighborhoods and schools) providing a good education to children in order for youth to be successful. The majority of this group emphasized the need for school administrators to hire good teachers and to improve conditions of schools. The key to a successful educational experience for many caregivers is simply having a *"teacher teaching [children] well in school."* However, caregivers

acknowledged that this is more complicated than simply hiring strong educators. One caregiver said that she agreed with the fact that “*we need better teachers...[and we] need someone to come in and say ‘Let’s pay these teachers \$75,000 a year, give them free supplies, give them an incentive to teach these kids.’*” This was a sentiment echoed by other caregivers; that is, that in order for children to have access to top-notch educators, something in society must shift. One caregiver described how children may be better served if society valued education and teachers more highly. She pointed out that:

*“Because how can you expect an adult who’s barely scraping by to be a positive role model in your life? When they’re...upset about things...You can’t pay your bills and you want them to come and teach your child?”*

Other parents pointed to a lack of leadership within the school district as an area for improvement. One caregiver said that districts should be looking for “*...better administrators to these schools to manage the money,*” in order to ensure fair pay to teachers and access to needed resources (e.g., “*in school they need...more people to translate to the Spanish people*”). Another caregiver discussed ways in which school cultures might be changed from administration down to students, in order to ensure that all students have a chance to succeed. One mother said that she thinks,

*“[schools] need to learn...every child is different...[schools] need to understand every child is different and they come from very different households...[schools] need to take time to pinpoint which [students] are going through stuff instead of just throwing them together like that.”*

A father of a young boy agreed with the importance of school providing more than an academic education, noting that children are best served by an education that prepares them academically

and socio-emotionally. He said that he would like for schools and society in a broader sense to focus

*“socially, promoting the kids to promote...and applaud other kids that are excelling. Because sometimes in school, you get picked on for being real smart. But it's like, if a lot of the other kids would push their classmates to do better, it could help eliminate that whole thing of them [trying] to be someone that they are not and trying to hide the fact that they are smart.”*

While Education emerged as the smallest of themes across interviews, it is clear that the issue weighs heavily on the minds of many caregivers, and that the concept of “*education*” may be taken to mean many different things (e.g., academics, social learning, emotion identification, development of identity). For a number of caregivers, it appears that a good education -- whatever that means to them-- is essential for children’s goal attainment and later success.

### **Between Group Comparisons**

The number of caregivers who identified specific themes across interview questions was also examined by their child’s asthma status (i.e., asthma versus non-asthma). Generally speaking, caregivers of children with asthma had higher frequencies of responses across themes than their non-asthma counterparts. For Question 1 (i.e., Caregiver Goals) caregivers of children with asthma made more mentions of all themes, with the exception of the None, Unknown theme. Non- asthma caregivers evidenced a higher number of responses from which this theme emerged. Indeed, when comparing group rates of theme mentions, caregivers of children with asthma contributed to 60% of total mentions across all themes for this question (i.e., 870 codes).

**Table 4***Cross-Group Analysis by Asthma versus Non-Asthma - Total Number of Sources (Q1)*

Theme	Total # of Sources	# of Sources for Families with a Child with Asthma	# of Sources for Families without a Child with Asthma
Achievement	223	140	83
Actualization	132	89	43
Role of the Individual	131	76	55
Safety & Security	119	61	58
Connection	108	64	44
Family	60	39	21
Environmental Influences	58	33	25
None, Unknown	39	17	22

In addition to examining cross-group frequencies across total mentions of themes, the frequency at which individual caregivers discussed themes within their interviews was also calculated.

**Table 5***Cross-Group Analysis by Asthma versus Non-Asthma - Individual Mentions of Themes (Q1)*

Theme	# of Caregivers with a Child with Asthma ( $n = 41$ )	# of Caregivers without a Child with Asthma ( $n = 44$ )
Achievement	38	37
Actualization	37	24
Role of the Individual	38	28
Safety & Security	33	30
Connection	32	25
Family	27	14
Environmental Influences	23	16
None, Unknown	26	18

It is interesting to note when comparing the two tables that the frequency at which asthma versus non-asthma caregivers mentioned specific themes looks different when examined from a broader perspective (i.e., comparing total number of mentions) in contrast to a more individual level. For example, while a similar number of caregivers brought up the theme of achievement (i.e., 38 caregivers of a child with asthma versus 37 caregivers of children without asthma), when looking at total number of mentions, caregivers of a child with asthma discussed this theme more frequently in their interviews (140 mentions versus 83 mentions). Similarly, caregivers of a child with asthma were more likely to mention the theme of family, and they discussed this theme more in-depth, as compared to their non-asthma counterparts. However, across both tables, a similar number of caregivers in both groups mentioned safety and security, and they seemed to have discussed this about the same amount.



A similar pattern was evidenced for Question 2 (i.e., Caregiver Beliefs), in that caregivers of children with asthma had higher frequencies of responses across all themes, as compared to the non-asthma caregivers. These caregivers contributed 61% of total mentions across all themes for this question (i.e., 458 codes).

**Table 6**

*Cross-Group Analysis by Asthma versus Non-Asthma – Total Number of Sources (Q2)*

Theme	Total # of Sources	# of Sources for Families with a Child with Asthma	# of Sources for Families without a Child with Asthma
Positive Attention	287	173	114
Consistency	108	66	42
Internal Motivation	22	16	6
External Supports	21	12	9
Education	20	13	7

**Table 7***Cross-Group Analysis by Asthma versus Non-Asthma - Individual Mentions of Themes (Q2)*

Theme	# of Caregivers with a Child with Asthma ( $n = 41$ )	# of Caregivers without a Child with Asthma ( $n = 44$ )
Positive Attention	36	34
Consistency	26	25
Internal Motivation	11	6
External Supports	14	11
Education	9	6

With respect to caregivers' beliefs about what children generally need in order to reach the kinds of goals that they described for their own child, individual responses clustered around two main themes: positive attention and consistency. While the total numbers of mentions favor higher frequencies of discussion from caregivers of a child with asthma, the individual level suggests that caregivers reported very similar beliefs around what children need in order to be successful. An interesting difference may be found in the theme of individual motivation. Caregivers of children with asthma were more likely to mention this theme (i.e., 11 caregivers compared to 6 caregivers), and they were more likely to discuss it in depth (i.e., 16 mentions compared to 6 mentions).

## Discussion

### Summary and Discussion of Findings

Asthma is a major public health concern that disproportionately affects Black youth, as well as children living in under-resourced, urban environments (Akinbami & Schoendorf, 2002;

Center for Disease Control and Prevention, 2014). While there is a large body of research examining the impact of asthma on children and families, the majority of the existing literature has focused on these aspects within the context of improving adherence rates (Jandasek & Fedele, 2014). Yet rates of asthma adherence remain consistently suboptimal (McQuaid, Kopel, Klein, & Fritz, 2003). One reason postulated for this relates to the increased number of competing priorities that some studies documented for caregivers of color, as compared to their white counterparts, including stress, substandard housing, lack of social support, and other factors (Naja, Permaul, & Phipatanakul, 2018; Wu et al., 2008). Increasing our understanding of caregiver goals may be one avenue for improving conceptualizations of competing priorities to adherence.

The current qualitative study addressed this gap in the literature through the use of semi-structured interviews with Black caregivers of children with and without asthma who lived in high burden, urban areas. The aims of the current study were (1) to conduct a qualitative analysis of caregiver goals for their children, using grounded theory techniques to elucidate themes across goals for child socialization and development, and (2) better understand differences and commonalities among caregivers of similar backgrounds who are or are not raising a child with asthma. It was hypothesized that caregivers would report a wide range of experiences and goals, including significant positive influences and burdens attributed to raising a child. Furthermore, it was hypothesized that caregivers would discuss specific aspects of their parenting, including the role of neighborhood or community context, as well as caring for a child with a chronic illness.

