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NAVIGATING THE MICHELLE P. WAIVER: A NARRATIVE EXAMINATION OF THE IMPACT OF PARENT CAREGIVER-RELATED UNCERTAINTY AND DECISION MAKING FOR CHILDREN WITH DISABILITIES

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NAVIGATING THE MICHELLE P. WAIVER: A NARRATIVE EXAMINATION OF THE IMPACT OF PARENT CAREGIVER-RELATED UNCERTAINTY AND DECISION MAKING FOR CHILDREN WITH DISABILITIES

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Communication and Information
at the University of Kentucky

By
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Lexington, Kentucky
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2019

ABSTRACT OF DISSERTATION

NAVIGATING THE MICHELLE P. WAIVER: A NARRATIVE EXAMINATION OF
THE IMPACT OF PARENT CAREGIVER-RELATED UNCERTAINTY AND
DECISION MAKING FOR CHILDREN WITH DISABILITIES

The Michelle P. Waiver (MPW) is the primary means of health insurance for more than 10,000 people in the state of Kentucky. The waiver is especially popular among families with young children with disabilities because it is robust in its benefit offerings and also one of the few Medicaid resources that does not include parental income as a qualifying factor in eligibility. Through the waiver, children receive a medical card as well as additional coverage for medical expenses that fall beyond the scope of traditional health insurance. For these young children to gain access to the comprehensive offerings of the MPW, their parents must apply for the waiver, negotiate the terms of service, and make critical health care decisions on their behalf, or at least until they reach adulthood—although this responsibility often extends throughout the child's life. The present study builds upon recent research on parental uncertainty in caregiving for children with complex care needs. By combining two ecological approaches to health communication research, Brashers's (2001) uncertainty management theory (UMT) and Ball-Rokeach, Kim, and Matai's (2001) communication infrastructure theory (CIT), my aim in this dissertation was to explain how meso-level (e.g., community organization) interactions influenced parental caregivers' experiences of uncertainty. I collected data through narrative interviews with 31 parents of children who are currently receiving services through the MPW and analyzed them using narrative thematic analysis. The analysis focused on the community-level communication that contributes to parent caregivers' ability to successfully access and negotiate care within the MPW system. Findings show that parents experience unique personal, social, and medical uncertainties related to the MPW. In addition, the findings demonstrate that MPW-related uncertainty and decision making are managed with a variety of strategies aimed to decrease, increase, or maintain desired levels of uncertainty. Finally, findings showcase how one's connectedness to community storytelling at the meso level, particularly within online communities and disability network communities supports their adaptive management of MPW-related uncertainty. This project contributes to the health communication literature theoretically by (a) expanding the conceptualization of the uncertainty in illness framework to include the means of health care (i.e., Medicaid) as a consequential element of an individual's illness experience, (b) identifying two additional strategies of uncertainty management (i.e. advocacy and vigilance), and by (c) extending existing notions of residency, connectedness, and belongingness within the CIT framework to include membership in online and disability-specific networks. Practically, this project offers important insights that can guide future research exploring the role of meso-level communication in parent caregivers' management of waiver-based care, such as in identifying the need for a systematic communication process that introduces potentially eligible families to the MPW.

KEYWORDS: Uncertainty Management, Decision Making, Disability Health, Medicaid

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CHAPTER ONE: INTRODUCTION AND RATIONALE

In the present study, I aim to explore the role of community-level communication in influencing the uncertainty experiences of parent caregivers of children with disabilities (i.e., under the age of 18) in accessing and negotiating Kentucky's Michelle P. Waiver (MPW). The MPW is a Medicaid-funded Home and Community-Based Service (HCBS) waiver program designed to assist persons with disabilities in their financing of community-based health care. According to Kentucky's Medicaidwaiver.org (2019), HCBS waivers aim to "provide services to persons with intellectual and developmental disabilities in Kentucky" (para. 4).

In recent years, the term "disability" has evolved to include a wide variety of conditions, such as physical impairments, intellectual challenges, psychiatric diagnoses, sensory considerations, neurological disorders, learning disabilities, physical disfigurements, and the presence of disease-causing organisms in the body (Disabled World, 2019). However, the disability population that meets the state of Kentucky's eligibility requirements for MPW applicants includes individuals with intellectual and developmental disabilities. The National Institute of Health (NIH, 2019) defined *intellectual disability* as the following:

> A group of disorders characterized by a limited mental capacity and difficulty with adaptive behaviors such as managing money, schedules and routines, or social interactions. Intellectual disability originates before the age of 18 and may result from physical causes, such as autism or cerebral palsy, or from nonphysical causes, such as lack of stimulation and adult responsiveness. (para. 1)

Intellectual disabilities affect individuals' mental capacities, including their learning, problem-solving, and decision-making abilities, and they are typically indicated by an IQ test score of approximately 70 to as high as 75 (American Association on Intellectual and Developmental Disabilities [AAIDD], 2019). The NIH (2019) defined *developmental disabilities* as any "severe, long-term disability that can affect cognitive ability, physical functioning, or both. These disabilities appear before age 22 and are likely to be life-long" (para. 2). Developmental disabilities include, but are not limited to, diagnoses such as cerebral palsy, epilepsy, autism, Down syndrome, intellectual disabilities, and vision impairment. Such disabilities can involve sensory-related impairments (e.g., Williams Syndrome, Fragile X), metabolic disorders (e.g., Phenylketonuria), degenerative disorders (e.g., Rhett syndrome), and impairments related to parental use and abuse of substances during pregnancy (e.g., fetal alcohol syndrome; Medline Plus, 2019). Oftentimes, intellectual disabilities and developmental disabilities co-occur (AAIDD, 2019). In such cases, the developmental disability (e.g., Autism, Down syndrome) is offered as the primary diagnosis, whereas the intellectual disability is treated as a symptom of the developmental disability.

Family caregiving is a significant dimension of disability. The U.S. Census Bureau estimated that more than 1.7 million children (under the age of 18) have an intellectual or developmental disability (Brault, 2012). Most children with intellectual or developmental disabilities live at home with a family member who assists them, in varying degrees, in accessing and facilitating their health care and personal care needs (Brault, 2012). The National Alliance for Caregiving (2009) estimated there are 16.8 million unpaid caregivers who provide care to children with special care needs under the

age of 18 in the United States. Yet researchers have given far less attention to the unique experiences of this sub-population of caregivers providing care to children compared to adult caregivers providing care for aging parents. Studies show that caregivers of children with disabilities or long-term illnesses are mostly female, which is similar to caregiver demographics for adult patients (Family Caregiver Alliance, 2018). However, the average age of parent caregivers is 40.6 years. This is younger than the average age of caregivers of adults (49.2 years). Another key difference in the experiences of parental caregivers of children with complex care needs and adult caregivers is the length of time spent caregiving. Adult caregivers typically occupy the role for about four years, whereas parental caregivers often assume the role in some capacity for the remainder of their life or the child's life (FCA, 2018). Several studies suggest that the longer an individual serves in a caregiver role, the more likely the person is to experience substantial declines in overall health (Murphy, Christian, Caplin, & Young, 2007; Schulz & Beach, 1999), including depression, social isolation, emotional stress, and loss of financial security (FAC, 2018).

To provide further context for the present study, I begin this chapter by giving a brief, historical account of the unique health care conditions that persons with disabilities and their family caregivers face in securing equal access to health services in their own communities. In addition, the significance of the MPW is explained. I also highlight several challenges associated with disability health research before focusing on the unique decision making and treatment adherence challenges that parent caregivers of children with disabilities are expected to negotiate for their child. Finally, I conclude with a description of the aims of the present study.

Disability Health Care

Prior to the 1970s, the primary health care option for persons with disabilities who required complex care was institutionalization, whereby they left their families and were isolated from their communities in exchange for health care provided by state-run facilities (Lakin, Hill, & Bruininks, 1985; Prouty, Smith, & Lakin, 2003). However, a series of notable court battles, largely brought about through family- and community-level advocacy, exposed a pattern of abuse and neglect occurring within many institutional facilities across the United States (Lakin et al., 1985; Prouty et al., 2003), thus leading to revolutionary changes in the health care system for persons with disabilities and their families. Since then, several laws and protections have been established to offer those with disabilities and their family caregivers additional choices and access to care within the community rather than them relying on care facilities (American Bar Association, 2018). Today, many of the laws and protections passed over the previous 20 years are again being renegotiated to reduce the rising cost of health care in the United States. Therefore, persons with disabilities and their families must prepare for new and consequential changes to the health care they have come to rely on—particularly those dependent on health care subsidized by Medicaid (Kaiser Family Foundation [KFF], 2018).

In 1981, HCBSs funded through Medicaid were instituted in some states to help support individuals and caregivers in their efforts to access quality health care in the community. Many of these programs include a Consumer Directed Option (CDO) that allows participants to choose their own care providers for the care services they receive under the waiver. Certain family members and friends can be hired as paid caregivers,

including spouses, parents, and adult children. According to the National Council on Disability (NCD, 2018), the average cost of institutional care is roughly $188,318 per individual per year versus an average of $42,486 per individual per year for Medicaid-funded HCBSs. The funds for Medicaid waivers are provided through a jointly funded federal/state health insurance program, which today covers over 10 million individuals with disabilities in the United States (Medicaid and CHIP Payment and Access Commission [MACPAC], 2017). The term "waiver" is significant because when recipients of the HCBS waivers become eligible for Medicaid funding, they are also given permission to "waive" currently existing Medicaid rules that require individuals with complex needs to receive health care services exclusively in an institutional setting. Essentially, by law, individuals must apply and be given permission to waive a condition requiring that they leave their communities and families to access advanced health care. In doing so, the beneficiaries (i.e., persons with a disability), or legal caregivers on behalf of the persons with a disability, agree to coordinate their own specialized care within their own homes and communities.

In sum, over the past 50 years, the number of individuals choosing Medicaid waivers over institutionalized care has steadily increased (KFF, 2018). Consequently, the costs of managed care programs, such as HCBS waiver programs, have also risen, from $93 billion in 2002 to more than $158 billion in 2015 (MACPAC, 2017). Faced with a growing national debt, lawmakers at the state and federal levels have expressed an interest in exploring opportunities that reduce the cost of care for long-term supports such as HCBS waiver programs (Gibson, Gregory, & Pandya, 2003), thus leaving the future of HCBS waivers in a state of perpetual uncertainty. For instance, as recently as January

2018, the Centers for Medicare and Medicaid Services (CMS) released new guidelines for states pursuing waivers (e.g., imposing work requirements in Medicaid as a condition of eligibility). It remains to be seen if these new requirements will be enforced, what other provisions CMS might approve, and how these changes to the waiver system will affect the costs, access, enrollment, and burden experienced by MPW waiver recipients and their families (KFF, 2018).

Kentucky's Michelle P. Waiver

The MPW is a HCBS waiver program offered exclusively in the state of Kentucky. Kentucky currently offers six HCBS waivers, supporting more than 33,000 residents in their choice to access home- and community-based care. The MPW was created as a settlement in response to a lawsuit filed in 2002 between Kentucky's Protection and Advocacy and the Cabinet for Health and Human Services. At the time of the lawsuit, Kentucky's Supports for Community Living (SCL) waiver, another Medicaid waiver that provides community-based residential services, included over 3,000 adults with disabilities on the waiting list, meaning thousands of families were left without the health care their loved ones needed as they waited for a spot to open. The lawsuit, named after a young woman named Michelle Phillips, sued Kentucky for not sufficiently addressing the number of individuals waiting for services. The six-year-long litigation resulted in a court-ordered expansion of Medicaid and the creation of the MPW.

The intention of the MPW program was to provide a blend of home- and community-based support services (e.g., assessment, reassessment, case management, minor home adaptation, adult day health care, homemaker, personal care, attendant care, and respite care), as well as additional specialized services that were previously available

exclusively through the SCL waiver. The SCL waiver was designed to provide individuals with intellectual or developmental disabilities an alternative to institutionalization by subsidizing their access to more local, community-based residency in intermediate care facilities. Unlike the SCL waiver, the MPW does not offer residential care but rather includes the option to hire qualified providers to administer in-home-based and community care in the caregiver's home, school, or community environments. This feature made the MPW an attractive option for families with young children with significant disabilities. The MPW is one of only two Medicaid waivers in Kentucky available to children, and it does not include parental income as a criterion for eligibility; rather, the child's degree of need alone is considered. Today, the waitlist for the MPW has swelled to more than 8,000 individuals, many of whom are children (Complex Child Magazine, 2019).

Waiver access and availability continues to be renegotiated at the policy level, both federally and statewide. There are currently several ongoing efforts in Kentucky to redesign current Medicaid waiver offerings, including the MPW. In 2018, Kentucky's Medicaid waiver programs were reapproved with two notable changes (KFF, 2018). First, reapproval included requirements that the state submit implementation and monitoring protocols to the CMS for approval. Second, reapproval opened the door for including an evaluation of potential work requirements and other provisions for beneficiaries (KFF, 2018). A lawsuit was immediately filed by a group of Medicaid enrollees to contest these changes and is presently ongoing (KFF, 2018). Meanwhile, the state of Kentucky's Cabinet for Health and Family Services (CHFS) hired an independent consulting company named Navigant Consulting to review the state's offering of its six HCBS

waivers. In 2018, Navigant Consulting, based on its analysis of Kentucky's waivers, which included statewide focus groups with 67 waiver participants, 128 caregivers, 156 managers and executives, and 137 direct waiver support professionals, released its recommendations for improving the waiver programs. The CHFS intends to implement many of the recommendations provided by Navigant Consulting over the next three years. This decision will likely have a major impact on the ways in which persons with disabilities and their families access and experience health care in the state of Kentucky.

Disparity in Health Care for Persons with Disabilities

Research related to the impact of health care policy on the individual experiences and health outcomes of persons with disabilities and their family caregivers is scarce, despite a growing body of evidence suggesting that disability health is the most under-addressed health disparity in the United States (Krahn, Walker, & Correa-De-Arajuo, 2015). According to the U.S. Department of Health and Human Services (2008), a health disparity is defined as

> a particular type of health difference that is closely linked with social or economic disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial or ethnic group, religion, socioeconomic status, gender, mental health, cognitive, sensory, or physical disability, sexual orientation, geographic location, or other characteristics historically linked to discrimination or exclusion. (p. 29)

Individuals and groups who experience health disparities are at greater risk for certain diseases and possess higher mortality rates compared to less-affected individuals and

groups (Centers for Disease Control and Prevention [CDC], 2018). Krahn et al. (2015) argued that health disparities persist among the disability health population because health professionals and researchers themselves too readily attribute secondary health and wellness declines as symptoms of the primary disability or condition and, as a result, fail to utilize general wellness and preventive opportunities to address preventable secondary conditions. For example, individuals with disabilities possess higher rates of obesity and tobacco use, lower rates of preventive dental care, and higher rates of newly diagnosed cases of diabetes and cardiovascular disease than their nondisabled peers (U.S. Department of Health and Human Services, 2002). Similarly, Kirschner, Breslin, and Iezzoni (2007) found that many individuals who possess disabilities are also less likely to receive basic primary and preventive care services, such as X-rays, weigh-ins, pelvic exams, colonoscopies, vision screenings, and physical examinations. Furthermore, the Office of the Surgeon General (2005) reported that individuals with disabilities— compared to their peers without disabilities—have a higher risk of falling, and they experience mental illnesses (e.g., depression) at a higher rate.

Several studies have concluded that the lack of preventive care and early intervention for persons with disabilities leads to undiagnosed health problems that, when left untreated, reduce life expectancy and quality of life (Cooper, Melville, & Morrison, 2004). The causes of death for individuals with intellectual or developmental disabilities closely mirror those of the general population (e.g., coronary heart disease, type 2 diabetes, respiratory illnesses, and cancer), except for individuals born with Down syndrome, who typically die due to dementia-related causes (Walker, Rinck, Horn, & McVeigh, 2007). However, the average age of death for persons with disabilities is

63.3 years for males and 69.9 years for females, compared to the general population's average age of death, which is 76.3 for males and 81.1 for females (National Core Indicators, 2017; Walker et al., 2007). These trends warrant a deeper look at the health care systems in place for persons with disabilities, but there are a number of challenges that researchers encounter when investigating questions related to disability health.

Challenges to the Study of Disability Health Research

There are several important challenges to studying disability health in terms of health disparity. The first challenge is that most federally funded research covering health disparities does not recognize or report on individuals with disabilities as a disparity population (National Council on Disability, 2018). Further, according to the NCD (2018), federally funded disability research remains concentrated on disease prevention efforts and provides little incentive for research aimed at improving access and quality of health care for individuals with disabilities. For researchers and practitioners looking for evidence-based practices designed to improve health disparities, particularly in terms of access to care and in increasing the use of available services and treatments, there is not an extensive body of literature from which to draw from in designing targeted interventions to address the needs of persons with disabilities. In discussing patients with complex care needs, including persons with disabilities, Rich, Lipson, Libersky, and Parchman (2012) stated that "additional research would help to clarify the optimal strategies and policies to ensure that high-quality primary care services are more widely available to these patients" (p. 32).

A second challenge to studies of disability health involves designing research that can account for the fragmented and disjointed health care system that persons with

disabilities must navigate in order to meet their various, individual needs (Hall, Wood, Hou, & Zhang, 2007). According to Ervin, Hennen, Merrik, and Morad (2014), "Health care for people with IDD [Intellectual or Developmental Disabilities] is an amalgam of related but distinct component parts, is frequently uncoordinated and can be extraordinarily difficult to access" (p. 83). Not only must persons with disabilities manage a host of interrelated symptoms and conditions but they also must seek care from providers who have not been fully trained to provide the level of comprehensive care required and who do not frequently consult with one another about the patient (Ervin et al., 2014). In many cases, patients are forced to choose between inadequate health care or piecemeal care, wherein the patient or caregiver on the patient's behalf is required to assemble his or her own network of providers to manage a variety of primary and secondary conditions (Emmerich, 2006).

Third, public interest in disability-related issues, which often drives funding and support for disability research, remains inadequate. According to the World Health Organization (2011), negative public perceptions of disability perpetuate lower expectations, discriminatory practices, and marginalization in society for individuals with disabilities, whereas positive attitudes lead to acceptance and inclusion. Pruett, Lee, Chan, Wang, and Lang (2008) reported that the public perception of persons with disabilities in the United States is largely negative and misinformed, and that these negative attitudes have contributed to compromised health care for such individuals. For instance, individuals with disabilities are more reliant on publicly funded health care, which, as discussed above, occurs primarily through Medicaid and is accompanied by rules and practices that vary widely from state to state (Larson, Lakin, & Hill, 2013).

Waiver-based options are considered to be optional and are determined by the state, and, therefore, at any point, they can be capped, revoked, or revised by lawmakers who are elected by the public. Because Medicaid was written with an institutional bias, by law, states are only required to provide long-term services and supports through institutionalization, meaning the availability of home- and community-based waivers, such as the MPW, is not guaranteed.

Research related to public opinion about Medicaid programs shows mixed results. For instance, Stuber, Maloy, Rosenbaum, and Jones (2000) surveyed 1,400 Medicaid eligible patients from 30 community health centers, located in ten different states, finding that 50% of respondents reported perceiving at least one aspect of stigma-related problems associated with participating in Medicaid, such as feeling bad about themselves, thinking they are looked down upon, or feeling more at risk of being treated badly due to their Medicaid use. In analyzing data gathered through a nationally representative survey administered by the KFF, Grogan and Park (2017) found that Medicaid is viewed most favorably by individuals with an important connection to waiver-care information or resources. Adults with current and previous Medicaid coverage, as well as individuals with a close family member or friend with Medicaid coverage, were more likely to support increases in spending. Whereas, individuals connected to Medicaid solely through their child's coverage were no more likely to support Medicaid expansion than those with no connection. A limitation of this finding is that it does not separate individuals connected to children with disabilities from children receiving Medicaid benefits through the Children's Health Insurance Program. Still, this finding raises an interesting question regarding how parent caregivers of children with

disabilities might feel about using Medicaid, given its potentially stigmatized position in American culture.

Finally, and of particular relevance to the present project, several studies have showcased how health outcomes for persons with disabilities are often linked to the efforts and effectiveness of their family caregivers, yet research that explicitly explores such links is limited (Agosta & Melda, 1995; Ireys, Chernoff, Devet, & Young, 2001; King, Teplicky, King, & Rosenbaum, 2004). As second-order patients, family caregivers routinely attend clinical appointments and actively collaborate with associated providers to discuss specific medical and behavioral treatment options, as well as make critical health care decisions (Wittenberg-Lyles, Goldsmith, Ragan, & Sanchez-Reily, 2010). For children who are eligible for the MPW, parents must apply for the waiver on their behalf, navigate the rules and regulations of the waiver, and make both immediate and long-term decisions about their child's specialized community services and treatment. Little is known about this decision-making process for parent caregivers when navigating waiver-based care, despite the growing body of evidence linking health outcomes and disparities for persons with disabilities to the efforts and effectiveness of their family caregivers in successfully navigating complex, medical systems of care (Agosta & Melda, 1995; Ireys et al., 2001; King et al., 2004).

The Parent Caregiver's Role in Disability Health Care

Children with disabilities often have the most to gain from early intervention access and community-based resources (CDC, 2018). Studies show that a young child's level of exposure to early intervention is positively associated with improved health outcomes (Center on the Developing Child at Harvard University, 2007); increased

language and communication ability (American Speech-Language-Hearing Association, 2008); and improved cognitive development and social/emotional development (Hebbeler, Barton, & Mallik, 2008). Families also benefit from their child's early intervention. Past studies have linked early intervention to decreased stress in the household and improved family relationships (Hebbeler et al., 2008). However, many parents of children with complex care needs feel overwhelmed by the level of care their child requires (Cohen, 1993), which may delay their decision making and seeking of healthcare resources. Therefore, in studying disability health disparities among children with disabilities, research must expand its focus to those intimately involved in the caregiving and decision making for children with disabilities, which is most likely to be their parents.

Parental Caregiving and Decision Making

A significant aspect of parental caregiving for children with disabilities involves medical decision making. It is the case, that in general, family caregivers are often given great latitude (i.e., control) when making decisions about their child's treatments and adherence (Cantor, 2005). Decision making in all health contexts includes the choices, judgments, and conclusions that guide health behavior (Sparks, 2008). According to Sparks (2003), uncertainty, technical language, emotion, and the probabilistic anticipation of unknown health outcomes can complicate the decision-making process for family caregivers. Ultimately, in reviewing the literature related to decision making, Sparks and Villagran (2010) concluded that "sound decision making in health care relies on effective communication among providers, families, and other external sources of information, combined with the ability to process information" (p. 75).

According to the CDC (2018), early intervention regarding treatment and related therapies for children with intellectual or developmental disabilities can significantly improve their interactions and communication ability, which then also improves their response to all other forms of therapy. However, the financial cost of early intervention deters many families from accessing early intervention (Anderson, Dumont, Jacobs & Azzaria, 2007). For instance, recent data from the CDC (2018) suggested that about 1 in 68 children have some form of autism spectrum disorder—a 30% increase from 2008 to 2010. A standard treatment option for many children with an autism disorder is Applied Behavioral Analysis (ABA) therapy. The average cost of ABA therapy is $120 per hour—or an estimated $46,000–$47,000 per year—and private health insurers are often reluctant to cover ABA costs (Special-learning Inc., 2019). Many children with intellectual or developmental disabilities will also require speech, occupational, or physical therapies, which can range from $40–$200 per hour. These therapies can also be uncovered, capped, or can require co-payments by traditional health insurance plans (Special-learning Inc., 2019). Further, traditional health insurance often excludes reimbursement for therapeutic equipment and at-home, environmental adaptations that caregivers require to facilitate at-home treatment (Special-learning Inc., 2019). The associated costs of adhering to recommended treatment for children with disabilities forces parents, who must provide care within their financial means, to make strategic decisions about which treatments are most necessary and affordable for their child (Anderson et al., 2007).

Given the expense of these treatments, deciding to access the MPW is a potentially critical decision for caregivers of children requiring multiple forms of

community-based care because it provides coverage to meet many health care needs that are excluded under traditional insurance plans, including environmental and accessibility adaptation services; personal assistance; behavior supports; occupational, physical, and speech therapies; and respite care for the caregiver. Still, even when a child becomes eligible for the MPW, the number of eligible treatment hours must still be negotiated with Medicaid and there are a limited number of certain types of providers in the state (e.g., behavioral support) to meet the demand for services.

As noted previously, when persons with disabilities elect to receive care through an HCBS waiver, such as the MPW, a legal caregiver on their behalf agrees to coordinate the specialized care required within the home and community. According to Crump (2018), many families of children with disabilities are unaware of the resources that exist in the community, including available therapies, service providers, support groups, and education workshops designed specifically to support the informational needs of parent caregivers. In addition, parent caregivers also become responsible for locating providers and negotiating the allocation of treatment hours through Medicaid (U.S. Department of Health and Human Services, 2010). These circumstances may also complicate the decisions caregivers make regarding treatment and services for their child.

Finally, parent caregivers also face important decisions about the future care of their child should they no longer be able to provide care themselves. Recent Kentucky-specific data reported by National Core Indicators (2017) suggested that 46% of parent caregivers were not advised about emergency care planning at their last service planning meeting, and, nationally, 51% of family caregivers surveyed indicated that their child lacked a future care transition plan. Nationally, fewer than half of parents of children with

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disabilities have an adequate future care plan in place (University of Illinois at Urbana-Champaign, 2018). This lack of future planning is potentially threatening to the health care of children with disabilities. Research has demonstrated that children with intellectual or developmental disabilities are more likely to be placed in institutional settings if care plans are not in place when the parent who is providing care for the child dies or can no longer continue the role due to sickness, age, or death (University of Illinois at Urbana-Champaign, 2018).

Parental Caregiving and Treatment Adherence

Once parental caregivers of children with disabilities have made treatment decisions, they must also work to adhere to the treatment plan they have chosen for their child. On average, over $300 billion per year of avoidable health care costs generally occur due to treatment nonadherence (NEJM Catalyst, 2017). According to Haskard-Zolnierek and Thompson (2016), patient adherence refers to "the extent to which a patient's health behavior corresponds with the agreed-upon recommendations of the health care provider" (p. 1). This statement is consistent with growing research suggesting that treatment adherence depends on effective communication between the patient and a medical provider (Chesney, 2000; Murphy, Roberts, Martin, Marelich, & Hoffman, 2000; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004).

For children with disabilities, treatment adherence often refers to therapeutic adherence (Gajdosik & Campbell, 1991; Jin, Sklar, Oh, & Li, 2008). This includes adhering to recommended therapy treatment frequency, accepting activity or dietary restrictions, and keeping scheduled appointments with medical providers and specialists (Gajdosik & Campbell, 1991). Studies have shown that when a therapeutic regimen is

longer term, which is typically the case for children with lifelong disabilities, adherence is much lower than for short-term regimens (Galil, Carmel, Lubetsky, Vered, & Heisman, 2001). Poor treatment adherence to long-term therapy in children with developmental disabilities and special care needs has been a concern voiced by the medical and rehabilitation community for decades, yet there remains little research that has explored the factors that contribute to parent caregiver nonadherence in this context (Jin et al., 2008). In addition, therapeutic nonadherence has significant financial consequences for society as whole. Specifically, therapeutic nonadherence has been linked to additional urgent care visits, increased hospitalizations, and higher long-term treatment costs (Bond & Hussar, 1991; Svarstad, Shireman, & Sweeney, 2001).

There are several conditions of the MPW that add further complexity to parent caregivers' treatment adherence. Under the MPW, parents can choose an option that allows them or someone they know to be paid to perform at-home treatment tasks as a specialized care provider. To date, research has not explored parent caregivers' communication processes when obtaining the knowledge to facilitate specialized treatment and therapy for the child as a paid provider themselves. Nor has research addressed the unique communication challenges of training at-home providers (e.g., community living support workers, respite workers, schools) to perform the needed services and treatment plan.

A common finding in research related to treatment adherence is that individuals' evaluations of how closely the treatment fits within their daily lives often predicts their level of adherence (Siegel & Gorey, 1997; Siegel, Schrimshaw, & Dean, 1999). Beals, Wight, Aneshensel, Murphy, and Miller-Martinez (2006) found that when caregivers

hold strong attitudes about the difficulties in medication management or are skeptical of treatment, they are also more likely to be nonadherent. For instance, Santer et al. (2014) claimed that caregivers for children with chronic illnesses often report that treatment adherence frequently interferes with both their relational goals and their desire to provide a "normal" life for their children with illness, as well as their other children. In an examination of home exercise compliance among caregivers of children with disabilities, Rone-Adams, Stem, and Walker (2004) found a significant relationship between family problems, stresses at home, and treatment regimen compliance.

Ultimately, caregiver decisions about medication and treatment nonadherence have significant health consequences for persons with disabilities (Iuga & McGuire, 2014). Yet, little consideration has been given to the systematic constraints of waiver-based care, including the heavy reliance on parent caregivers to coordinate the optimal care conditions that would help to reduce their child's potential health disparities. Parent caregivers navigating the MPW on behalf of their child face additional complexities when making decisions regarding their child's treatment and services because they must also coordinate care between various levels of Medicaid and various service and treatment providers within their community.