Overall, 13 themes emerged across the caregiver goals for their children, as well as beliefs about goals for children domains that reflected the aims of the current study. These domains also reflected the influence of perceived barriers and supports regarding goal

attainment. The findings from this study highlight areas for future research and provide useful information for clinicians and medical providers.

### **What are caregivers' goals for their children?**

**Descriptions of Goals.** The primary aim of this study was to better understand Black caregivers' goals for their children within low-resourced urban settings. Approximately half of the sample were caregivers of children with asthma. Caregivers from both groups were asked the same, standardized interview question about their goals for their child who participated in the study. Some caregivers provided in-depth replies to this initial question, while others gave brief answers and were therefore prompted for more information using standardized prompts (e.g., goals for personality, career, etc.). Many of caregivers' responses can be connected to previous work on caregivers' goals for their children across cultures (i.e., Dix & Branca, 2003; Harwood, Miller, & Irizarry, 1995), as well as specific socialization or developmental goals relevant for Black families (e.g., Hill, 1997).

*Achievement.* This theme emerged from caregivers' responses to questions about general goals, personality goals, relationship goals, and career goals, and was the most commonly described theme. Caregivers described goals for their children to “*be something*” and attain educational, financial, and their own personal success. For many caregivers, this was defined by graduating high school and attending college, as well as having a “*professional*” career (e.g., white collar or professional athletics). The theme of educational attainment is in line with work by Dix and Branca (2003) that suggested achievement in school is a common goal for parents and caregivers across cultures.

With respect to Black caregivers, specifically, in her book on Black families, McAdoo noted that educational attainment has traditionally been a source of pride for many African

American families (McAdoo, 2002). She goes on to suggest that “the greatest gifts Black families have been able to bestow upon their children are the...skills necessary to succeed in school” (McAdoo, 1997, pp. 147). Education is often seen as key to upward mobility, despite the effects of systemic racism that can contribute to the expectation and realization of decreased academic achievement for Black children (Ogbu, 1974). Overall, results from the current study that highlight the theme of Achievement corresponds to Hill’s (1997) typology of African American family strengths. His work highlighted Black families’ messages supporting a high achievement orientation, as well as a strong work ethic (Hill, 1997). Barbarin, McCandies, Coleman, and Hill (2005) describe the historic role of academic achievement in Black families as a “means of shaping the destinies of African American children” and have promoted education as a “central value” (p. 227).

Although neighborhood and school contexts are undeniably linked to youth academic achievement, families and parents are critical to positive outcomes in this domain, as they are able to buffer and interpret the effects of those more distal contexts (Barbarin et al., 2005). Among low-income Black families, parental expectations is a consistent predictor of youth academic achievement, controlling for other demographic variables (Reynolds & Gill, 1994). Early caregiver expectations are predictive of later school success, as well (Butterly & Hill, 2003; Hill & Bouffard, 2003). There is a large literature highlighting the relevance and importance of caregiver support and emphasis on academic achievement in Black youth (e.g., Jeynes, 2005; Wu & Qi, 2006). Additionally, there is emerging evidence supporting that racial and ethnic socialization is positively related to academic and cognitive performance for Black students across age groups (Hughes et al., 2009). Specifically, particular categories of racial/ethnic socialization messages, such as those related to awareness of racial barriers, have

led to better grades (Sanders 1997) and higher academic performance in African American students (Bowman & Howard 1985). Additionally, both maternal and paternal reports of socialization messages about African American history, heritage or racial pride are predictive of better grades among adolescents (Brown et al., 2009). Racial/ethnic socialization messages specific about self-worth and cultural pride are also associated with greater academic curiosity and persistence in the classroom (Neblett et al., 2006). Thus, African American families' historical and cultural emphasis on academic achievement is bolstered by Black caregivers' messages to children about their self-worth and self-efficacy.

*Actualization.* Dix and Branca (2003) also proposed happiness as a universal goal that caregivers share for their children. The current study's results support this idea, with the theme of Actualization emerging from caregivers' descriptions of their own goals for their children. While the words "*be happy*" were rarely used in this sample of interviews, caregivers did describe desires for their children to maintain a "*positive attitude*" and to do things that would make them happy. Caregivers expressed a desire for their children to continue growing and becoming "*the best*" version of themselves. This emphasis on being the best and doing things to be happy and confident in oneself supports previous findings that African American parents of young children placed significant emphasis on self-maximization goals than European American caregivers (Suizzo, 2007). One interpretation for this is that promoting self-esteem among children is deemed important in African American culture as one way of buffering children from the negative effects of racism and minority status (García Coll et al., 1995; Spencer & Markstrom-Adams, 1990). Suizzo (2007) noted that one explanation for her finding is that European American parents may rate self-enhancement goals lower than their African American counterparts because they may be more confident that their children will have access to future

opportunities for achievement. She mentioned that because they are not exposed to the discrimination faced by ethnic minority families, white parents may have greater trust and confidence in the systemic processes that have allowed them to obtain and maintain positions of power (Suizzo, 2007). Although the current study was not designed to examine the underpinnings of caregivers' specific socialization goals, it may help inform future studies that aim to better understand caregiver goals and the socialization processes that influence them.

*Connection.* The role of social connection was evident across interviews and emerged as a theme related to personality and relationship goals. Consistent with one of Dix and Branca's (2003) universal goals for caregivers, many caregivers in this study shared that they hoped their children would have friends and maintain positive social relationships with peers and members of the community. A key aspect of this theme was the role of respect. Caregivers said that they hoped their children would both receive and give respect to those around them, especially those who are older and in a position of authority (e.g., older family members, teachers, parents). This finding is also consistent with previous work that showed the importance placed on being obedient and respectful of elders in the family and the community within Black families (García Coll et al., 1995). The socialization goals of African American parents-- including those around demonstrating respect to elders-- may reflect values that originated from their traditional community, those of the mainstream American culture, as well as those that have arisen from the unique challenges they faced as an oppressed group (García Coll et.al, 1995; McAdoo, 2002). Similarly, early work by Nobles et al. (1979) cited in McAdoo's *Black Families* (1997) highlights the role of positive social relationships within Black culture as a source of connection, attachment, validation, worth, recognition, respect, and legitimacy that prepares youth for responding to complex or unfamiliar experiences outside of their home or community. Overall, it

is not surprising that caregivers, particularly caregivers of color, would emphasize the importance of their children's connections to others.

*Safety and Security.* Perhaps in contrast to, or as a complement to, the goals of self-actualization and achievement, a number of caregivers also described goals related to an overall sense of safety, security, and stability. This theme emerged from many descriptions of practical or pragmatic goals that caregivers described (e.g., “get a job”), as well as hopes that their children will stay the course and follow in their caregivers' footsteps. Interestingly, this is where we might expect caregivers to have described health-related goals or asthma-specific goals; however, there was only one mention of asthma within this domain (the other fell within “What needs to happen in order for your child to reach the goals you have for him/her?”). Dix and Branca, proposed that the safety and health of a child reflects a near-universal goal for caregivers across cultures (2003).