The Present Study

Health communication ("the study of messages that create meaning in relation to physical, mental, and social well-being," Harrington, 2018, p. 9) has proven to be a useful perspective from which researchers can explore individuals' specific social experiences, as well as the unique interpersonal communication dynamics that influence health behavior. In recent years, health communication research has been recognized by the

federal government as a necessary part of its strategy to eliminate health disparities, and was, for the first time, included as an objective in the Healthy People 2010 agenda and continued in the Healthy People 2020 initiatives. Studying health communication from an ecological perspective is particularly helpful toward achieving the goal of eliminating health disparities. Scholars have long contemplated the political, physical, cultural, and demographic structures that affect individuals' ability to fully participate and engage in their communities (Castells, 2000; Sampson, Morenoff, & Earls, 1999; Verba, Schlozman, & Brady, 1995). From a communication perspective, these conditions can create both inequity and uncertainty in health care, and such conditions can only exist through continuous processes of communication and interaction.

The purpose of the present study was to further scholarly understanding of parent caregivers' negotiation and management of waiver-based health care, including how the uncertainty they experience ultimately affects their ability to make decisions regarding the health care of their child. In particular, I explore the uncertainty caregivers face when engaging the community-level of their communication ecology to access the MPW along with the other wavier-related treatment and services for their children. I aimed to answer these two overarching questions: What conditions of the MPW experience lead caregivers to feel uncertain when trying to access and negotiate treatment and services, and how do parental caregivers appraise and manage this uncertainty? In what ways are caregivers influenced by their communication infrastructure, particularly at the community level, when managing their uncertainty and making decisions about the health care of their child?

CHAPTER TWO: THEORETICAL FRAMEWORKS

In this chapter, I first provide an overview of Brashers's (2001) uncertainty

management theory (UMT) and Ball-Rokeach, Kim & Matai's (2001) communication

infrastructure theory (CIT) as two particularly useful theoretical frameworks for

exploring the factors that influence parental caregivers' experiences of facilitating care

for their child with disability within the boundaries of the MPW system. I end the chapter

by providing a rationale for integrating these two ecological frameworks as a means of

answering three theoretically and practically significant research questions.

Uncertainty Management Theory

Uncertainty has been recognized as an important construct in studies of

communication behavior for more than 50 years (Babrow, Kasch, & Ford, 1998; Berger

& Calebrese, 1975; Brashers, 2001; Mishel, 1988; Shannon & Weaver, 1949).

Uncertainty occurs "when details of situations are ambiguous, complex, unpredictable or

probabilistic; when information is unavailable or inconsistent; and when people feel

insecure in their own state of knowledge or the state of knowledge in general" (Brashers,

2001, p. 478). Early research in this area assumed that uncertainty was universally

unwanted and that individuals are motivated to reduce uncertainty. For instance, Berger

and Calebrese's (1975) uncertainty reduction theory argued that when individuals

experience uncertainty, they feel less confident in their ability to predict, understand, and

respond to a given interaction and, therefore, are motivated to reduce their uncertainty,

most typically by seeking information. Over time, additional uncertainty research

expanded the initial conceptualizations of the conditions of uncertainty as well as the

possible responses to it. In articulating UMT, Brashers (2001) clarified his departure from

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previous reductionist models, arguing that "the field's historic focus on uncertainty reduction is both a cause and symptom of underdeveloped ideas about uncertainty and methods of managing it" (Brashers, 2001, p. 478). UMT research has demonstrated that uncertainty can take multiple and forms (sometimes simultaneously) and, in some cases, might not lead to attempts to reduce uncertainty (Brashers, 2001). For instance, individuals may prefer to maintain or even increase their uncertainty in some circumstances. Building on Mishel's (1990) theory of uncertainty in illness, which describes how patients cognitively interpret illness-related events, Brashers (2001) argued that the idea of management versus reduction more accurately characterizes the range of emotional and behavioral responses to uncertainty, especially in health contexts.

To understand the role of uncertainty in health contexts, Brashers (2001) argued that it is necessary to explore the processes of communication that contribute to an individual's appraisal and behavioral response to the sources of uncertainty. Brashers (2001) argued that "across contexts, people engage in or avoid communication so that they can manipulate uncertainty to suit their needs . . . Research studies that account for these factors have important consequences for the practice of health care" (p. 491). According to Brashers (2001), health-related uncertainty often falls into three broad categories: personal, social, and medical sources. Examining the context-specific sources of health-related uncertainty enhances our ability to explain its influence on health behavior as well as to develop strategies designed to improve individuals' management of and ability to cope with the health-related challenges they face.

Sources of Uncertainty in Caregiving

Personal sources of uncertainty in caregiving. Personal sources of uncertainty regarding illness often involve individuals' negotiation of complex or conflicting roles, identities, and responsibilities. This form of uncertainty is common among individuals living with complex illnesses or disabilities and their caregivers. Mishel (1999) commented that "unlike uncertainty in acute illness—where uncertainty is somewhat localized in the issues of diagnosis, treatment, and recovery—the uncertainty in chronic illness involves more areas of life and influences in daily routines and activities" (p. 269). Discovering the disability diagnosis of a loved one and coming to terms with the impact the disability may have on family life can be biographically disruptive (Bury, 1982). When individuals assume the role of caregiver, their expected life courses change, and they must learn new ways to operate in the world. Biographical uncertainty can present itself when caregivers must renegotiate their identities and roles (Cohen, 1993); these renegotiations often involve communication with others. For instance, caregivers may be required to make adjustments to their career plans (Clarke-Steffen, 1997) and must disclose the disability status of their loved ones in a variety of public and private contexts to obtain the resources they need. Ultimately, this biographical disruption contributes to a questioning of one's self, one's role, and one's value in the world (Bury, 1982). Parent caregivers of children with disabilities feel this disruption twice over because they must negotiate what the diagnoses mean for their own life and the life of their child.

A key aspect of personal uncertainty in caregiving is a person's identity. Cohen (1993) suggested that when a child is diagnosed with a chronic illness, such as a lifelong disability, parents begin an emotional process of recognizing that the expectations they had imagined for themselves in terms of becoming a parent and raising a child will now

be dramatically altered, and this creates a heightened sense of uncertainty. Similarly, Charmaz (1994) noted that many people experience identity dilemmas when diagnosed with a chronic illness that contributes to their experience of illness uncertainty. There is evidence that parent caregivers of children with complex diagnoses negotiate conflicting personal identities after their child's diagnosis. According to Jones (2014), "when a cure is not likely, parents have tremendous fear that their child will suffer emotionally or physically and often worry that they may not be able to provide the support necessary" (p. 214). This questioning of role efficacy and ability is a consistent theme in the extant literature on parental identity and uncertainty. For example, Maurer et al. (2010) found that parent caregivers often struggle with their desire to be a "good parent." Although the definition of a "good parent," in some ways, is a personal construction, research also demonstrates that caregivers' definitions of "good parenting" in critical illness are influenced by individuals' social experiences, such as their family, community, and through interactions with providers (Hinds et al., 2009).

Personal uncertainty also includes the financial implications of illness. The financial responsibility caregivers assume can be substantial. For instance, annual health care expenses for children with disabilities are more than triple those of other children (Newacheck & Kim, 2005). Individuals may feel uncertain when negotiating their child's disability status with insurance and managing the unpredictable, long-term financial consequences of being caregivers (Brashers et al., 2003). Parent caregivers of children with disabilities must also plan for their children's care in the event that something happens to them. A recent study by the University of Illinois at Urbana-Champaign (2018) reported that fewer than half of parents with children with disabilities make long-

term plans regarding who will care for their children in the future, should they become too sick or die before their child. Furthermore, unique rules govern the amount of assets individuals receiving Medicaid-funded care can receive. Therefore, thoughtful financial and future planning is an important consideration for parent caregivers, and it can create a good deal of uncertainty.

In summary, extant research has identified identity and financial concerns as personal sources of uncertainty. These are individual-level personal sources of uncertainty; less is known about more community-level personal sources of uncertainty. When examining the growing dependence on family caregivers in facilitating care for individuals with disabilities in the community, it is important to consider the sources of personal uncertainty that might contribute to caregivers' willingness to engage with others when accessing and negotiating their children's health care at the community level.

Social sources of uncertainty in caregiving. Caregiving parents also experience uncertainty in relation to the broader community. Brashers and Hogan (2013) explained that social forms of uncertainty can include unpredictable social reactions, unclear relational implications, and social support issues. Perhaps the most pervasive source of social uncertainty that persons with disabilities and their families face throughout their daily lives is stigma (Goffman, 1963) and the accompanying shame (Lazare, 1987).

In recent years, the concept of perceived stigma has drawn interest from health professionals and researchers due to the burden it adds to uncertainty and illness management (Brashers et al., 2003; Michel, 1990). According to Weiss, Ramakrishna, and Somma (2004), in addition to delaying help-seeking, stigma can also lead to

discontinuation of needed, effective treatment. Similar to patients, family caregivers may also become targets of stigma through a process Goffman (1963) calls secondary (or courtesy) stigma. Secondary stigma involves the disapproval that friends, families, and close others encounter as a consequence of associating with a stigmatized individual or group. The fear of being stigmatized may cause family caregivers to further isolate themselves from their social circles and, by default, become further disconnected from valuable resources and opportunities to help themselves and their patients (Reinhard, Given, Petlic, & Bemiss, 2008). Thus the role of stigma is an important form of social uncertainty to explore in the consideration of community-level influences on parental uncertainty related to the MPW.

The long-term nature of caregiving for children with disabilities may also have unique consequences for developing or maintaining social relationships in the community. For instance, in a study of parent caregivers, White and Hastings (2004) determined that parenting a child with unique needs often leads to a disruption in the informal support systems. For example, caregivers often receive less contact from friends, family, and extended family overall, and, as a result, are also denied the normative feedback and expertise other parents often use to navigate the many stages of their children's lives, thus creating a gap that often remains unfilled. In addition, Speraw (2006) found that caregivers experience mixed levels of acceptance when seeking support from their faith-based communities; although some caregivers felt such communities were accepting and inclusive of their children with disabilities, others reported feelings of isolation and rejection. In another study, Obst and White (2005) found that when caregivers feel a sense of belonging in the communities in which they live, they feel they

have benefited from those associations, which in turn facilitates parents' ability to manage the social uncertainty related to seeking and coordinating MPW-based care for their child.

Although several previous studies have demonstrated that quality relationships can lead to increased information and social support that buffer the experience of stress in caregiving (Cohen & Wills, 1985), the communicative work in asking for and receiving support is a complex process (Burleson & MacGeorge, 2002; Goldsmith & Albrecht, 2011) and one that can in fact exacerbate uncertainty. Lincoln (2000) reported that many caregivers suffer from social support burden, a condition where the additional work associated with seeking, maintaining, and receiving social support becomes overwhelming for the caregiver. Similarly, although studies have demonstrated that caregiver wellness improves when caregivers receive instrumental, emotional, and informational support (MacLeod, Skinner, & Low, 2012); their receptiveness to support is dependent upon a variety of factors, including relational closeness, the context of a support message, and the message itself (Feng & Lee, 2010). It thus becomes important to note that social support is not always helpful (Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Lincoln, 2000); rather, individuals perceive support in different ways, and even well-intended support from others is often not perceived as such (Goldsmith, 2004), which can heighten uncertainty.

To summarize, existing research has examined the influence of unpredictable social reactions, unclear relational implications, and social support as sources of uncertainty at the individual level, but less is known about how these sources of uncertainty are experienced at the community level. Given that parent caregivers who

facilitate the MPW are tasked with creating and managing strategic social relationships

with community partners, to facilitate the at-home and community-based care of their

child, it is important to consider the sources of social uncertainty that might constrain

their ability to do so effectively.

Medical sources of uncertainty in caregiving. There are also a number of

medical sources of uncertainty for parental caregivers. One common medical source of

uncertainty among parental caregivers is the etiology of their child's diagnosis.

Oftentimes, uncertainty about the illness persists due to ambiguous, complex, or

unreliable information that individuals or caregivers are given early in the diagnostic

process (Babrow et al., 1998). Despite having high information needs, caregivers are

often only given pieces of information about the diagnosis (Clarke-Steffen, 1993). Even

in instances when diagnostic information is relayed clearly, this new information

commonly raises a caregiver's curiosity about what the illness will mean for both the

patient and themselves (Cohen, 1993). From the moment of diagnosis, caregivers are

thrust into a new reality that is both confusing and unexpected.

In addition, an emerging body of research has indicated that insufficient

communication from health care providers contributes to the medical uncertainty of

caregivers. The complexity of the child's illness or condition creates information-related

uncertainty for parent caregivers that can further hinder their ability to make decisions

about treatment (Kerr & Haas, 2014). When health care providers are unable to interpret

symptoms, provide treatment, or fulfill the role of a credible authority, they can also

cause anxiety-producing uncertainty for parents to manage (Kerr, Harrington, Scott,

2019). For example, past research found that when healthcare authorities provided

unreliable or insufficient information they violated patient expectations and intensified

their feelings of uncertainty (Brashers et al., 2006). Results from a systematic review of

treatment nonadherence in pediatric long-term care concluded that input provided by

health professionals to parent caregivers plays an important role in treatment adherence

or nonadherence. It is widely understood that when treatment decisions are complex,

even the most autonomous decision maker will often strongly consider the opinion of a

medical provider (Brashers et al., 2006; Bradbury, Kay, Tighe, & Hewison, 1994; Kerr et

al., 2019; Kerr & Haas, 2014; Hyde, Punch, & Komesaroff, 2010). Medical authorities

are also members of the meso level, and therefore worthy of consideration in this study

exploring the uncertainty experienced by parental caregivers of children utilizing the

MPW.

A final medical source of uncertainty for caregivers involves overcoming

knowledge barriers in terms of complex medical terminology. Wittenberg-Lyles,

Goldsmith, and Ferrell (2013) explored the use of medical terminology with caregivers of

hospice patients and found that caregivers often lack prior knowledge of medical

language. Parent caregivers of children with complex care needs also face terminology

challenges when seeking information about their child's illness (Clarke-Steffen, 1997;

Cohen, 1993) which can hinder their uncertainty management (Miller, 2014). When

caregivers lack adequate understandings of medical knowledge, such as technical

language, they often recall less information and possess a diminished ability to follow

treatment instructions (McCarthy et al., 2012).

In summary, uncertainty related to the etiology of illness, insufficient information

from health care providers, and complex terminology are three commonly experienced

medical sources of uncertainty. The communication input of the health care providers

(i.e., community-level interactions) throughout the illness trajectory can influence the

uncertainty and management responses of patients and caregivers managing complex

illnesses. Given that parent caregivers coordinate their child's care with multiple

community providers, it is important, in this study of uncertainty related to the MPW, to

examine the sources of medical uncertainty at the community level.

Uncertainty Appraisal and Strategies of Uncertainty Management

UMT assumes that uncertainty is a neutral cognitive experience and that

individuals appraise the uncertainty they feel in terms of their emotions (Brashers,

Neidig, Haas et al., 2000). These emotional responses that stem from the appraisal of

uncertainty will often result in communication interactions with others. Studies of

uncertainty appraisal suggest that people first determine the meaning of an event based

on its negative, positive, or neutral relevance to their lives (Brashers, Neidig, Haas, et al.,

2000; Lazarus & Folkman, 1984; Mishell, 1988). Negative emotional responses motivate

reduction strategies, whereas positive emotional responses (i.e., when uncertainty is

framed as beneficial in some way by the individual, for example, because it preserves

hope) motivate uncertainty maintenance strategies (Brashers, 2001). Neutral appraisal

occurs when individuals conclude the source of the uncertainty is irrelevant to their more

pressing goals or concerns. Lazarus (1991) proposed that negative and positive appraisals

of uncertainty could co-occur, but little research has explored this possibility.

In the present study, understanding parent caregivers' appraisals of uncertainty

related to the MPW system can shed light on how they manage their uncertainty to access

and facilitate their child's care. A review of past studies demonstrates that three common

uncertainty management strategies are motivated by individuals' appraisal of uncertainty and can be observed across contexts, including information seeking, avoidance, and social support (Brashers, 2001). Moreover, two recent studies have proposed that reframing strategies can be useful when uncertainty is simultaneously appraised both positively and negatively (Cohen et al., 2016; Darnell, Buckley, & Scott, 2018).

Information seeking. Brashers, Neidig, Haas, et al. (2000) posited that when uncertainty is appraised as dangerous, negative emotions will lead an individual to reduce uncertainty. As Langer (1994) explained, "information gathering serves the purpose of differentiating options and creating options" (p. 45). Seeking information can ameliorate the negative emotional reactions associated with threats posed by uncertainty by helping individuals make sense of an event or issue and thus reduce their uncertainty (Brashers et al., 2009; Mishel, 1988). Hauser and Kramer (2004) found that information needs are significant for caregivers who are tasked with the responsibility of understanding the patient's experience, finding patient resources, making decisions, and establishing a support system for themselves. Communication strategies used by individuals seeking information to meet their needs can vary, depending on the salience of their various goals or desired state of uncertainty (Brashers, Neidig, Haas et al., 2000).

Information-seeking strategies can be active, passive, or experiential (Brashers, 2001). A parent caregiver of a child with an intellectual or developmental disability might employ information-seeking strategies when attempting to access treatment or services that are perceived to be out-of-reach due to financial or logistical reasons or in overcoming health literacy barriers. For instance, prior research has suggested that frequent use of medical jargon, purposeful ambiguity in medical encounters, and cultural

insensitivity to health conditions can lead to ineffectiveness and dissatisfaction in decision making for caregivers (Ragan, Wittenberg-Lyles, Goldsmith, & Sanchez-Reily, 2008). To overcome these challenges, an active information seeker uses direct requests to obtain information, usually from family and friends, before opening up to health care providers or more distant networks. A passive information seeker tends to look for information without deploying direct information-seeking efforts and favors listening to the experiences of their social support networks as a means of gathering information (Brashers, 2001). An experiential seeker will acquire information by "doing" and seeing what works, or by observing what others do and then retaining their experiences as critical knowledge. Regardless of which method is utilized, the goal of information seeking remains the same. That is, an information seeker is motivated to locate information that will allow them to create a cocoon of certainty for themselves, despite its correctness (Brashers, 2001).

Avoidance. When uncertainty is appraised positively (often because it allows a person to preserve hope), a common management strategy is avoidance. Remaining hopeful often entails actively avoiding information or strategically seek out information that allows them to maintain feelings of optimism (for example, by getting a more optimistic second opinion). According to Brashers (2001), "avoidance can shield people from information that is overwhelming and distressing and can provide an escape from a distressing certainty by maintaining uncertainty" (p. 483). Avoidance is communicated consciously and unconsciously through social withdrawal, reduced disclosure, discounting negative information, and discrediting sources of information (Brashers, 2001; Cohen, 1993). For instance, in a study of family caregivers for dementia patients,

Lee, Barlas, Thompson, and Hong Dong (2018) found that caregivers often avoid initial diagnostic assessments because they perceive the potential for stigma related to the disease. Similarly, several studies have shown that high levels of ambiguity in regard to decision-making outcomes can be paralyzing for many parent caregivers of children who require specialized care (Boss, 1999; Joosa & Berthelsen, 2006). Studies have shown that when individuals utilize avoidance as a management strategy, they actively ignore information or strategically regulate the information and conversations to which they are exposed to minimize exposure to unwanted information (Barbour, Rintamaki, Ramsey, & Brashers, 2012).

Social support. Social supporters can influence the appraisal and management of uncertainty (e.g., increase or decrease it) in several ways. Brashers, Neidig, Goldsmith (2004) found that social supporters can help others reduce unwanted uncertainty related to information needs by taking on the information-management role themselves. Divan, Vajarathar, Desai, Strik-Lievers, and Patel (2012) discovered that, after a period of social withdrawal, parent caregivers often attempt to develop networks with an organization or group associated with their child's diagnosis or the special care needed to better navigate experiences and seek advice. In addition, Divan et al. (2012) observed that connections to other disability families are especially helpful in accessing and navigating information. Price, Bush, and Price (2017) suggested that social support networks play a critical role in connecting parent caregivers to "external systems," such as treatment providers, services, information, and family support services (Price et al., 2017, p. 88). Social supporters also can bolster the individual's decision-making efficacy and the development of self-

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advocacy skills (Brashers, Haas, Klingle & Neidig, 2000) by assisting in the collaboration or evaluation of information.

Social supporters can also help increase positively-appraised uncertainty (e.g., hope) by providing a stable relationship where individuals can seek validation, encouragement, and the opportunity to discuss and reevaluate their uncertainty as a part of life (Brashers, 2001). In Kapp and Brown's (2011) qualitative analysis of the role of parent caregivers' social support systems, parents reported that their social, instrumental, and network support systems were their most important resources when positively coping with the uncertain health outcomes associated with their child's special care needs.

Reframing. The reframing strategy is rooted in Lazarus's (1991) psychological stress theory, which acknowledges that individuals can experience primary and secondary appraisals when faced with a stressor. Primary appraisals are most often associated with concerns about the potential for conditions that threaten an individual's well-being, whereas secondary appraisals include the feelings (i.e., the condition is evaluated as good or bad) associated with the stressor (Lazarus, 1991). Folkman and Lazarus (1984) argued that primary and secondary appraisals occur simultaneously. Further, Lazarus (1991) posited that these two appraisals can be incongruent and therefore stimulate a cognitive response in which a person works to better align the dual appraisals. Recent uncertainty scholarship has begun to examine the possibility and functions of dual appraisal and uncertainty management more closely. For instance, Cohen et al. (2016) found that when considering whether to participate in cervical cancer screening, Appalachian women simultaneously appraised their uncertainty as a positive and negative experience. Additionally, Darnell et al. (2018), in their study of adolescent women who had

experienced miscarriage, found that participants utilized reframing as a means of reappraising the negative feelings they held about their uncertainty. Several participants reframed their negatively-appraised uncertainty as a "second chance" to make behavior changes that would lead to a desired future (i.e., positive appraisal). This possibility of dual appraisal expands the scope of Brashers's (2001) original conceptualization of uncertainty appraisal.

In summary, prior research has suggested that individual-level appraisals of the sources of uncertainty motivate individuals' uncertainty management based on people's assessment of risk or opportunity (Brashers & Hogan, 2013), yet less is known about how community appraisals (e.g., stigma) can shape an individual's response to uncertainty.

Communication Infrastructure Theory

As both an ecological and a communication-focused theory, CIT emphasizes the environmental conditions that contribute to community members' individual, interpersonal, organizational, and societal decision making within a geographic region (Matsaganis & Golden, 2015). The CIT perspective positions researchers to better explain how interactions and the sharing of ideas and values among various levels of an ecology contribute to individual-level health behavior. Broad et al. (2013) explained the process of ecological communication and outcomes as "those multi-model communication connections, shaped by particular social and cultural conditions that are actually employed by an individual as a means to construct knowledge and to achieve goals" (p. 328). CIT provides a specific lens through which researchers can explore ecological relationships between a communicatively constructed environment and the communication actions that occur within it (Kim & Ball-Rokeach, 2006). Specifically,

through CIT, researchers can identify the formation of a communication infrastructure as a socially constructed product of a community's storytelling network (STN) and communication action context (CAC).

The Storytelling Network

Storytelling from a CIT perspective is defined as any type of communicative action that addresses residents, their local communities, or their lives in these communities (Ball-Rokeach et al., 2001). The STN operates at multiple levels and includes micro-, meso-, and macro-level social actors (Ball-Rokeach et al., 2001; Kim & Ball-Rokeach, 2006). Micro-level actors within a community include the physical residents and their close interpersonal networks (i.e., friends, family, neighbors). Meso-level actors include community organizations, community-oriented media, and grassroots or aggregated networks that focus on a particular area or population (e.g., a center for disabilities or nonprofit advocacy). Meso-level storytellers are focused on a particular section of the city or segment of a population (Kim & Ball-Rokeach, 2006). Local media are also considered members of the meso-level community. CIT posits that local media is also an important part of the meso-level landscape. Finally, macro-level storytelling involves those messages received from mass-media organizations (e.g., national news media) and other larger governing institutions and organizations (e.g., state and national government) that help shape the culture, stories, and experiences of a community. Kim and Ball-Rokeach (2006) explained macro-level storytelling as stories that refer to "the whole city, the nation, or even the world, where the imagined audience is broadly conceived as the population of the city, county, or region" (p. 179). According to Kim and Ball-Rokeach (2006), "When residents talk about their community in neighborhood

council meetings, at a neighborhood block party, at the dinner table, or over the fence with neighbors, they become local storytelling agents themselves—participating in an active imagining of their community" (p. 179). Importantly, past research shows that an individual's connectedness to an integrated STN can have a positive impact on their receptivity and access to critical health messages (Manos et al., 2001).

In the current study, I concentrate on the influence of community-level (i.e., meso-level) storytelling on parent caregivers' communication and experience when accessing and navigating the MPW system. Given the aim of the MPW, which is to meet the needs of individuals with disabilities who prefer to receive specialized services and treatment in their home or community rather than in institutional settings, it seems likely that individuals' connections to a strong meso-level STN are critical to the achievement of desired health outcomes. For children of the MPW, the associations that their parent caregivers are able to make within their STN on their behalf will ultimately determine the level and quality of care that they receive.

The Communication Action Context

A communication action context (CAC) is defined as the physical, psychological, sociocultural, economic, and technological properties that exist in a community and actively enable or constrain communication between members of an STN (e.g., residents, community organizations, or media; Ball-Rokeach et al., 2001). When communities have physical spaces for their residents to connect and talk to one another, stories can be told and resources can be shared more easily (Wilkin & Ball-Rokeach, 2011). Habermas (1984) first proposed the idea of a socially constructed CAC, stating that it is achieved through rational discourse and describing communicative action as a necessary activity in

the formation of societies. Fisher (1989) suggested that, rather than looking solely at rational discourse, narrative paradigms might be better suited to explaining how people tell and listen to stories and make decisions about their actions. The CIT perspective likewise assumes that communities are built on shared stories. Kim and Ball-Rokeach (2006) explained the importance of the CAC in building community through narratives: "Local communities are based on resources for storytelling about the community; without any resources for constructing stories about the local community and sharing them with others, it is impossible to build a community" (p. 177). Evaluating the CAC of a particular community, therefore, includes a consideration of the community's physical layout (e.g., the built environment), its psychological environment (e.g., the community members' perception of safeness or stigma), its "communication hotspots" (e.g., places and spaces where residents gather to talk), and its comfort zones (e.g., community institutions that help residents feel connected; Wilkin et al., 2011).

Residency, belonging, and connectedness. Residency, belongingness, and connectedness are three psychosocial factors that are particularly salient in describing individuals' communication and engagement within their communication infrastructure. According to Ball-Rokeach et al. (2001), *residency* can enable or inhibit storytellers. Individuals living in a specified geographic community, or who are part of a distinct ethnic group, occupy a unique CAC made up of their own storytellers at various levels who can influence the flow and content of communication.

Belongingness refers to "a resident's feeling of attachment to a residential area that motivates everyday acts of neighborliness" (Ball-Rokeach et al., 2001, p. 9). More specifically, an individual's sense of belongingness contributes to willingness to engage

with other members of the community. Ball-Rokeach et al. (2001), in a study of seven ethnic communities, found that individuals' levels of participation in storytelling within their community were the strongest predictor of belongingness. This finding raises an important question that is relevant to the present study: Do family caregivers of children with disabilities who have or seek the MPW have a place to tell their story in the community? Previous research on CIT has established that feelings of belongingness in the community increase community members' collective efficacy and participation in community events (Ball-Rokeach et al., 2001; Kim & Ball-Rokeach, 2006). It is often the case among health disparity populations that STNs are more fragmented and difficult to find, and, as a result, individuals and families are limited to isolated storytellers at the micro level (e.g., family and friends), who may also have limited connectedness to broader resources and information (Wilkin & Ball-Rokeach, 2011).

Finally, CIT also posits that the *degree of connectedness* between individuals and all three levels of the STN can influence their goal attainment. Kim and Ball-Rokeach (2006) found that a greater degree of connection to the STN, meaning the more links that an individual had to various members of the community, was positively associated with increased civic engagement, levels of belonging, collective efficacy, and civic participation.

Field of health action. Matsaganis and Golden (2015) defined a field of health action (FHA) as the "sociomaterial context that comprises a place-specific set of structural conditions and interpretive resources, within which residents may be more or less inclined to seek particular health-care services and respond favorably to health-promotion interventions" (p. 168). FHAs include those spaces and places where health

care services can be introduced, accessed, or provided, and they encompass the subjective interpretations and feelings that have been cultivated about such services within the communication infrastructure (e.g., Medicaid stigma). The FHA can increase (e.g., positive connections to health resources for families) or limit individual agency through informal (e.g., stigma) and formal (e.g., systematic lack of information or access) means of social control. In the present study, I seek to identify those features of the CAC (i.e., connections to the STN, physical spaces to talk about the MPW, and societal conditions) that might constrain or facilitate parent caregivers' ability to manage their MPW-related uncertainty by creating a FHA that is more or less accessible and supportive of the needs of children with disabilities and their parent caregivers.

In summary, according to CIT, when social actors are more connected to local resources at each level, they are more likely to be knowledgeable about diseases, outcomes, and resources (Kim, Moran, William, & Ball-Rokeach, 2011), and they will show more interest in actively seeking health information (Kim & Kang, 2010). CIT allows researchers to analyze the relationships among the different communication infrastructure levels and health outcomes for populations facing health disparities. To date, communication research has not examined the specific social experiences of waiver-based care and communication. In the current study, I explore the role of the meso-level STN and CAC in educating, linking, and influencing caregivers' experience and management of uncertainty when seeking care and making decisions for their child.