While safety was widely discussed by caregivers, specifically in the context of neighborhood safety and the impact of exposure to violence, preventative health care -- mental or physical-- received almost no attention. This may be in line with the idea put forth by Riportella-Muller et al. (1996) that Black families living in urban settings can have a high burden of competing responsibilities that are barriers to the use of preventive health care services. In their study of parental health beliefs and asthma management, Wu and colleagues (2008) found that parents of racial/ethnic minority children had more concerns about medications and higher levels of worry about competing life issues such as housing, income, safety, jobs, and family relationships; this was true after controlling for income and education. It may be that long-term health outcomes are outweighed for many of this study's caregivers by more immediate priorities. However, it is also important to note that caregivers' responses were within the context



of answering general questions about their goals, rather than specifically addressing health-related topics. It may also be that cultural differences in beliefs about health and healthcare generally shape caregivers' cognitions about the health of their child.

There are a number of studies examining cultural variations in beliefs about healthcare and preventative medicine that may bolster this finding. Potential explanations for disparities in overall health care use include differences in health insurance, resources for out-of-pocket costs, geographic proximity to care and adequate transportation, health literacy and knowledge, cultural traditions favoring nontraditional or noninvasive care, confidence or self-efficacy in the ability to complete prescribed regimens, trust and cultural compatibility with physicians, and the effects of both subtle and overt racism (Katz, 2001). Black families may receive messages over their lifetimes that subtly discourage or even prevent them from getting what they need, across medical settings and in the broader environment (Williams, 1994). Similarly, the paucity of minority physicians may influence preferences for care (Larkey, Hecht, Miller, Alatorre, 2001). Less than 11% of all US physicians but more than 20% of all patients identify as either Black or Hispanic (Association of American Medical Colleges, 2019). Thus, many patients of color who would prefer an ethnically-matched physician cannot find one. In fact, many patients live in areas with few physicians nearby (of any race or ethnicity) and experience this lack of access as a major problem (Saha et al., 2000). It may be, then, that the lack of discussion about health as a goal for their children in these interviews is reflective of a larger cultural view on health care usage, shaped by historic challenges and experiences with systemic racism. The current study was unable to address these interpretations, but future research focused on ethnic minority caregivers' experiences in the health care system and how those experiences shape beliefs and health care usage is warranted. The issues of environmental influences and systems-level barriers

became prevalent in caregivers' discussions of 1) what they believe needs to happen in order for their child to accomplish the goals they described for them and 2) perceived barriers and supports to those goals. These concerns are discussed below.

Taken together, the current findings support previous literature that suggests the presence of several universal goals for caregivers (Dix & Branca, 2003). They also support previous work highlighting specific goals or rationales relevant for Black families (McAdoo, 1997). Caregivers highlighted specific goals around achievement, actualization and happiness, as well as social connection, and safety and security. However, the results from this study do not include health as a component of safety and security, despite half of the respondents raising a child with a chronic illness. Caregivers' discussion about the perceived barriers and supports to their goals for their children may offer additional insight into this unique finding.

**What supports and barriers do caregivers describe in relation to their goals for their children?** Another study aim was to apply qualitative methods to caregivers' own descriptions of perceived supports and barriers to the goals that they have for their children, in order to elucidate strengths-based themes. Too often, research focuses on family shortcomings and caregiver dysfunction, especially with regards to pediatric illness (e.g., Cousino & Hazen, 2013). While positive aspects of family and caregiver-child relationships were described across interviews, a large portion of sources also described barriers and difficulties in their lives. This was especially clear within descriptions of child characteristics, family dynamics, and neighborhood safety.

*Role of the Individual.* A particularly interesting theme that emerged from these interviews about *caregiver* goals was that of the Role of the Individual in goal selection and attainment. This theme was evident across multiple categories, including perceived supports and

barriers, as well as caregivers' descriptions of what they believe needs to happen in order for their child to reach the kinds of goals they have in mind for them. Caregivers mentioned their own role or individual contributions to these goals (positive or negative), highlighting their boundary-setting, provision of resources, and provision of love and support. Some caregivers described their own personalities as supports; for example, one caregiver described how she works to empathize with her children before becoming upset with them. She saw her individual ability to empathize with her children as a strength to help them get where she wants them to go.

Rather than delving into their own roles in goal attainment, caregivers instead placed a significant emphasis on specific child characteristics or attributes, including the repetition of children needing to choose their own goals and pursue them, rather than following any plan set by the caregivers themselves. This idea that children shape their own destiny was sometimes quite positive (e.g., "*she can do whatever she puts her mind to*") but could also reflect on negative attributes that must be changed in order for the child to be successful. Specifically, there was discussion of the need for boys to be tough and not be seen as "too sensitive." There was also fairly ubiquitous descriptions of children needing to change their attitudes, though this was rarely defined or elaborated on.

It is interesting to note that the theme of the Individual emerged from these interviews so clearly, particularly when the literature has so often emphasized the importance of family, friends, and environment on children's socio-emotional development, educational achievement, and mental health outcomes (e.g., Rivers & Scanzoni, 1997). Within a socio-ecological context (i.e., development in context), though, it follows that while caregivers do emphasize the importance of family, friends, and the environment, within these key socio-ecological contexts they also emphasize the importance of children finding their own identities.

It is important to consider that, especially in multicultural populations such as the United States, parents from different cultural groups share ecologies such as neighborhoods and schools, and their cultural models are therefore influenced by both their cultures of origin and their exposure to the cultures of neighboring families (Suizzo, 2007). Research on U.S. ethnic group cultural models of parenting has shown that these models are multidimensional, and may share elements of both individualism and collectivism. Indeed, there is a significant literature detailing the theory that agency and autonomy are basic human needs and cross-cultural caregiver goals (e.g., Kâgitçibasi (1996a, 2005)). This model suggests an ecocultural theoretical perspective to explain how dimensions of individualism and collectivism coexist in parents' goals (Kâgitçibasi (1996a, 2005)). This model postulates that autonomy, an aspect of individualism, contains two orthogonal dimensions: agency (vs. control and obedience) and separateness (vs. relatedness). In accordance with Self-Determination Theory (Deci & Ryan, 2000), agency and relatedness can be thought of as basic human needs and therefore universal parental socialization goals. This allows for an alternative to traditional independence vs. interdependence socialization models. Instead, there is the possibility of an emotional interdependence model that promotes both obedience and self-reliance such that children are socialized to become self-determined but connected to others (Kâgitçibasi, 1996a).

This interweaving of goals for children to be independent and simultaneously connected may also be bolstered by Black caregivers' racial socialization strategies. Racial socialization is a multidimensional process emphasizing both the collectivism values of politeness, equality, group loyalty, and ethnic pride, and the individualism values of achievement, self-respect, and self-confidence (Peters, 2002). In her study examining caregiver goals within African American, Mexican American, and Chinese American families, Suizzo and colleagues (2006) found that,

while relatedness and connection were equally valued across groups, agency and independence were most valued by African American and Mexican American caregivers. The fact that agency was most highly valued by African Americans may be explained by cultural models of racial socialization. For example, the individual items associated with agency include self-strengths that may be viewed as protective factors in the face of potential discrimination. Ogbu's theory (1994) differentiating minority groups according to their status may be particularly helpful in understanding this difference. That is, the historical conditions and circumstances under which people became residents of the United States impact the development of their value systems (Ogbu, 1994). As descendants of involuntary residents who are ethnic minorities, African Americans may value agency more than other minority groups whose ancestors immigrated voluntarily. As they continue to suffer discrimination, African Americans may promote the values associated with agency as part of the racial socialization process of teaching children about their cultural identity and preparing them for possible experiences of discrimination (Ogbu, 1994; Suizzo, 2007).

*Family.* The theme of Family emerged across interviews within several categories, often within perceived supports and barriers. Families were sometimes seen as great supports to children's development and as enhancing the likelihood of children reaching the goals their caregivers have for them. Caregivers described their gratitude for uncles, aunts, and grandparents that lend a hand and help children with homework or after school activities.