An Integrated Approach

My goal in integrating UMT and CIT is to be able to examine the uncertainty experienced by parent caregivers navigating the MPW with greater specificity and

nuance so that future research can have a robust and targeted knowledge base to draw from in developing interventions to improve waiver-based care. The integration of these two theories makes sense for several reasons. First, both theories offer ecological perspectives on the study of health behavior influences. Most health communication research to date has focused on individual determinants of health behavior, such as health beliefs, self-efficacy, and the degree of beliefs and attitudes (Dutta, 2008; Neuhauser & Kreps, 2014). More recently, it has become clear that research considering the broader forces of communication is necessary for a fuller understanding health behavior and outcomes (Niederdeppe, Gollust, Jarlenski, Nathanson, & Barry, 2013). As theoretical frameworks that are constructed with an ecological perspective in mind, integrating UMT and CIT provides a robust response to this interdisciplinary call to place a greater emphasis on the environmental conditions that contribute to community members' health decision making.

Second, at the heart of both approaches lies a focus on the relationship between an individual's interpersonal interactions and the belief that better-quality interactions can lead to better management of individual- and community-level risks. Brashers (2001) acknowledged that an individual's social network can influence their appraisal and management of uncertainty in both positive and negative ways. Further, Brashers, Hsieh, Neidig, and Reynolds (2006) suggested that individuals who are managing complex care will actively seek out credible authorities to help them make sense of their experience. Likewise, Kim & Ball-Rokeach (2006) suggested that a community's storytelling system can serve as a type of credible authority that also influences behavior. In this study, I try

to make sense of the role of community storytelling in connecting parent caregivers to the knowledge they desire to facilitate the MPW.

Third, both theories encourage a shift in focus toward normative models of communication rather than rational-linear models. In describing the significance of taking a normative perspective, Brashers (2001) wrote, "normative theories help to explain what people do and what people should do to manage their uncertainty effectively (p. 490). The CIT approach also recognizes the normative influence of an individual's social environment on decision making by acknowledging how the STN itself is a quagmire of normative influences. A normative understanding of communication acknowledges the subjectivity of health behavior, and rather than aiming to predict the direction or level of communication in explaining health outcomes, shifts the focus to explaining what is more or less effective and appropriate in a given context (Goldsmith, 2004).

Research Questions

My first objective in this project is to identify the unique, meso-level uncertainty sources related to parent caregivers' access and negotiation of the MPW. Previous scholarship in both CIT and UMT has established many individual- and micro-level tensions that people experience when managing complex illness or health disparity (Brashers et al., 2003, Wilkin, 2013). Therefore, in this study, I shift the focus to those unique influences of the meso (i.e., community) level that facilitate or discourage access to optimal care. It is important to study meso-level influences because they play a crucial role in stimulating conversation about health behaviors within neighborhoods and also often are responsible for regulating the flow of resources to the community (Wilkin, 2013). By applying both theoretical frameworks, I hope to provide not only a description

of the meso-level sources of uncertainty that are reported by family caregivers but also to explain how communication at the meso level contributes to the uncertainty appraisals and management and responses of caregivers when making decisions and adhering to treatment plans when negotiating care for persons with disabilities in their communities. Therefore, I proposed the following two research questions:

RQ1: What meso-level uncertainties do parent caregivers experience related to the MPW system?

RQ2: How do parent caregivers appraise and manage their meso-level uncertainty related to the MPW?

a: How are parent caregivers' appraisals and management of MPW uncertainty related to decision making?

b: How are parent caregivers' appraisals and management of MPW uncertainty related to treatment adherence?

My second objective in this project is to identify the discursive elements of parental caregivers' CAC. This includes identifying the psychosocial conditions of the community (e.g., stigma, processes) that constrain the sharing of stories and information related to the MPW, and locating the physical places and spaces (i.e., communication hotspots) that are available for discussing the MPW at the meso level and that enable storytelling about the MPW (Villanueva, Broad, Gonzalez, Ball-Rokeach, 2016; Wilkin & Ball-Rokeach, 2006). In order to better understand the environmental context of meso-level storytelling related to the MPW and its influence on parental caregivers' uncertainty and management experiences, the following research question was proposed:

RQ3: What environmental barriers or facilitators within the communication action context constrain or enable parent caregivers' ability to manage MPW-related uncertainties?

CHAPTER THREE: METHODS

In this chapter, I provide a detailed description of the methods used in this dissertation project. First, I explain the recruitment of participants and describe my sample; second, I detail the procedure (i.e., demographic questionnaire and narrative interview protocol); finally, I describe how I analyzed the data and drew conclusions about my findings.

Recruitment of Participants

Eligible participants for this study included parent caregivers who were at least 18 years old and currently providing care for a child (under 18) with an intellectual or developmental disability receiving benefits through the MPW. The final sample included a total of 31 parent caregivers ($n = 27$ female parent caregivers, $n = 4$ male parent caregivers). All but one female parent caregiver was the biological mother of the child. One female caregiver was the aunt of the child but had obtained legal custody. All male parent caregivers were the biological father of the child.

This final sample included participants from 26 different zip codes in the state of Kentucky, representing all nine human service regions (Kentucky CHFS, 2019). Specifically, the sample was comprised of participants from the Cumberland Region ($n = 2$, 6.45%); the Eastern Mountain Region ($n = 1$, 3.23%); the Jefferson Region ($n = 3$, 9.68%); the Northeastern Region ($n = 3$, 9.68%); the Northern Bluegrass Region ($n = 11$, 35.48%); the Salt River Region ($n = 1$, 3.23%); the Southern Bluegrass Region ($n = 6$, 19.35%); the Lakes Region ($n = 2$, 6.45%); and the Two Rivers Region ($n = 2$, 6.45%).

The participants ranged in age from 31 to 52 years old, with a mean age of 40.48 years ($SD = 8.38$). The sample was composed of White ($n = 30$, 96.77%) and Asian

American ($n = 1$, 3.23%) participants. The majority of the parents were married ($n = 27$,

87.1%); 4 participants identified their current relationship status as single, never married

($n = 1$, 3.23%), in a serious relationship ($n = 1$, 3.23%), or other ($n = 2$, 6.45%). The

respondents' completed level of education also varied: high school degree/GED ($n = 1$,

3.23%); some college ($n = 6$, 19.35%); 2-year degree ($n = 1$, 3.23%); 4-year

degree/bachelor's degree ($n = 12$, 38.71%); master's degree ($n = 5$, 16.13%); doctoral

degree ($n = 4$, 12.9%), and professional degree (i.e., MD, JD; $n = 2$, 6.45%). The parent

caregivers' average yearly household income ranged between less than $20,000 ($n = 2$,

6.45%); $20,000–$39,999 ($n = 3$, 9.68%); $40,000–$59,999 ($n = 2$, 6.45%); $60,000–

$79,999 ($n = 4$, 12.9%); $80,000–99,999 ($n = 8$, 25.81%); $100,000 or above ($n = 11$,

35.48%); 1 participant ($n = 3.23\%$) elected not to report income. The respondents also

indicated various employment statuses, including full-time employment outside of the

home ($n = 10$, 32.26%); part-time ($n = 3$, 9.68%); full-time at home ($n = 10$, 32.26%);

student full-time ($n = 1$, 3.23%); and other ($n = 4$, 14.29%); 4 respondents ($n = 4$,

14.29%) chose not to indicate their current employment status. Lastly, the length of time

the parent caregivers had been managing the MPW for their child ranged from 2 to 18

years, with a mean length of 10.16 years ($SD = 3.77$).

Following approval from the Institutional Review Board (IRB), I recruited the

participants in two ways. First, I posted a recruitment social media post on Facebook,

which resulted in 15 interviews. Second, I sent a recruitment email through a statewide

disability network listserv, inviting any interested participants to contact me. This

listserv, which included agencies and support service providers across the state, was

available to me through a committee member's connections to the state's disability

networks. The listserv email resulted in 16 interviews. I conducted all interviews between September 1, 2018, and December 31, 2018.

The Pilot Interviews

Prior to the collection of the data for this dissertation, I conducted three pilot interviews. The purpose of the pilot interviews was to refine the interview protocol and to become more sensitized to the potential sources of uncertainty most relevant in this understudied context. The pilot sample included participants who ranged in age from 37 to 51 years old, with a mean age of 43.6 years ($SD = 7.02$). All the participants were White, all were from Kentucky, and all were married ($n = 3$, 100%). The respondents' completed level of education varied: high school degree/GED ($n = 1$, 33.33%); 4-year degree/bachelor's degree ($n = 2$, 66.67%). The parent caregivers' average yearly household income varied as well; \$40,000–\$59,999 ($n = 1$, 33.33%); \$60,000–\$79,999 ($n = 1$, 33.33%); \$80,000–99,999 ($n = 1$, 33.33%). The respondents indicated various employment statuses, including full-time employment outside of the home ($n = 1$, 33.33%) and full-time at home ($n = 2$, 66.67%). MPW experience ranged from 5 to 18 years, with a mean length of 10 years ($SD = 7$).

Castillo-Montoya (2016) posited that pilot interviews are essential for conducting effective qualitative research because they provide a useful format for ensuring that interview questions align with the research questions, for refining the interview protocol, and for affording feedback from participants about the interview protocol. As a result of the pilot interviews, I made three significant changes to the interview protocol.

First, I reduced the number of questions related to parent caregivers' experiences when first finding out about the diagnosis of their child. Participants' stories related to the

child's initial diagnosis were rich and emotional, and they clearly marked a turning point in the biographies of the parent caregivers (Bury, 1982). However, they offered little insight into parental caregivers' uncertainty and experiences related to accessing and navigating the MPW; other than reporting that at diagnosis no one mentioned the MPW. The revised protocol asked only one question about the diagnosis and limited the use of follow-up or probing questions about the diagnosis.

Second, I realized that when asking about treatment adherence, parent caregivers were more concerned about therapeutic adherence than adherence to prescriptions. During the pilot interviews, participants shared that having a medical card alleviated the financial dilemmas they faced in affording an intensive prescription regimen for their child—although they also noted that prior to having the MPW, treatment adherence related to prescription medication was still a concern. Rather, parent caregivers pointed out that the more pressing issues they faced related to the MPW involved trying to work with Medicaid to find qualified people to provide therapies in the home and community and also in coordinating with community partners, such as the school, to receive therapies in the child's natural environments. I adjusted the interview to reflect these priorities.

Third, prior to conducting the pilot interviews, I had not considered the use of application language as a source of uncertainty for parental caregivers. All three of the pilot participants reported some level of difficulty in learning how to best report the developmental progress of their child in order to increase their child's chances of becoming eligible for the waiver. It became clear that this unique condition of the MPW application process should be explored. The following item was added to the interview protocol as a result of this finding:

Some caregivers have discussed a secret code or language that they felt was essential when applying for the MPW. Is this something that you felt you had to learn? (Probe: Can you tell me about how you were able to obtain that knowledge? How did you feel about using this language to describe your child?)

Procedure

Once interested participants made contact with me through email, I followed up with a phone call to explain the study and to allow them the opportunity to decide if they would be comfortable participating in the interview. Prior to participation, I provided all potential participants with an IRB-approved consent letter (Appendix A), which informed them of (a) the purpose of the research (i.e., to learn about parent caregivers' experiences with the MPW), (b) the activities entailed in participation (i.e., engaging in a face-to-face or phone interview lasting approximately 60 minutes and completing a short survey), and (c) the remuneration benefit for participation (i.e., a $20 Visa gift card).

At the end of the call, I asked the participants if they would prefer an in-person interview or an interview over the phone. One participant elected to meet face-to-face (3.23%), with all others choosing the phone interview ($n = 30$; 96.77%). When a participant agreed to take part in the study, I sent him or her a link to the demographic survey through Qualtrics at the conclusion of the call. The brief questionnaire (see Appendix B) requested key demographic information (i.e., age, gender, race, marital status, and work status) and background information about the caregiver and the patient (i.e., relationship to patient, caregiving duration, hours per week providing care, diagnosis). In the same email containing the survey link, I provided the participants with a participant number to enter at the start of the survey so that I could track participation in

the survey and send reminders if needed without asking for their names through Qualtrics, thus further protecting their anonymity. All the participants successfully completed the demographic survey.

During the interview, I asked the parent caregivers to share their experiences by responding to interview questions in an open-ended process of narrative elicitation (Lindlof & Taylor, 2011). The interview questions were loosely guided by Brashers's (2001) UMT and Ball-Rokeach et al.'s (2001) CIT, and I designed the interview protocol (Appendix C) to (a) encourage the sharing of stories related to the parent caregiver's uncertainty, appraisal and management in first learning about and accessing the waiver (e.g., "When you think about how you felt about applying for Medicaid initially, was Medicaid something that you associated with being a good thing or a bad thing?"; "If negative, how did you reconcile those feelings?") (b) identify the parent caregivers' meso-level community (e.g., "Can you think of a time when you heard about the Michelle P. Waiver or waiver services in general discussed on the local news, Facebook, a newsletter, a flyer at the library, or some other public venue?" "How did this experience help you find information or support-related to the MPW?"), and (c) understand how parents utilized and made decisions within the MPW system (e.g., "Can you tell me about one specific treatment or service decision provided through the MPW that was hard to make?" "What community resources were available or unavailable that made this decision more or less difficult?"). I ended the interview by asking the participants about their connection and engagement with disability networks and advocacy communities.

Following the interview, participants were asked about their interest in and availability for participation in future research related to this project, including a member

checking exercise. For participants interested in future research, I verified relevant

contact information (i.e., mailing address, email address, phone number).

Data Analysis

An initial step in narrative analysis is to create a narrative text. This involves

transcribing what was said verbatim and reconstructing the process of narration to

represent participants' accounts accurately (Riessman, 2008). Often the interactional

dynamics of storytelling are lost in the process of transcription (e.g., tonality, rate of

speech; Gubrium & Holstein, 2008). Therefore, it was essential that I maintained

analytical control over my data by listening to the audio recordings and making notes on

the transcripts (i.e., narrative text) to explain important contextual clues that might aid in

my interpretation. For example, I made several notes in regard to parent caregivers' tone

when answering questions about their own personal biases related to Medicaid. Often the

parent caregivers explicitly stated that they were ashamed of their past negative

characterizations of Medicaid (i.e., a benefit for poor people), although some admitted

that these biases persist as a source of uncertainty for them. I made sure to note these

emotional undertones in the transcripts.

In addition, after each interview, I created a brief memo, ranging from a

paragraph to a page in length, to capture and retain important contextual elements and

insights to maintain the fidelity of the data during analysis and in reporting the results

(Saldaña, 2009). Saldaña (2009) suggested there are at least three potential benefits of

using memos throughout the interview, transcription, and coding process: (a) memos

document the progress and trajectory of interpretations, (b) they more efficiently generate

potential links between themes, and (c) they allow researchers to record instances wherein they may have influenced the interaction.

Once the narrative text was finalized, the narrative analysis began. Specifically, I employed thematic narrative analysis (Williams, 1984), an analytic method that prioritizes what participants report about their experience rather than how they tell a story or give an answer (Riessman, 2008). The goal of narrative analysis is not to evaluate the truthfulness of the narrator's story but rather to understand the human experience (Saldaña, 2009). What separates a thematic narrative analysis from other forms of analysis is the focus on the sequence of the teller's story in that one event leads to another in meaningful and important ways (Riessman, 2008). Given that the focus of this research was to identify the sources of uncertainty related to the MPW, especially in terms of participants' communication processes in first accessing the waiver and then in making decisions for their child, attention to the order of events was important. Understanding the order of events was also useful for providing additional context about when and where uncertainties occurred, or community stories were heard and told.

A useful approach when examining narratives is to allow a priori theoretical concepts to generate thematic categories across the individual narratives while also remaining open to new insights (Williams, 1984). In the present study, I identified thematic categories in participants' accounts based on a priori theoretical concepts from the UMT and CIT frameworks. Specifically, in the first round of coding, three coders (including me, one graduate student, and one undergraduate student), all with training in communication research, analyzed the 578 double-spaced pages of transcripts that resulted from the 31 interviews. During the initial round of coding, we read the

transcripts independently and coded for the three a priori themes related to sources of uncertainty (i.e., personal, social, and medical sources) as described by Brashers et al. (2003). I asked all the coders to copy and paste participant comments illustrating the various sources of uncertainty they observed in the data into an individual Excel file for comparison. In identifying the sources of uncertainty, I asked the coders to look only at those sources that were influenced in some way by a meso-level condition or interaction (rather than micro- or macro-level conditions or interactions). Recognizing that the uncertainty experience is multi-layered and that participants' narratives can often include references to multiple thematic concepts in a single story or answer, coders were instructed to assign the dominant code when such cases occurred (Owens, 1984). According to Owens (1984), a dominant theme can be identified (a) by looking for the reoccurrence of meaning within the unit, (b) by identifying repetition of words or phrases, and (c) by recognizing forcefulness in vocal tone, dramatic pause, or inflection. Ultimately, a dominant code should reflect the most salient meanings to be discovered, and therefore coders were asked to interpret theme dominance based on the established definitions of medical, personal, and social sources of uncertainty (Brashers, 2001; Brashers et al., 2003) and Owen's (1984) criteria. After the first round of coding, we met to discuss and organize our initial findings.

There were many similarities in our salient themes, which allowed us to efficiently refine our inclusion criteria for the three primary categories of meso-level uncertainty (i.e., personal, social, and medical). We then discussed and agreed upon relevant subcategories under each of the three domains. We identified three personal-level sources of uncertainty related to parents' competing identities (i.e., parenting

competency, redefined work or career roles, and personal Medicaid bias); two social sources of uncertainty (i.e., unpredictable responses of community members and insecurity in future backing of the MPW); and three forms of medical uncertainty (i.e., insufficient and unavailable waiver knowledge, hidden application and renewal language, and system-level mistakes by Medicaid). As we defined these categories, we discovered that the sources of uncertainty (i.e., personal, social, medical) observed in the transcripts fit well within the sources of uncertainty framework (Brashers 2001; Brashers et al., 2003) and therefore should be maintained during the next stages of coding. In addition, we identified three MPW-related decisions that contributed to parent caregivers' medical uncertainty (i.e., decisions about plan type under the MPW, decisions about treatment nonadherence, decisions about future planning). At the conclusion of the first round of coding, we refined the coding system to also account for uncertainty appraisal and management, and the barriers to and facilitators of uncertainty management within the CAC.

To identify the strategies that participants utilized when managing their MPW sources of uncertainty, previously established themes of uncertainty management (Brashers, 2001; Lazarus, 1991) guided our coding. These a priori themes included (a) information seeking (b) social support (c) avoidance and (d) reframing. Given that communication in uncertainty management is motivated by appraisals and emotional responses (Brashers, 2001), coders were asked to code for instances where participants discussed their evaluations (i.e., threat or opportunity, or both) of MPW-related uncertainty and the management strategies (i.e., information seeking, social support, avoidance, reframing) they utilized to achieve a desired level of uncertainty (i.e., reduce,

maintain or increase). Guided by the principles of CIT (Ball-Rokeach et al., 2001), we also coded for barriers to and facilitators of participants' uncertainty management within the CAC. A barrier included any physical or psychosocial feature or condition of the community that constrained storytelling between individuals and meso-level entities about the MPW, and thus hindered participants' ability to effectively manage MPW-related uncertainty. A facilitator then, included those physical or psychosocial features or conditions that enabled storytelling about the MPW between the individual and meso-level entities and contributed to the adaptive management of MPW-related uncertainty.

In the second round of coding, we agreed to independently code the 31 interview transcripts again using the refined coding scheme. We then met a second time to further clarify the conceptual categories and to define the relationships among them. Again, we utilized Excel to organize and compare our individual codes, to observe any discrepancies, and ultimately to collapse our codes into a finalized coding scheme. After coding for the multiple strategies of uncertainty management, we agreed that the present findings were consistent with past research (Brashers, 2001; Lazarus, 1991) in that we found evidence of each of the four a priori codes related to the strategies of uncertainty management (i.e., information seeking, social support, avoidance, reframing). We were less successful in locating exemplars that showcased how participants' uncertainty management and decision making was shaped by their positive (i.e., perceived opportunity), negative (i.e., perceived threat), or dual appraisal (i.e., both positive and negative) of their uncertainty. After in-depth discussion with the dissertation chair, we found that our appraisal codes more accurately reflected participants' feelings and interpretations of the possible outcomes and consequences that might be associated with

their uncertainty, which were often threatening. However, assessment of outcome is not how Brashers (2001) conceptualizes the construct of appraisal. Brashers (2001) suggests that appraisal occurs when the condition and experience of uncertainty is evaluated as good or bad. Therefore, in order to better capture appraisal as defined by Brashers (2001) in coding, we decided that we would return to each source code (RQ1) in the third round of coding to look for additional discussion where the participant explicitly stated how they felt about the uncertainty itself, and then how they reconciled those feelings, rather than recording instances that showed participants discussing the potential outcomes of the uncertainty as contributing to their uncertainty management choices.

In this meeting, we also discussed the addition of advocacy and vigilance as distinct strategies of uncertainty management. Advocacy strategies in the present study included efforts by the participant to engage with the meso level in order to educate their community about the waiver by sharing their own MPW-story. There was some discussion among the coders about how participants who utilized advocacy appraised their uncertainty (i.e., negative appraisal or dual appraisal). Ultimately, it was determined that the advocacy strategy should be further explored in a third round of coding, particularly in terms of its relationship with appraisal. Vigilant strategies included participants' efforts to control for potential negative outcomes (e.g., the potential for waiver loss) by taking on administrative and therapeutic duties themselves, and by applying additional oversight over meso-level processes in order to reduce feelings of uncertainty. The group reached agreement on vigilance during the discussion. Finally, in comparing our coding for the barriers to and facilitators of uncertainty management within the CAC, we identified that three barriers (i.e., lack of systematic entry, poor case

management, constraints due to social control) and two facilitators (i.e., online communities and disability networks) were salient in the data.

At the conclusion of the second meeting, we determined that the use of a priori theoretical codes (Williams, 1984) as a means of generating narrative categories was representative of our data and allowed us to remain open to the possibility of new categories. A new thematic scheme that included the a priori categories established in the first two rounds of coding (i.e., sources of uncertainty, strategies of uncertainty management, functions of appraisal), with the addition of two new categories exploring advocacy and vigilance as strategies of uncertainty management, and also five new categories related to the barriers to and facilitators of uncertainty management within the CAC was finalized.

Finally, all three coders read the 31 transcripts in their entirety a third time using the final conceptual coding scheme to confirm that the thematic framework we had constructed accurately reflected the data and that we had not missed other potentially related concepts. Specifically, we coded for the three sources of uncertainty, the appraisal and management of uncertainty, and the facilitators and barriers of uncertainty management within the CAC. In re-coding the functions of appraisal as defined by Brashers (2001), we were unable to sufficiently locate enough data that showed participants explicitly describing their feelings about the uncertainty experienced and how their evaluations of the uncertainty shaped their management strategy decisions. For clarity, we decided to remove data and participant accounts specific to appraisal from our reporting of the findings in Chapter 4. In the findings, I report that we were unable to answer this part of RQ2. I have added an extended explanation of our insights regarding

appraisal within the discussion of findings in Chapter 5. This decision to remove appraisal from the findings also resolved the discrepancies under consideration by the coding team regarding whether the appraisal was negative or dual appraisal of uncertainty.

During the third meeting, which occurred virtually, the coders discussed and agreed that saturation in the data had been met regarding our specific codes. In the following section, I explain the criteria guiding the coding team's determination of saturation.

Establishing Saturation

Although there is no one set of standards to use in evaluating saturation in qualitative research (Guest, Bunce & Johnson, 2006), there are several generally accepted principles that were used in determining saturation for this dissertation. According to Fusch and Ness (2015), saturation is reached when (a) sufficient data has been collected so that the study can be replicated, (b) data collection continued until no new information was attained, and (c) an exhaustive coding process was conducted. In addition, we considered O'Reilly and Parker's (2012) conceptualization of saturation, which posits that saturation is best determined by evaluating the appropriateness of data and the adequacy of the sample in terms of the philosophical aims of the study (O'Reilly & Parker, 2012). Therefore, to ensure confidence in the accuracy and appropriateness of the current findings (Bowen, 2008; Kerr, Nixon, & Wild, 2010), while also remaining cognizant of the epistemological underpinnings of this current study (O'Reilly & Parker, 2012), the coding team agreed that the following benchmarks would guide our determination of saturation. First, the sample size should be deemed sufficient based on

qualitative research standards. Second, the coding process should be considered thorough and complete. Finally, our explanation and application of our theoretical position, method, and analytic process should be transparent, congruent, and appropriate given the intentions of this research (Gaskell, 2000; O'Reilly & Parker, 2012).

Sample sufficiency. To determine the sufficiency of our sample size, we discussed the (a) actual number of participants in the final sample, (b) the *fitness* of the participants interviewed, and the (c) richness and thickness of the data. Guest et al. (2006) argued that saturation can be achieved with as few as six interviews so long as the interview depth is appropriate. The current sample of 31 participants and average length of interviews ($n = 48$ minutes), which yielded nearly 600 pages of transcripts, provided sufficient evidence of our commitment to interview depth.

Next, we discussed the inclusion criteria for the study versus the sample collected to ensure participant fit. Morse et al. (2002) suggested that when evaluating a sample size, the researcher should reflect on how well recruited participants could offer insight into the research topic. In this study, I asked research questions about how caregivers of children (18 and under) currently receiving the MPW experience uncertainty at the meso-level. I successfully recruited 30 biological parents and one custodial caregiver of children currently receiving the MPW. This sample provided a good fit for the research questions posed in the current study.

Finally, we considered the richness and thickness of the data in order to determine sample sufficiency. Dibley (2011) proposed that the richness and thickness of the data is a key indicator of saturation. Fusch and Ness (2015) defined richness as the level of detail, nuance, and layers that can be explored within the data, whereas thickness refers to

the quantity of data collected. In discussing both the quantity (thickness) of our transcripts and the deeply personal and complicated stories that could be observed within the transcripts (richness), which are further evidenced in the extended exemplars provided in Chapter 4, the coding team concluded that the data met this criterion for saturation.

It is also noteworthy that exhausted resources, time, or a lack of participation did not determine the end of recruitment, which Fusch and Ness (2015) warn are not reasons to claim saturation. If needed, a second email was approved to be sent to the large disability network Listserv that produced 16 of the 31 interviews. However, after consulting with the coding team and the dissertation chair, I determined that additional interviews would not likely result in new themes or information that could further answer the research questions posed for this dissertation.

Coding completeness. By involving other members of the coding team in a deep discussion about the interpretation of the data, I worked to ensure that we were open to the emergence of new or underexplored themes not accounted for by theory, which was demonstrated by our addition of advocacy and vigilance as strategies of management (Glaser & Strauss, 1967). This process helped to ensure that data were not forced into fixed categories but rather were considered for best fit into an a priori category or elucidated as a possible new theoretical concept (Corbin & Strauss, 2007). Ultimately, after the third round of coding we determined that we had accounted for all the data, would not find new themes or categories with continued coding, and had sufficiently answered the research questions with depth, breadth, and nuance (Burmeister & Aitken, 2012; Rubin & Rubin, 2012).

Philosophical congruence and transparency. According to O'Reilly and Parker (2012), saturation is reached when the data collected appropriately satisfies the philosophical aims of the research. To determine philosophical congruency, the coding team first reviewed the central aim of this dissertation, which was to gain insight into the conditions of the MPW experience that lead caregivers to feel uncertain when trying to access and negotiate treatment and services, and to better understand the ways in which parents appraise and manage their uncertainty at the meso level. The coding team agreed that this aim embodied a social constructivist orientation and that the utilization of an interpretive method (i.e., narrative interviews) and an interpretive analysis (i.e., narrative thematic analysis) was congruent with this aim. In assessing the data itself as philosophically congruent, the coding team agreed that the intricate stories gathered through the narrative interview process effectively illuminated the subjective and socially constructed experience of uncertainty from the perspective of parent caregivers. Further, in reviewing the reporting of the procedures and the coding process, the coding team and the dissertation chair, determined that a replicable level of discovery was achieved and sufficiently outlined (O'Reilly & Parker, 2012; Walker, 2012). Finally, in writing about the methods utilized in this data collection and analysis, I have provided a reflexivity statement (at the end of this chapter) to make transparent my own exploratory and naïve position as a researcher in this context.

In sum, this inquiry was theory-driven in that theoretical perspectives informed the research questions asked in this study and guided the interpretation of the data (Alvesson & Skoldberg, 2009). In reporting the findings, I utilized longer exemplars, which is consistent with reporting narrative analysis. These longer excerpts allow the

reader to comprehend the direction and thoughts of the narrator, which is in keeping with

Polkinghorne's (1995) recommendation to report in a manner that showcases "how and

why a particular outcome came about" (p. 19). The utilization of a narrative thematic

analysis permitted me to emphasize the raw content of the participants' stories

(Riessman, 2008). As Braun and Clarke (2014) have observed, such analysis "offers a

really useful qualitative approach for those doing more *applied* research, which some

health research is, or when doing research that steps outside of academia, such as into the

policy or practice arenas" (p. 1).

Member Checking

Lincoln and Guba (1985) argued that to further evaluate and confirm the

credibility of qualitative analyses, when possible, it is important to complete a process of

member checking with a subset of participants from the study. To do this, I randomly

selected, through the use of an online random name draw, 6 participants (20%) from the

sample (who agreed to further research activity) to participate in a member checking

activity that included a summarized version of the results. This method, known as a

member check of synthesized data (Harvey, 2015), is appropriate "when the purpose of

the member check is to explore whether results have resonance with the participants'

experience" (Birt, Scott, Cavers, Campbell, & Walter, 2016, p. 1, 805). This method

provided an in-depth approach for triangulating data by allowing participants to add

further data if they felt the interpretation and analysis was insufficient in any way or if the

meaning of their experience had changed since the interview.