There is an extensive literature documenting the importance of extended family relationships among Black families. Studies of African American parents' goals and values for children have shown that family and kinship networks are highly valued (Hill & Sprague, 1999; McAdoo, 2002b). Children are taught to fulfill their obligations toward their family through

reciprocal helping behaviors (McWright, 2002). This is in line with what some researchers describe as a “helping tradition” among Black families (e.g., Cheatham & Stewart, 1990, Martin & Martin, 2016). This tradition consists of cultural values and norms that family and community members should help others, not only their immediate family in the home (Rivers & Scanzoni, 1997). For many of the caregivers in the current study, this has been their experience with family members. Family are supports and helped their children in reaching the goals that caregivers set for them. Some caregivers described the helpfulness of extended family in raising children and providing opportunities for them. Others described a sense of connection and support from their immediate and extended family that will help their children face the world and be successful.

However, in the current study, caregivers also barriers such as difficulties with co-parenting, co-parenting with family members from an older generation (e.g., aunties and grandmothers who are “*old school*”), and difficulties of raising children as a single parent. Still others described a desire to protect their children from family members who struggle with addiction or mental health concerns. It seems as though caregivers shared several difficulties within their families across specific challenging situations (e.g., co-parenting, having family members with substance use problems). These situation-specific challenges likely do not outweigh the myriad supports that families provide to caregivers, but highlight specific family dynamics that are difficult and may present as obstacles to caregivers’ goals for their children. Indeed, as noted by McAdoo in *Black Families* (2002), some theorists have questioned whether kin support networks help or hinder upward mobility for Black families and youth (Pleck, 1979; McQueen 1971). Some work has shown that the size and strength of the family network and kin relationships is being challenged by the needs of multiple generations in the family, combined

with declining resources within that same network (Jarrett & Burton, 1999; McDonald & Armstrong, 2001; Roschelle, 1997).

*Environmental Influences.* While the theme of Family was prevalent across discussions of supports and barriers, another theme emerged across these categories. Caregivers described the role of Environmental Influences as both potential supports and barriers to the goals they have for their children. Common perceived supports included neighborhood facilities, such as recreation centers and parks, as well as extracurricular opportunities for youth, like Scouts or sports. Some caregivers even described their general neighborhood as a support to their children, noting perceived relative safety, and connection to neighbors.

While a handful of caregivers mentioned positive aspects of their community (e.g., sense of connection, perceived ease of accessing resources like tutoring or recreational activities), the emphasis on exposure to neighborhood violence and safety concerns rose to the top of caregivers' descriptions of barriers to their children's success. Environment was often discussed as a significant barrier to caregivers' goals. Specifically, caregivers described the negative aspects of their neighborhood as prohibiting socialization and play (i.e., playing basketball at the park), influencing others' perceptions of their child's worth (i.e., "*he's from that neighborhood*"), and affecting their family's mental health (i.e., "*there's just a lot of anxiety, depression...*"). Families living in low-income, urban areas are disproportionately subjected to higher levels of poverty, exposure to family violence, and exposure to community violence (Bellin et al., 2014; Lindstrom Johnson et al., 2013). With respect to caregivers' goals for their children, it is important to note that exposure to neighborhood violence has been linked to several barriers to success, including higher rates of depression, anxiety, posttraumatic stress disorder, sleep disturbances, academic difficulties, antisocial behavior, aggressive behavior, and

substance use in youth (Cooley-Strickland, Quille, Griffin, et al., 2009; Margolin & Gordis, 2004; Overstreet, 2000). The current study's caregivers' focus on the environment as a barrier to their plans for their children is warranted.

**Implications of results.** While there were several themes that emerged in the current study that were in line with previous work on parenting beliefs, caregiver goals, and socialization practices, especially in Black families, there were unique findings, as well. For instance, the theme of the Role of the Individual was more often discussed than themes of relatedness. While the themes of Family and Connection emerged across interviews, they were less often discussed when compared to the child's individual role in shaping his or her own future. While the literature on ethnic minority caregivers' socialization goals points to agency and relatedness as co-existing universal parental socialization goals (e.g., Kâgitçibasi, 1996a), it was interesting to note how frequently this theme of individual responsibility emerged when compared to themes of Family and Connection.

Perhaps the most interesting finding in this study, however, is the lack of discussion around health and asthma. Though caregivers were not directly asked about health-related goals or asthma-specific goals for their children, but rather were asked about their general goals for their children, there were only two mentions of asthma across all interviews. A driving force behind this project was to better understand potential differences between caregivers' goals for children with and without asthma within families who share several demographic similarities. As mentioned previously, one reason for the lack of difference and the dearth of asthma-related discussion may be attributed to caregivers' competing priorities. As described in the Wu et al. (2008) study, caregivers of color report substantially higher numbers of competing priorities to asthma management, as compared to white caregivers. Studies have shown that four domains



deserve special evaluation as potential divers of racial/ethnic disparities in asthma. The first two domains are lower expectations about treatment and control, and parental concern about adverse effects from anti-inflammatory medications, which have been associated with lapses in appropriate use of asthma controller medications. The third domain is positive interactions with providers, which are important in self-management of chronic illness, and the fourth is competing family priorities that are common barriers to the use of preventative health care services for children (Wu et al., 2008). These competing family priorities include housing, home or neighborhood safety, job, personal/family relationships, income/making ends meet, parents' own health or other family members' health. For Black families living in under-resourced urban areas, these issues often must take precedence over asthma management for their child.

A potential explanation for this also relies on information regarding caregivers' perceptions of asthma severity and potential mortality. They must weigh this against more acute needs (e.g., safety, resources, school). Asthma, unlike many other chronic illnesses, has associated symptoms that are usually reversible when treated with medications. Consequently, with proper treatment, the condition should only minimally affect daily living. Thus, for families who are balancing a number of challenges (i.e., competing family priorities), it may be that asthma takes the metaphorical "back seat" while a child is asymptomatic and appears well. However, obstacles such as lack of medical insurance coverage may encourage episodic care and inadequate follow-up and monitoring. Out-of-pocket expenditures for healthcare and prescriptions may impose an undue hardship on individuals and their families and negatively influence the caregivers' seeking preventative care for their children (Falvo, 2005).

Applying the phenomenological variant of ecological systems theory (PVEST e.g., Spencer, 2006; Spencer & Tinsley, 2008) lens to these results, however, we see that what could

be perceived by researchers as supports and barriers may not be experienced as such by the families in this study. Spencer and colleagues argue that social science scholarship frequently ignores the stable trauma statuses of families of color as they engage in everyday developmental tasks with varying levels and sources of support (Spencer et al., 2019). More specifically, the noted situations of relative support or difficulty are not acknowledged in research vis-à-vis their relationship-based salience (Spencer et al., 2019). This suggests that the absence of cultural competencies potentially compromises the intended efficacy of services to recipients; they fail to function as an envisioned supportive system to the advancement of child development (Spencer et al., 2019). For medical providers and other providers working with families of color and youth with chronic illness, it may be that what we think is helpful or a support may not actually be effective or supportive to those we hope to serve. This points to the need for understanding not only the ways in which different levels of context can influence development (i.e., Bronfenbrenner, 1979), but also to assess and acknowledge human development (e.g., development of parenting, youth identity development) *within* contexts as it is influenced by factors like race and social class. In order to understand identity development (e.g., parental and youth), goals, and behavioral outcomes, research must address diverse individuals' meaning making processes (Spencer et al., 2019).

### **Clinical Implications**

With regards to the current study's finding that when asked general questions about their goals for their child, asthma management did not emerge in this list for Black caregivers in an urban setting, it is imperative that both clinical protocols and intervention efforts take this into account. Specifically, in thinking about the issue of morbidity as it relates to adherence, interviews like the ones presented here highlight that adherence is likely not only about families'

motivation or education. For many families there are more pressing concerns than managing a chronic illness. The current study's results support the idea that a systems-level approach to supporting children and families managing asthma would be more useful than simply targeting the child or parent-child dyad. Indeed, studies suggest that the most effective approach to prevention and treatment of childhood asthma includes not only ongoing medical treatments but also a) education of child and family, b) promotion of the child's sense of empowerment, c) strengthening family support systems, d) collaboration with school personnel, e) development of behavioral interventions for the child and family, f) enrollment in recreational programs (Haas & Haas, 1987).

Behavioral and multicomponent interventions have historically demonstrated more positive effects on asthma adherence and health outcomes than interventions simply utilizing educational approaches alone (Graves, Roberts, Rapoff, & Boyer, 2010). More pertinent to the current study is that organizational interventions (e.g., policies and system-level) also have been described as "probably efficacious" for asthma (Lemanek, Kamps, & Chung, 2001). Examples of organizational interventions that have been found to improve adherence for families managing a pediatric chronic illness include simplifying regimens, increasing supervision by health care providers, improving clinic convenience (e.g., short waiting times, follow-up visits with the same provider), and boosting accessibility to health care services (Lemanek et al., 2001).

There are, of course, individual-level factors to be addressed. Areas where psychologists may be especially helpful to families and medical teams include addressing misperceptions of respiratory symptoms, medication beliefs, adherence, and health care access and utilization (Fritz et al., 2010; Jandasek et al., 2011; McQuaid & Abramson, 2009; Warman, Silver, & Stein, 2001). While none of these issues were brought up within the current study, this may actually be

reflective of caregivers' beliefs about their child's asthma; that is, perhaps this is not so serious of a condition, and that their child might simply "*grow out of this asthma thing.*"

Indeed, caregivers' perspectives must be included in efforts to address poor child health and development among urban families of children with asthma, and both clinical and policy interventions will have greater success if they capitalize on parents' strengths, insights, and desire for a better life for their children. Providers must recognize ways in which things like household food insecurity, financial stress and other material hardships, as well as the physical and mental health of parents are affecting children's health and development, and must seek ways to help caregivers address hardships (Knowles, Rabinowich, Ettinger de Cuba, Becker Cutts, & Chilton, 2016). By looking more broadly and ensuring that nutrition, housing, and energy assistance programs work together to support families, such environmental supports may prevent parents from having to face trade-offs for basic needs. In addition, screening for some of the stressors described by the caregivers in the current study during health assessments would allow providers to better identify toxic stressors and better connect families to public assistance programs and mental health services (Knowles et al., 2016). Additionally, clinicians and policymakers alike should ensure that parents have more opportunities to describe their hardships directly to professionals and to partner with providers (e.g., physicians, psychologists, social workers) to identify the solutions to address them (Knowles, Rabinowich, et al., 2016).

### **Study Strengths and Limitations**

**Strengths.** Although caregiver goals for their children are associated with specific parenting behaviors, few studies have examined caregiver goals for youth with pediatric chronic illness, including asthma. Moreover, few studies have examined perceived barriers and supports to caregiver goals among urban, Black families. The current study used qualitative methods to

obtain richer descriptions of these experiences than what is possible through survey methods. Several strengths are evident.

First, this study relied on interview data from Black caregivers living in an under-resourced urban setting. Rather than relying on self-report measures or questionnaire data that may not be culturally relevant or normed, the current study allowed for the emergence of various patterns and themes in the participants' own words and descriptions. This type of information provides additional support to the development of creation of effective, culturally relevant, and culturally tailored prevention and intervention programs that can support Black families, especially with regard to health management and reducing asthma morbidity among Black youth. It is a strength of this study to have interview data from both families with and without a child who has asthma, as we are able to elucidate the common goals and concerns that cross-cut health status and may indicate higher order goals and priorities, as they supersede health-related goals.

Additionally, it is not enough to simply understand and be able to describe what caregivers' goals are. Researchers and interventionists (including medical providers) must understand families' perceived support and barriers to attain those goals. Thus, being able to examine barriers and supports to goal-seeking or achievement directly from the caregivers is of real value to efforts aimed at promoting effective help-seeking and help-giving. The current study offers themes in caregivers' described barriers and supports to their goals for their children in addition to describing what those goals are. Understanding these challenges and supports would allow interventionists to use family and community-based strengths to bolster families and improve health outcomes, as well as target modifiable barriers to child health and socio-developmental outcomes.

A third strength includes the study's use of a qualitative approach to data analysis. This approach was designed to identify the factors that were most relevant to Black caregivers living in a low-resourced, urban area. The current study represents a contribution to the qualitative literature and to the literature on pediatric asthma, caregiver goals for their children, and health disparities in Black youth, as findings ranged from broad range themes to detailed information and covered a variety of themes that were important to caregivers. The present study's ability to capture the lived experience of participants in the language within which they felt most comfortable was a significant contribution to the qualitative literature on caregiver beliefs and goals within our sample.

A final strength of this study was that great care was taken in the preparation and implementation of the study to maintain qualitative integrity. For example, qualitative integrity was instilled from the beginning with the training of interviewers to minimize biases or pulling of particular responses to the use of memos in creating an audit trail.

**Limitations.** Although the present study provided rich descriptions of the lived experience for this sample of Black caregivers raising children with and without asthma, several limitations should be considered.

First, it is important to note that the EPI was not developed with qualitative analysis in mind. While it was administered as a semi-structured interview, and caregivers were asked the same set of standard questions, there was some variability in the frequency as to how often prompting questions were implemented across interviewers. In reviewing the initial transcriptions, there were some instances of interviewers accepting single-word answers or non-answers (e.g., "*I don't know*"), rather than using designated prompts to elicit richer, more complete responses to the target questions.

Similarly, although the larger project (i.e. FoR-VA study) aims to examine contextual risk and protective factors for child emotional and immune health outcomes, health-related goals and behaviors was not a primary target in the EPI. One explanation for the dearth of health-related goals described in this study may be that caregivers were not specifically asked about health or asthma, and thus, their answers were not primed to involve these kinds of goals. However, when participants were not able to generate examples for goals on their own, probing questions were used to facilitate the interviews. This semi-structured interview process allowed the interviewer to access more information from participants than would have been possible otherwise (e.g., without use of probing questions, limited details could have been given). Although this method adds to the richness of the data, it may also have influenced the type of examples caregivers gave and may have decreased reports of other types of goals that they would consider to be of high importance but did not report. In a similar vein, the use of open-ended questions to assess caregiver goals and perceived supports and barriers might only measure socialization/developmental goals of which caregivers were conscious and which were salient to them at that time (Wang & Tamis-LeMonda, 2003). It has been hypothesized that caregivers of different ethnic backgrounds might otherwise vary in their goals for children when directly asked about specific qualities (Wang et al., 2003). For example, in their study examining differences in socialization practices between Taiwanese mothers and American mothers, Wang and colleagues (2003) found that mothers' values differed when asked to provide free responses to what values they would like to instill in their child as compared to when they were asked to rank order a list of predetermined socialization values. Taiwanese mothers rated and ordered "assertiveness" as more important than U.S. mothers, yet only 4 Taiwanese mothers mentioned assertiveness in

their open-ended task, as compared to 12 U.S. mothers (Wang et al., 2003). Patterns like these may reveal a distinction between implicit and explicit parenting values.