If a participant agreed to the exercise, I sent him or her an email that contained an

outline of the major findings (See Appendix D, Tables 1-3) with instructions and four

questions to consider. I then asked participants to return their thoughts within one week. If a parent did not wish to participate, I selected another name through the online draw until six parent caregivers were recruited. This only occurred once.

In their feedback during the member check, the parent caregivers were largely in agreement with my analysis. One participant expressed that the analysis regarding the hidden or secret language required when accessing or renewing the MPW did not reflect his experience because he did not feel the language required for the MPW was a barrier for him personally. He noted that, "Medicaid is a business; people should expect to use professional language when filling out the paperwork." After discussing with the other coders, consensus was that the theme was strong enough in the data to be included, and therefore this feedback did not significantly alter the major findings of this study; however, it does shed light on the variable nature of uncertainty in that what is uncertain for one individual or group may not be uncertain for others (Brashers, 2001). All other member check feedback reinforced my interpretation of the data, with participants adding additional personal examples or sharing their agreement and gratitude for the work. For example, one participant wrote in her response to a question about the sources of uncertainty related to the MPW, "Yes! This looks good to me, and thank you for understanding. I really hope you can get this to someone to do something to make the MPW easier to find and to deal with." Ultimately, the use of member checking added an additional opportunity to triangulate the validity and confirmability of the data analysis.

Reflexivity in Analysis

This project has been conceptualized and pursued through my preferred lens as a naturalistic inquirer. As an outsider to the MPW world, I spent an enormous amount of

time learning the language of the waiver and differentiating it from other waivers, all while trying to keep in check my preconceived notions about Medicaid as a form of health care. In the year prior to this dissertation project, I began taking disability health courses through the Human Development Institute as a supplemental context for my doctoral studies. My interest in the disability context first stemmed from my own relationships with persons who manage invisible disabilities (e.g., attention deficit disorder, high functioning autism, depression, and anxiety disorders). I began the program to learn more about these invisible conditions. During my time in the program, I learned of the broader disability community, their marginalization in society, and their health care experience. As a health communication scholar, I could not help but notice that (a) many of the health care inequities that persons with disabilities faced were rooted in low-quality communication and (b) my own discipline of health communication has done little to shed little light on individuals' experiences in this context. In making these observations, I sensed an opportunity to bridge my scholarly interests.

In choosing narrative interviews as a method, I wanted participants in this dissertation study to feel as if they were storytellers when answering my questions. As an interviewer, I endeavored to be empathetic and gracious. Reinharz (1984) described this mentality as the *lover model*, which values mutual respect, versus the *rape model*, wherein researchers take what they want and then leave. I knew that participants could be potentially skeptical of my intentions, so, in every way that I could, I reinforced my intention to honor their story, to protect their identity, and to share my results with persons in positions of power. Defending this dissertation is the first step in upholding this promise. Further, as a narrative interviewer, I dialed back any effort to control the

conversation and instead gave agency to the storytellers. It is through this relinquishing of control that deeply emotional accounts can be collected (Lincoln & Guba, 1985). The pursuit of objectivity was never my goal.

It is also important to note that, in completing this project, my motive was not to advocate for or against any current policy or the waiver system, but rather to shed light on the human experience behind the system. Suhay (2017) suggested that in exploring the "politics of scientific knowledge, science, these days, is political" (p. 1). Past researchers have warned of this tenuous position. For instance, Moore (1903) cautioned that, when scientists believe they can determine what "should" be done from what is true, they commit the most severe type of naturalistic fallacy. I am not an outspoken advocate for any singular cause, nor am I one that ignores the challenges of policy and politics. Instead, my goal was to create spaces where ideas could be shared, to build bridges, to listen. I believe this orientation afforded me the ability to gain the trust of this hard-to-reach population and to gain access to the private doubts and worries they have experienced. To safeguard against my immersion in the interviews and the bond that I created with many of my participants along the way, I tried to bolster the credibility and trustworthiness of my findings by including in the interpretation of the data (a) members of the coding team who had little to no experience in this context, as well as (b) the participants themselves, through member checking in the analytic process.

CHAPTER FOUR: FINDINGS

Providing care for a child with a disability can be an uncertain and unpredictable experience. For the participants in this study (i.e., parent caregivers of children currently utilizing the MPW), assuming the added responsibility of accessing and navigating the waiver and having to rely on community-level resources when making MPW-related decisions about their child's health care and treatment adherence—invoked waiver-specific forms of personal, social, and medical uncertainty (RQ1). The findings suggest that parent caregivers' utilize various strategies when managing their uncertainty related to the MPW (RQ2); and that several features within the CAC seemed to constrain or facilitate their management of MPW-related uncertainty (RQ3). In this chapter, I outline the findings regarding each of the three research questions guiding this study, providing data from the interviews as exemplars of each uncertainty source and management strategy, as well as each barrier and opportunity in the CAC.

RQ1: Meso-level Sources of Uncertainty

Participants described several communication interactions with community-level entities such as community-based health and human services organizations (e.g., local Medicaid offices), doctors' offices, community-oriented media, public opinions, and grassroots or aggregated networks (e.g., disability networks or nonprofit organizations) as influential in shaping their experience of MPW-related uncertainty. The participants in this sample reported various personal (i.e., caregiver competing identities), social (i.e., unpredictable responses of community members, insecure political backing of Medicaid waivers), and medical (i.e., absence of waiver knowledge, hidden application and renewal

language, system-level mistakes by Medicaid) sources of uncertainty that resulted from their interactions at the meso level. These results are summarized in Table 1.

Personal Sources of Uncertainty

Parents discussed how the various community-level interactions that were required in facilitating their child's use of the MPW contributed to their feelings of identity-related (i.e., personal) uncertainty. Recognition of these personal sources of uncertainty were often prompted by an interaction with a meso-level entity or in considering what their new identity meant from a meso-level perspective (e.g., becoming a person who receives government assistance). Unlike the competing roles experienced at the personal or micro level of an individual's neighborhood (which include role conflicts with family members, close friends, and the self), in this study, participants described experiencing role conflict and management in coming to terms with their community-level identity as a parent of a child receiving the MPW. Specifically, I found that parent caregivers experienced at least three role tensions in this context: (a) threats to their parenting competency, (b) redefined work and career roles, and (c) personal Medicaid biases.

Parenting competency. Many caregivers felt that the process of proving that their child was eligible for the MPW to Medicaid personnel or staff involved communicating the child's atypical development or behavior. This process of verbalizing their child's deficiencies to a meso-level community member was an unsettling experience for many parent caregivers, which often spawned feelings of personal doubt concerning their parenting competency. For example, Caroline reflected on the defensiveness she felt when answering questions during the application process:

They would ask in the application process or even on renewals and stuff that we're doing now, "Is it [the child's behavior] a safety at risk?" Well, your first instinct is, "No," because if I say yes, then that's saying I'm a bad parent.

Layne, a registered physical therapist, felt that with a medical background she should have been able to navigate the MPW effectively on her own, or at least understand the process. Yet, when asked to answer questions related to the MPW by Medicaid personnel, she unexpectedly felt a sense of incompetence related to the terminology. This was an uncertain and potentially threatening experience for Layne, who assumed that having a medical background would have made her better equipped than others without the same level of training. She said,

> I'm a physical therapist, and I felt like because of my background, there should be something I could do for her to help her. But all the work, all the terminology, is specific to each agency. So, even Michelle P., and some of the initials that people would spell out, "Do you have this or that?" I'd have to ask, "Okay, what does that mean? You're jumping." So definitely there is a terminology barrier. Unless you know to ask, it might just go over your head.

Parents also described instances wherein Medicaid personnel (i.e., a meso-level entity) directly questioned their competency in managing the MPW. Several participants discussed feeling that MPW parents are assumed to be at fault when there is a paperwork or filing error during the application or renewal process, and this is a reoccurring source of frustration and role negotiation that they must manage as a facilitator of the MPW. Megan spoke about the unfair assumptions that she feels are made about caregivers' competency when applying for and renewing the MPW.

> I took in all of the signed paperwork and said, "I have all of the signed paperwork and you are saying you didn't get it, so I just want to drop it off and make sure that you have it and that you will acknowledge that you have it before the 30th of this month, or 31st, or whatever." And assuming I was in the wrong, the lady made me sit through the entire damn interview again, but that is how you are treated, like it is your fault and not theirs every time. Well, I am a sophisticated caregiver. I can read the regulations!

Megan, who holds multiple advanced degrees and has an accomplished professional

background, felt frustrated by what she saw as inefficiencies at the Medicaid office. From

Megan's perspective, Medicaid personnel assumed that she was incompetent as a

caregiver when mistakes occurred, which was an unwelcome personal source of

uncertainty for her and many other parent caregivers interviewed for this study.

For some participants, it was the *process* of applying for health care, such as

sitting in the Medicaid office, rather than the child's *illness* itself, that contributed to their

conflicted identities. For instance, despite feeling competent and successful as a working

professional, Madeline sensed that she lacked adequate know-how in navigating the

Medicaid system based on her experiences at the local Medicaid office, which then

initiated a sense of personal concern or reckoning for her to evaluate or reconcile.

Further, in the following extended exemplar, several additional potential sources of

uncertainty (e.g., Medicaid bias, unpredictable responses at the meso level) can be

observed in Madeline's account. However, as she completes her story, Madeline shares

that, taken together, these sources of uncertainty contributed to her feelings of parental

incompetence and thus heightened her uncertainty, and therefore parenting competency

was deemed the appropriate dominant code in the analysis.

> I work from home. I own my own business. I do everything from a computer,
> pretty much, or a phone. So, I would take my laptop [to the Medicaid office]
> because I knew I'd be sitting there for hours. And people would come in, and
> there are lots and lots of people very deserving of the services that are out there.
> And there are also lots of people that take advantage of the system, of course. And
> I would see all these people coming in that I felt probably, and this may be, I'm
> pretty open and honest, but this may not be nice to say, but I would see people
> rolling in when I've been sitting there for an hour and a half, and they look as if
> they could probably hold a job. But they were there to get services. Or food
> stamps. Or whatever they needed. But I felt as if they were taking advantage of
> the system based on the conversations, I would hear them talking about their
> lives, as I'm sitting there waiting. And they would be taken care of right away.

And then I would sit there. And I would wait. And I would wait. I'm like, if I'm dressed professionally, if I look like I'm trying to work because I am trying to earn money to provide for my family, then I'm pushed to the side. But then someone who comes in in pajama pants who just got a tattoo and a new iPhone but is here for food stamps, they get seen immediately. Really? And my child, who can't provide for herself, can't be taken care of. It was really frustrating. I felt like this was their world. I felt like I knew nothing about it, and I just felt like a number.

For Madeline, applying for public assistance was an experience that she felt unaccustomed to and uncomfortable with, mainly because of how she saw herself (i.e., a provider for her family), versus other people who were receiving benefits through Medicaid (i.e., people who may be taking advantage of the system). Madeline felt that others were more successful in getting what they needed from Medicaid personnel because it was a system that they were used to.

Redefined work and career roles. A second identity theme that emerged in the data analysis captured the redefining or renegotiation of parental work or career roles. Some participants said they felt uncertain about depending on the MPW for income rather than their own career, knowing that it is not guaranteed to always be there. For instance, Becca shared how she tries to maintain her career for her sanity and because she knows that relying on the waiver for income is risky.

> When we first got her, I worked in a cardiovascular lab at the hospital. I'm still employed there, but I'm irregular part-time. That means I work maybe one day a month, just enough to keep a job title because it's sanity for me to say, yeah, I still have my career. I had to give up my full-time job, which threw us into financial hardship. So now I am her caretaker, and I do get paid through the program . . . I mean I feel blessed that we're on it, but I know that's not financial stability for me to depend on. I think that is [losing the waiver] always a concern and worry.

Many caregivers discussed their initial desire to maintain their former careers but felt forced to consider other options when it became clear through their interactions with community members that the meso-level community was unequipped to provide the services and health care their child needed. A majority of the parents interviewed for this

study had chosen to give up their former careers and instead elected to bill Medicaid for

the service hours that they provided for their child as a source of income. Several of these

parents admitted that the adjustment was uncertain for them at first because of the

identity shift required. Stacie explained that she wanted to work and to provide income

for her family, but, because of the behavioral issues her daughter had at school, she was

forced to renegotiate her career trajectory. Stacie explained,

> I couldn't keep a job because of [child's name] disability. But, I do work. I do about 10 to 12 hours of therapy with [child's name]. I used to get jobs so that I could work [outside of the home] during the hours that she was in school, just to try to help, even if it was cleaning houses. I went to work for a restoration company where I could clean up fires if people had fires in their home. Anything that could help make a dollar. I wanted to work [outside of the home]. We own a plumbing company now . . . But I could never keep anything decent because I was constantly being called to come and get [child's name] from school because she is hard to take care of. We tried the public school system. I tried to work [outside of the home]; it just didn't work out for [child's name].

For Stacie, becoming a paid provider for her child through the MPW was not the work

role she envisioned for herself. Stacie discussed feeling that by working outside the home

she could better contribute to her family's financial stability. However, once she realized

that sending her child to a public school during the day was not feasible because of the

school's inability to meet her daughter's needs, she felt forced to reevaluate her career

identity and to work as her daughter's paid care provider.

Similarly, Andrea explained the uncertainty she experienced when resigning from

her teaching position to become an at-home paid provider for her child, which she felt

was necessary because of the school's inability to provide an acceptable level of safety

and care for her child.

> The main reason that I resigned from my teaching position was to home school her and try to take care of her. I really didn't want to resign. But two weeks before school was supposed to start in her first full year of school, they [the school] did

not know who was gonna be her aid. And they were supposed to be trained in how to handle her, because her spine is so fragile. I went there; I said "who's gonna be her aid? They're supposed to be trained by her IEP." And they [the school] just kept avoiding me. My biggest concern was the bathroom situation. So I said, "whoever you're getting is gonna see my daughter's private area. You cannot be switching who's gonna see my daughter's private area without telling us; she cannot communicate." I don't think they think about how it affects the emotions of a child to have a different adult seeing their private area all the time, and I told my husband, I said I'm not doing that to her. I can't do that to her. As much as I love my job, I can't do that to her. I understood that schools have money issues and budgets, and they're trying to do 30 kids and not just mine, but that is why I had to [become an at-home provider]. I taught for 14 years, so it was hard to give that up, but there was no way I could put her in an unsafe situation.

In sum, several participants discussed the personal uncertainty they felt when giving up their prior careers, which often involved renegotiating their own career trajectories after realizing that there was no one else in the community (e.g., the school, service providers) that could deliver the health services their child required.