Additionally, caregivers from different cultures may assign different meaning and interpretation to the same value or goal label. For example, caregivers may all endorse the relative importance of “independence,” but may also define it very differently (Wang et al., 2003). One example: studies have distinguished between “instrumental independence” and “emotional independence,” with the former referring to a child’s ability to be self-reliant, develop skills, and find ways to achieve his or her goals, and the latter describing a child’s ability to be alone or assert his or herself without excessive emotional support (Gonzalez-Ramos, Zayas, & Cohen, 1998; Osterweil & Nagano, 1991).

Similarly, we acknowledge that these findings are based on two interview questions at the end of a lengthy study visit. Although we attempted to correct for relative verbosity via the use of semi-structured prompts, caregivers who were more talkative could have mentioned more categories (see Peterson et al. 2014). Additionally, while we did record the self-reported demographic information of research assistants, we cannot control for the gender or ethnicity of the interviewers and any potential effects on participants’ responses.

It is also important to consider the role of race and ethnicity while questioning the meaning behind caregivers’ responses. Are we actually elucidating their concerns and fears in addition to their hopes, dreams, and expectations for their children? Moreover, it would be ideal to include a measure of caregivers’ personal degree of cultural identification in addition to their self-prioritized ethnicity. The larger FoR-VA study included measures on experiences of racism, which may also serve to enhance our understanding of the information gleaned from these interviews.



A final limitation to the current study is the lack of racial and ethnic matching between coders and caregiver participants. Though we try to enhance our collective understanding of a phenomenon via qualitative analysis, research cannot ever really capture an objective “truth,” though we may use a number of strategies to enhance the credibility of the findings (Merriam & Tisdall, 2014). While the current study implemented triangulation (e.g., Denzin, 1978), using multiple investigators (i.e. triangulating analysts, Patton, 2015), internal validity may have been improved with additional checks. Specifically, the use of member checks or respondent validation would bolster the current study’s findings. The solicitation of feedback about the study findings from a sample of participants would have been helpful in ensuring that we have “[ruled] out the possibility of misinterpreting the meaning of what participants say and do and the perspective they have on what is going on, as well as...identifying [our] own biases and misunderstandings of what was observed” (Maxwell, 2013, pp. 126-127).

As with all qualitative studies, this study is not meant to be representative of all Black families. The recruitment and sampling technique may have biased results toward either greater reporting of stress associated with parenting, or potentially, under-reporting of the stress as those who experience even greater stress may not have been willing to participate. Low participation of fathers-- while not unique to this study-- limits our understanding of experiences unique to male caregivers.

### **Future Directions**

While the current study has several strengths and weaknesses with regards to validity and generalizability, the results indicate the need for future work addressing the role of caregivers’ social and developmental goals for their children with respect to living with a chronic illness. This is especially important to better support caregivers who identify as racial or ethnic

minorities, as well as those who live in under-resourced urban areas, given the continued disparities in health outcomes for children of color, living in urban areas.

Future work should specifically target caregivers' goals for their children in light of their health status. This would not involve assessing disease- or adherence-specific goals (e.g., "When would you like to transition responsibility for medication management?"), but rather the same kinds of socio-emotional goals described in the current study, but with the child's asthma status being made salient to those being interviewed. For example, an interviewer might ask about caregiver goals for a child's extracurricular involvement, and if the caregiver described goals for their child to be a standout soccer player, the interviewer may question how the child's asthma may or may not affect this goal. Any interviews should be followed up with focus groups and presentation of the emerging data for member checking.

Another area for future work would be to not only better understand what caregivers want for their children, but how likely they perceive this is to happen. If the goal of understanding caregivers' goals is to leverage this information for improved health outcomes, it is key to assess caregivers' feelings of efficacy as it relates to helping children meet those goals. This is important for a few reasons, not least that feelings of efficacy are modifiable and easily addressed by providers (i.e., behavioral health intervention). Additionally, future research might attempt to understand the reasons caregivers offer for their goals by using a combination of qualitative and quantitative approaches. Why and how caregivers come to value certain qualities in their children is especially relevant to the study of minority and immigrant groups (Tamis-LeMonda et al., 2008). Regardless of their own socialization history, ethnic minority parents are likely to encounter different messages about socialization from within their own community and the mainstream community (Holden & Edwards, 1989). As mentioned above, the larger FoR-VA

study includes measures related to caregivers' experiences as ethnic minorities; future work may look to a mixed methods approach in combining qualitative data from their interviews with quantitative data derived from self-report questionnaires.

Similarly, it would be beneficial to expand our understanding of caregivers' perceptions of asthma seriousness via focus group or individual interviews subject to qualitative analysis. There are several studies that have quantitatively measured perceptions of asthma symptom severity, knowledge of asthma, as well as caregiver stress associated with managing pediatric asthma (e.g., Chen & Schreier, 2008; Kazak, 1989). However, there is very little qualitative data on the lived experiences of these caregivers, and even less on how caregivers view the relative seriousness of asthma, either with respect to their own child's asthma symptoms, or when comparing the morbidity or mortality of this disease to other diseases (e.g., pediatric cancer, obesity). Again, if we are to use this information to improve child health outcomes, especially for the underserved children in our communities, it is integral for intervention work to consider where families and caregivers are, with regards to weighing the relative risks of their children's chronic illness. If there is simultaneously a large number of competing priorities for families that makes asthma management difficult *and* caregivers report that they do not see asthma as a serious concern, this would indicate that there is room for shifting priorities as knowledge and awareness of asthma severity increases. In order to effectively intervene on low adherence and disproportionately high morbidity rates of asthma in children of color and children who live in urban communities, researchers and providers must meet families where they are and work to better understand caregivers' perceptions around asthma and competing priorities to the management of chronic illness.

Finally, a significant limitation of the current study is that results stem from a single interview session, representing a single point in time that a caregiver was asked to reflect on parenting practices and long-term goals for their children. Future research should involve longitudinal studies, following families over the course of children's development, in order to observe the ways in which caregiver goals change or remain constant over time and across developmental stages.

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## Appendix

Table 2

*Child, Primary Caregiver, and Family Characteristics for the Full FoR-VA Sample (n=96 dyads)*

Characteristic	
<b>Caregiver</b>	
Age, <i>M</i> years ( <i>SD</i> )	37.46 (10.15)
Sex (Female), <i>n</i> (%)	91 (94.8)
Race/Ethnicity, <i>n</i> (%)	
African American or Black	89 (91.7)
Caucasian/White	3 (3.1)
Mixed/Multi-Racial <sup>a</sup>	2 (2.0)
Other <sup>b</sup>	3 (3.1)
Relation to child, <i>n</i> (%)	
Biological Mother	84 (87.5)
Biological Father	5 (5.2)
Grandmother	4 (4.2)
Step, Adoptive, or Foster Mother	1 (1.0)
Aunt	1 (1.0)
Other, unspecified legal guardian	1 (1.0)
Relationship Status, <i>n</i> (%)	
Single/Never Married	72 (75)
Married	14 (14.6)

Divorced	5 (5.2)
Separated	3 (3.1)
Widowed	2 (2.1)
Currently living with a partner, <i>n</i> (%)	31 (32.3)
Education, <i>n</i> (%)	
Less than a high school education	31 (32.3)
High school or GED degree	32 (33.3)
Some college	23 (24.0)
Bachelor's degree	9 (9.4)

### Child

Age, <i>M</i> years ( <i>SD</i> )	8.79 (2.03)
Sex (Female), <i>n</i> (%)	46 (47.9)
Race/Ethnicity, <i>n</i> (%)	
African American or Black	88 (91.7)
Caucasian/White	1 (1.0)
Mixed/Multi-Racial <sup>d</sup>	4 (4.1)
Other <sup>b</sup>	3 (3.1)

### Household

Household Income (Past Year), <i>n</i> (valid %)	
0 - \$11,999	53 (27.1)
\$12,000 - \$23,999	20 (20.8)



\$24,000 - \$35,999	10 (10.4)
\$36,000 - \$47,999	3 (3.1)
\$48,000 - \$59,999	2 (2.1)
\$60,000 and up	5 (5.2)
Missing	3 (3.1)

<sup>a</sup> Includes mixed race unspecified (1.0%) and Black/Latino/Mexican (1.0%).

<sup>b</sup> One (1.03%) each: Moorish, Moroccan, and Salvadorian.

<sup>c</sup> One (1.0%) unknown/blank

<sup>d</sup> Includes mixed race unspecified (2.1%), mixed race and American Indian/Alaskan (1.0%) and mixed race including Scottish, Irish, and Black/African-American (1.0%).

### Table 3

Primary Caregiver, Child, and Family Characteristics for Current Study (n=85)

Characteristic

#### Caregiver

Age, *M* years (*SD*) 37.5 (8.12)

Relation to child, *n* (%)

Biological Mother 75 (88.2)

Biological Father 4 (4.7)

Grandmother 4 (4.7)

Other	2 (2.4)
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Education, *n* (%)<sup>c</sup>

Less than a high school education	29 (34.8)
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High school or GED degree	29 (32.6)
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Beyond high school	27 (31.5)
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**Household Income** (Past Year), *n* (%)

\$0-\$11,999	45 (52.8)
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\$12,000-\$23,999	19 (22.5)
-------------------	-----------

\$24,000-\$35,999	8 (10.1)
-------------------	----------

\$36,000-\$47,999	3 (3.4)
-------------------	---------

\$48,000-\$59,999	2 (2.2)
-------------------	---------

\$60,000 and up	5 (5.6)
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Missing	3 (3.4)
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*Appendix A***Demographic Information****ETHNICITY****ET1. How would you describe your race or ethnicity?** (Circle all that apply)

Caucasian/White	1
Black or African American	2
Puerto Rican	3
Dominican	4
Guatemalan	5
Colombian	6
Other Latino Subgroup Specify: _____	7
American Indian/Alaskan Native	8
Native Hawaiian or other Pacific Islander	9
Mixed or Multi-Racial Specify: _____	10
Other; Specify: _____	11
Don't Know	99
Refused	999

**ET2. How closely do you identify with other people from the same ethnic origin as yourself: very closely, somewhat closely, not very, or not at all?**

Very Closely	1
Somewhat Closely	2
Not Very Closely	3
Not at All	4
Don't Know	99
Refused	999

**ET3. In what country were you born?**

United States	1
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Other; Specify: _____	2
Don't Know	99
Refused	999

ET4. How old are you? \_\_\_\_\_ years

### CHILD DEMOGRAPHICS

Interviewer: *Now I'm going to ask for some general information about <child>.*

CDM1. Child's Date of Birth: \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
mm dd yyyy

CDM1a. Child's Age: \_\_\_\_\_ yrs

CDM2. *How would you describe your CHILD's race or ethnicity?* (Check all that apply.)

Caucasian/White	1
Black or African American	2
Puerto Rican	3
Dominican	4
Guatemalan	5
Colombian	6
Other Latino Subgroup Specify: _____	7
American Indian/Alaskan Native	8
Native Hawaiian or other Pacific Islander	9
Mixed or Multi-Racial Specify: _____	10
Other; Specify: _____	11
Don't Know	99
Refused	999

CDM3. Child's Sex:

Interviewer: Code without asking if possible

Male	1
Female	2
Other; Specify: _____	3

**CDM4. Child's Grade: \_\_\_\_\_**

Interviewer: Enter grade 0 (Kindergarten) or grade number (1-12)

**CDM5. What is your relationship to <child>?**

Biological Mother	1
Biological Father	2
Step, Adoptive, or Foster Mother Specify: _____	3
Step, Adoptive, or Foster Father Specify: _____	4
Grandmother	5
Grandfather	6
Other; Specify: _____	7
Don't Know	99
Refused	999

**SOCIAL ECONOMIC STATUS / INCOME**

*Now I want to ask you for some general information about you and the people living in your household.*

**SS1. Are you currently married, separated, divorced, widowed, or never married?**

Married	1
Separated	2
Divorced	3
Widowed	4
Never Married	5
Don't Know	99
Refused	999

**SS1a. Are you currently living with someone in a marriage-like relationship?** If needed, prompt: A romantic partner, boyfriend/girlfriend, etc., that lives with you and <child>.

Yes	1
No	2
Don't Know	99
Refused	999

**SS2. Is there another adult "head of household"/primary caregiver to <child> living with you?**

If no, SKIP TO SS5; if yes, ask who it is.

If PC says "FATHER" or "MOTHER," PROBE: IS THAT HIS/HER BIOLOGICAL, STEP, ADOPTIVE OR SOMEONE ELSE?

Biological Father	1
Biological Mother	2
Adoptive Father	3
Adoptive Mother	4
Stepfather (Spouse/Partner of PC)	5
Stepmother (Spouse/Partner of PC)	6
Other; Specify: _____	7
Don't Know	99
Refused	999

**SS3. How many years of school did <other caregiver> complete?**

If high school graduate, enter "12" years;  
if college graduate, enter "14," "16," etc. years.

Years: enter a number 0 – 17+	_____
Don't Know	99
Refused	999

**SS4. Is <other caregiver>**

**currently working outside of the home?**

<b>No (skip to SS5)</b>	<b>1</b>
<b>Yes, per diem or temp</b>	<b>2</b>
<b>Yes, regular part time</b>	<b>3</b>
<b>Yes, regular full time</b>	<b>4</b>
<b>Don't Know</b>	<b>99</b>
<b>Refused</b>	<b>999</b>

**SS4a. <OC> is a(n):**

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<b>Don't Know</b>	<b>99</b>
<b>Refused</b>	<b>999</b>

**SS4b. What does <OC>'s job entail (primary responsibilities, etc.)?**

Don't Know	99
Refused	999

**“Okay, now back to a few questions about you and your household members...”**

Note for data entry: For question SS5 in database, enter response from CDM5.

**SS6. How many years of school did you complete?**

If high school graduate, enter “12” years;  
if college graduate, enter “14,” “16,” etc. years.

Years: enter a number 0 – 17+	_____
Don't Know	99
Refused	999

**SS7. Are you currently working outside of the home?**

(Work/have a job in addition to being a parent and taking care of your home)

No (skip to SS5)	1
Yes, per diem or temp	2
Yes, regular part time	3
Yes, regular full time	4
Don't Know	99
Refused	999

**SS7a. You are a(n):**

Don't Know	99
Refused	999

**SS7b. What does your job entail (primary responsibilities, etc.)?**

Don't Know	99
Refused	999



**SS8. What is the total number of people living in your household, including you and <child>? \_\_\_\_\_**

SS8a. How many of <child>'s siblings live in the home? \_\_\_\_\_ (not counting <child>)

SS8b. How many adults (18+) are living in the home, including you? \_\_\_\_\_

SS8c. How many other people are living in the home, if any? \_\_\_\_\_  
(grandparents, uncles, cousins, friends, etc.)

**Can you tell me a bit more about the people who live with you? Is this how it typically is or have people been in and out temporarily?** (Record response verbatim)

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**NOTE:** The numbers in a, b, and c plus 1 for the target child should add to the total number of people in the home.

**SS9. Have you moved in the last year?** NO YES (circle one)

SS9a. If so, how many times? \_\_\_\_\_

SS9b. What is the primary reason for the move(s)?

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**SS10. Do you currently live in an apartment or a house?** \_\_\_\_\_

SS10a. Is it Section 8 supplemented? NO YES

SS10b. Is it in a housing project? NO YES

SS10c. How many bedrooms does your home have? \_\_\_\_\_

SS10d. Do you feel like this home is more temporary or pretty permanent?

---

SS10e. Do you feel safe where you are living? NO YES  
Why or why not?

---

SS10f. Do you like where you are living? NO YES  
Why or why not?

---

**SS11. What is the primary language spoken in your home?**

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### INCOME

**IN1. Now I want to ask you a few questions about your finances and household income. Please remember that everything you tell me in the interview is confidential.**

>>>> Hand PC the INCOME card <<<<

**Look at these figures and tell me which best represents the total household income before taxes for the PAST YEAR or the household income for the PAST MONTH. Count only wages and other money from employment for everyone living in this household including yourself. Do not include pensions, investments, or other financial assistance or income. (Your best estimate is fine.)**

NOTE: If necessary, help PC calculate total household income either by month or by year and circle in the correct column. If PC is most comfortable reporting weekly income, that is fine; just write it down then later multiply it by 52 and record that in the "YEAR" column below.

Enter the number from the year ~or~ month column of the <Income card>:

	YEAR	or	MONTH
	_____	or	_____
Don't Know	99	or	99
Declined/Refused	999	or	999

**IN2. Would you say that your family is financially better or worse off than other families?**

Much Better	1
Better	2
Same	3

Worse/A Little Worse	4
A Lot Worse	5
Don't Know	99
Refused	999

**IN3. Which of these phrases best describes your family's economic status?**

We live very well	1
We live comfortably	2
We live from check to check	3
Almost poor	4
Poor	5
Don't Know	99
Refused	999

**IN4. Do you currently have health benefits?**

Yes (see IN4a)	1
Partial (see IN4a)	2
No	3
Don't Know	99
Refused	999

**IN4a.** If yes, do you receive benefits through your work or another source? \_\_\_\_\_

---

**IN5. Do you receive – or have you ever received as an adult - the following?**

- IN5a. Medicaid .....  YES  NO, YES PAST  NO, NEVER
- IN5b. WIC .....  YES  NO, YES PAST  NO, NEVER
- IN5c. Unemployment benefits  YES  NO, YES PAST  NO, NEVER
- IN5d. Disability benefits .....  YES  NO, YES PAST  NO, NEVER

IN5e. Any other forms of public assistance.  YES  NO, YES PAST  NO, NEVER

**IN6. Do you own a car?**

Yes	1
No (see IN6a)	2
Don't Know	99
Refused	999

**IN6a. If you do not own a car, do you have access to reliable transportation?**

Yes	1
Sometimes	2
No	3
Don't Know	99
Refused	999

**IN7. Do you or does someone in your household pay for heat, electricity, or water?**

Yes	1
No	2
Don't Know	99
Refused	999

**IN8. In the past year, did your home receive energy assistance?**

Yes	1
No	2
Don't Know	99
Refused	999

Yes	1
No	2
Don't Know	99

Refused	999
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**IN9. Since** <name of current month> **of last year, has the [gas/electric] company sent you a letter threatening to shut off the [gas/electricity] in your house for not paying bills?**

**IN10. Since** <name of current month> **of last year, has the [gas/electric/oil] company shut off or refused to deliver the [gas/electricity/oil] for not paying bills?**

Yes	1
No	2
Don't Know	99
Refused	999

**IN11. Since** <name of current month> **of last year, were there any days that the home was not [heated/cooled] because you couldn't pay the bills?**

Yes	1
No	2
Don't Know	99
Refused	999

**IN12. Since** <name of current month> **of last year, have you ever used a cooking stove to heat the [house/apartment] because you couldn't pay the bills?**

Note: Not including a time the stove was used for heat during a power outage

Yes	1
No	2
Don't Know	99

Refused

999

*Appendix B*

**The Everyday Parenting Interview**

*Questions modified from Harwood (1992) and Newberger (1980)*

***“This next series of questions are designed to help us get to know you – as a parent – better... what your day-to-day life is like, what you think and feel about kids and parenting in general, and what challenges you or brings you joy. I’m going to videotape the interview, which allows me not to have to write everything down and we can just chat about this.”***

Prompts are to be asked as needed; if the parent addressed it in her/his response, you do not need to prompt.

**1. “Let’s start by talking about parenthood in general. We all know that parents are very different from one-another and being a parent means different things to different people. Tell me a little about YOU as a parent to YOUR child(ren).”**

**2. “What are your GOALS for <child>?”**

Allow time for the caregiver to answer, then...

**P: How about in terms of personality and personal traits?**

**Relationships? Education? Careers?**

**P: What do you think is going to have to happen for [child] to reach those goals?**

**P: Do you have certain things you think you do because of these goals? (parenting practices)**

**P: Are there things about [child], your family, or your surroundings that might make it easier**

**or harder for him/her to reach those goals?**

**3. “Tell me a little about <child>. What’s it like to be his/her mom.”**

Allow time for the caregiver to answer, then...

**P: Is there anything UNIQUE about him/her... that you do differently with him/her?**

4. ***“Okay, let’s speak more generally now. What do you feel children in general need the most in order to reach goals like that?”***

Allow time for the caregiver to answer, then...

P: ***How about from their families? Other places (like school, community, society)?***

P: ***What do you think gets in the way of success for kids these days?***

P: ***How does this apply to your kids, if at all?***

5. ***“Okay, let’s switch gears again. Now I’d like you to tell me a little about your day-to-day life with the kids. Are there a lot of hassles or are things pretty smooth?”***

Allow time for the caregiver to answer, then...

P: ***“What challenges you day-to-day, and what makes things easier?”***

6. ***“Whether or not there is another adult living in the house, some parents have a second caregiver who really helps with the kids all the time – a full partner in parenting - while other parents are more on their own when it comes to the kids. How is it for you?”***

Allow time for the caregiver to answer, then...

P: ***Is there someone who lives with you or is there and really helps you with the kids? Who?***

P: ***Is that person an occasional helper or like a FULL parent or partner in parenting?***

P: ***What about [child]’s father/other parent?***

7. ***“In general, what are your thoughts about the future for you and your family?”***

Allow time for the caregiver to answer, then...

P: ***Do you think things will get better, worse, or stay the same?***

### Vita

Megan Carlson was born on February 21, 1990, in Davenport, Iowa. She graduated from Waukee High School in Waukee, Iowa, in 2008. She received her Bachelor of Science in psychology, as well as a Bachelor of Arts with honors in English from the University of Iowa in 2012. Prior to graduating, Megan spent three years as an undergraduate research assistant at Iowa's Comparisons and Health in Psychology (CHiP) Lab. She then spent two years as a post-baccalaureate research assistant with the Child Development Lab under the direction of Dr. Grazyna Kochanska. She began the Developmental/Clinical Doctoral program at Virginia Commonwealth University in August 2014 and received her Master of Science degree in Clinical Psychology in 2016. Megan is currently completing a clinical internship year, with a pediatric psychology specialty, at Children's Mercy Kansas City and will graduate in August 2020 with her Doctor of Philosophy in Clinical Psychology, Child/Adolescent concentration, from Virginia Commonwealth University.