Medicaid bias. A third identity tension reported by participants in this study involved reconciling their own personal biases about what it means as a member of society to be a Medicaid recipient. For instance, Andrea admitted that she and her husband had a hard time with the stigma associated with Medicaid when originally applying for the MPW: "We struggled with it because there's such a stigma with Medicaid that, if you're on Medicaid, then you're bums." This was not an identity that Andrea and her husband wanted to take on, yet they did so to access the benefits provided by the MPW for their child. Heidi, who became the legal guardian of her niece after her niece's parents died, shared that her dad was resistant to her applying for the MPW at first because of his embarrassment about needing government assistance, which he associated with an undesirable identity.

My dad didn't like it at first. He was embarrassed a little. But me and mom knew that this [the MPW] could help us take better care of her. But yeah, I mean, you

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think Medicaid and you think food stamps, and no one wants to be that person. Well, I guess some people do, but most people think Medicaid and disability checks or food stamps [not waivers].

In the examples above, participants' comments illustrate that, even as beneficiaries of Medicaid (i.e., through the MPW), they hold some negative biases about what it means to receive health care through this means. Other participants expressed a sense of personal failure associated with requiring assistance through the MPW. Taylor explained how this new identity (i.e., receiving Medicaid) negatively conflicted with what she had envisioned for herself and her family.

> I am college-educated, my husband is college-educated, we were working; we really thought we had made it out of that. We thought of ourselves as contributors and now, because of life's circumstances, we felt like a failure somehow. It really humbles you. There was definitely a period of time where we both just felt really ashamed, really ashamed, didn't want people to know [about their use of Medicaid through the MPW].

Several participants explained that their personal bias against Medicaid sometimes delayed their willingness to seek meso-level resources, including the MPW. Chelsea said that she and her husband hesitated to apply for the MPW at first because of their own personal Medicaid biases and their lack of understanding about how the waiver system worked as insurance for persons with disabilities.

> We thought we did everything right. My husband worked his tail off to provide. We worked hard to provide for our kids. We thought that we were doing everything right and that we wouldn't need a service like that. The word Medicaid comes with that connotation with it, and that was a little bit of a hurdle. I didn't know that we would need something like this in our lives. But once we realized the way the system works as insurance; I think that stigma melted away for us and we just knew we had to get him help. If that required applying for Medicaid [through the MPW], then that required Medicaid.

In sum, parents were able to reflect on and share stories about specific meso-level interactions that shaped their experience in navigating the MPW and also their personal

sources of uncertainty (i.e., parenting competency, redefined work and career goals, and personal Medicaid bias). All three personal sources of uncertainty described by parents in this study involved a personal reckoning and a questioning of identity. Findings showcased that utilizing the MPW requires communication at the meso level and that parents often felt forced to assume these new identities in a very public and explicit way, which was unexpected, uncharted, and uncertain territory for them.

Social Sources of Uncertainty

Participants described how the various community-level interactions they engaged in to facilitate their child's use of the MPW contributed to social uncertainty in several ways. Specifically, participants reported two social sources of uncertainty at the meso level, including (a) the unpredictable responses of community members, and (b) the perceived insecure political backing of Medicaid waivers in their community.

Unpredictable responses of community members. Social sources of uncertainty arise when social reactions toward an illness are unpredictable or have unclear relational consequences for the individual. Several parent caregivers described experiencing social uncertainty when having conversations about their child's MPW status with community members. This is distinct from the personal sources of uncertainty related to Medicaid status and personal identity negotiation; instead this social manifestation of uncertainty is tied specifically to the social stigma related to receiving Medicaid assistance which then shaped the individual's perceived relationships in the community.

For some participants, their community as a whole possessed a limited understanding of Medicaid, which then challenged their ability to have meaningful conversations with various community members about the impact of the MPW on their

families. Parent caregivers felt that discussion of Medicaid can be controversial, which

discouraged them from sharing their own stories in the community. For instance, Chelsea

summarized the feelings of many participants in this study, who suggested that their

communities did not prioritize the care of persons with disabilities and their families who

rely on Medicaid waivers, such as the MPW. Chelsea explained how people are

suspicious of anyone who receives government assisted health care.

> It is very hard and very confusing and just feels like a punch in the face. You are
> just out there doing your best, and no one understands or cares or even believes
> you have the time. We have lost relationships with family members and friends.
> There are definitely people in our community that have strong opinions about the
> money and the help we receive. They just see it as us having hired help; they
> don't realize the 24/7 burden and commitment that it is to take care of a child with
> special needs. It is not the same.

According to Andrea, the broader community undervalues the work involved in caring

for a child with a disability through the MPW; therefore, she chooses to keep that

information private.

> I do not talk about it [status as a paid provider through the MPW]. I have found
> that people who do not have kids with disabilities or severe medical issues have
> no idea what it's like to raise a child with disabilities. There is a lot of
> misconception about what a parent of a child with disabilities does every day.
> They hear that you are making 15, 16 dollars an hour to take care of your child,
> and they think you're sitting at home watching TV. We don't turn on the TV 'til
> six o'clock at night. It's a full-time job, and I don't think people realize that. But I
> don't try to change their minds.

Andrea's uncertainty about the unpredictable and potentially unfavorable responses from

community members constrained her ability to communicate openly about her

experiences as a parent of a child receiving benefits through the MPW. Meredith

explained that having conversations about her child's waiver status with community

members has sparked debate in the past about who deserves Medicaid. Meredith shared a

specific example of a meso-level member who accused her of stealing from the elderly by

accessing the MPW. This accusation engendered feelings of guilt for Meredith,

> There is a stigma attached to it; I think. Definitely the lawyer for the state of
> Kentucky, and the Medicaid Department that tried to fight against us getting the
> Michelle P., that was probably my first experience at being made to feel really
> guilty about it. He [the lawyer] told me that I was taking a benefit away from the
> elderly by fighting to get the MPW for my child. When it was all said and done
> and we won, he even came over to me and he said, "Good luck finding someone
> that's willing to watch your daughter." They were just really, really nasty about it.

In addition to questioning the societal reactions of the general community when

discussing the MPW, parent caregivers also specifically referenced interactions at

doctors' offices (i.e., a meso-level entity) as a time when they experienced meso-level

social uncertainty. Participants in this study commonly discussed a desire to manage the

uncertainty of their doctors and the office staff when presenting the child's medical card,

which is accessed through the MPW, as a form of payment for health care services. For

instance, Taylor described the conversational strategies that she uses when presenting her

child's medical card.

> I can remember getting the medical card, which comes with Michelle P., and the
> first time I used [it], feeling like I needed to explain that I worked, and my
> husband worked, and we had private insurance, and this was for my son. I still do
> that sometimes. When you show the medical card, people automatically assume
> that you are poor and don't work. Just the other day, we were at an appointment,
> and they asked for insurance. I always give them the private insurance card first,
> and then, as they are looking that up, [I] say "and for whatever that does not
> cover, we have the Medicaid, my son has a disability." I just don't want people to
> think badly of us.

Likewise, Caroline described her inclination to provide reasons for why her child

receives Medicaid benefits when visiting the doctor and presenting the medical card. She

shared,

> I feel like I have to explain, and I want to explain, why my child is getting
> Medicaid. I don't want them to think that it's because [of] our circumstances

financially. So internally, I have that feeling that I know I will swallow my pride, and I do whatever I need to for my child, but I do tend to feel like I make excuses a lot when we go to doctors and stuff and stress to them, "He has a disability; this is why we're receiving this."

To summarize, the current findings revealed that parents were often uncertain about the social consequences of discussing their child's waiver status in the community, having experienced negative responses from community-level members in the past, and in sensing the controversial nature of Medicaid talk generally. In addition, participants shared that they worry about the uncertainty that others have about families utilizing the MPW, and that as a result they often feel compelled to explain why they need the waiver based on their child's disability. This form of uncertainty is unique to parents managing Medicaid-based care versus privatized care.

Insecure political backing of Medicaid waivers. Another meso-level source of social uncertainty involved the insecurity that parent caregivers felt about the future of Medicaid waivers. Some parent caregivers reported that the uncertainty they felt about the future of the MPW, combined with their knowledge about the scarcity of waivers (i.e., the waitlist), affected their willingness to discuss the MPW with other members of the disability community. Disability families were considered members of participants' meso-level communities rather than their micro-level communities (i.e., interpersonal) because these networks were not organically available to parent caregivers. Instead, they were often accessed through some formal channel or organization (i.e., a diagnosis-specific group). Chelsea shared that she feels reluctant to share her MPW-story given that no one in the community seems to understand or appreciate the value of the services provided by the waiver. This perception of community disinterest about Medicaid also contributed to Chelsea's worry about the future of the waivers. She stated,

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People who think, "Oh, well, you need to be earning that Medicaid, not just not working and not providing for your family and relying on the government to provide services and health care," they're having that conversation without understanding the special needs community that accesses Medicaid services through that same portal. They just don't get it when they're talking about Medicaid. And no one is out there asking for my opinion. No one's really interested. It's disappointing, disheartening. It makes me worry about the future. If people really feel this way about Medicaid, will they continue to invest in it?

Meredith shared that she hesitated to disclose her child's waiver status with the disability network that she had joined because she worried about the reaction of the other members and also feared that if more people were added to the waitlist, her child's waiver might be threatened.

The Michelle P., I feel like even with the disability parents, I think there's a sense of feeling like that if everybody gets on these programs, we're all going to lose it somehow, the more people that get on. So, I think, because there is a huge waiting list for Michelle P., even in my group of disability families, I was afraid to tell other parents that we had been approved. I knew that they were waiting, and we were very lucky in the time that we got approved for it. Right after that is when they went on a 5-year waiting list. Everyone went on this waiting list, so you had to keep it private.

Similarly, June was taken aback when she learned that many of the close connections that she had made in the disability community had never shared with her information about the MPW or the fact that their children were already receiving the waiver.

I learned that I had friends whose children also were on the waiver, but they weren't talking about the waiver because they were pretty much scared that if other people knew about the waiver, it would take the waiver away from their children. That was something that hit me.

Several participants also talked about the constant uncertainty they felt about the sustainability of the MPW. They acknowledged that the waiver program is not a guaranteed benefit and that their child could lose the waiver at any time. Taylor described the uncertainty she experienced regarding the insecure future of the MPW and the lack of

transparency from policymakers in communicating about the future of the waiver. She

said,

> I'm not a political person. I personally believe that we're not told the truth
> anyway. I feel like nothing's really honestly given to us [by policymakers]. I think
> we're always just feeling like it [the MPW] can be taken away, so let's just be
> grateful we have it today.

Layne discussed the impact of the waiver on her family and her concerns about the

MPW's insecure future.

> Because there's a lot of families that, I mean including myself at a point in time,
> that without those programs we just could not have made it. I think there's always
> the dreaded feeling that the state's going to just one day going to pop up and say,
> "Hey, we're not doing this anymore." If you're in Kentucky, you're only going to
> learn from a family, or another parent about what is going on with waivers.

In short, the perception of an insecure future for Medicaid waivers in the state of

Kentucky because of the lack of support from community members was a social source

of uncertainty for parent caregivers.

Medical Sources of Uncertainty

Participants explained numerous ways in which community-level interactions

were a source of medical uncertainty that were uniquely relevant to the MPW

management experience, including (a) absence of waiver knowledge, (b) hidden

application and renewal language, and (c) system-level mistakes by Medicaid.

Absence of waiver knowledge. Several participants shared that, prior to having a

child with a disability, they had no previous knowledge of the existence of the MPW.

Finding out about the waiver only occurred after the family had begun to face substantial

financial insecurity concerning their ability to afford treatments and services for their

child. In other words, facing an inability to manage their financial uncertainty within their

own private networks, caregivers discussed sharing their vulnerable story with a wider

audience in the hopes that someone might be able to point them in the right direction of available resources. Oftentimes, this occurred through a chance meeting with a community member who was outside of the caregiver's inner circle. For instance, Kelli described her own absence of knowledge and the accidental way she found out about the MPW through a client of her sister-in-law.

> I had no experience with people with disabilities, and I had never heard of a waiver in my life. This was an entirely different world, and it's hard you know because you don't choose it. But there you are, and you are desperate for help. . . . It was actually my sister-in-law at the time who found out from a client that worked with kids with disabilities, and she called me and said, "Hey you might want to look into this." And I did, and all I could think was, if this works, this would help so much.

Layne discovered the MPW after connecting with a group at her church for parents of children with disabilities. Layne revealed that it was a small group discussion at the church that ultimately introduced her to the MPW,

> We go to a big church here in [city, church name]. And they have a small group there that is for parents with special needs children. I mean, it's kind of like a Sunday school at church. And every time before we would do whatever it was we were there to do. We would start off with resources, "So, what are some resources you guys have found?" So, that's literally where, that's when it hit me. Like, "Okay, so who do I call to get this Michelle P.?" So, it was from the small group.

Although Layne's discovery of the MPW was less direct compared to those of previous exemplars, like the other participants, Layne had no previous knowledge of the MPW. In addition, it was a meso-level source rather than a medical source that eventually connected Layne to information related to the MPW.

Several participants reported that, after facing financial insecurity in trying to afford the treatments required for their child, they sought advice from meso-level members, but they did not know to ask about the MPW specifically. Chelsea described

the seemingly happenstance community-level communication that led to her introduction to the MPW.

> I had discovered it [the MPW], actually, when I went to get a loan. I had opened a coffee shop, and the loan officer told me about Michelle P. He was asking why I worked, why I had a full-time job. And I was like, "Well, how else do you pay your bills?" and he told me about the program. He was like, "I know someone who is on this program. She's able to stay home and care for her disabled child." Like I said, I worked with a school full of doctors. Nobody mentioned it. I learned about it from the loan guy.

According to Mary, it was only after she was denied coverage through her primary insurance, and after she began asking for financing options from her son's service provider to continue his treatment, that someone employed by the hospital finally mentioned the MPW.

> That's funny because he [her child] was in speech therapy through the hospital and he was doing lots of therapies at Children's [Hospital] from speech to physical therapies. It's all kinds of different group therapies. Well, my insurance had denied his speech [therapy], said it wasn't medically necessary and there was no way that I could pay for it out of my pocket. I was talking to some lady in the Financial Department at Children's Hospital. We were looking at several different options. My husband made too much money for me to get any kind of grants or anything like that. Finally, she said to me, have you ever heard of a MPW? I'm like, "Nope. I have no idea what you're talking about."

Unlike the previous participants who showcased an absence of knowledge about the MPW, Becca had some understanding and prior experience working with Medicaid generally. Becca's child had already qualified for a medical card that covered the costs of most prescription medications; however, even with some Medicaid exposure, Becca had never come into contact with information specific to the MPW, and therefore her understanding of Medicaid was incomplete and thus uncertain. According to Becca, she had never considered Medicaid as a supplemental program for persons with disabilities. She further explained that although the medical card was useful in providing coverage for

many of the clinical and prescription treatments that were needed for her child, it did not

cover the various additional supplies that were required to facilitate her daughter's care at

home.

> I didn't know it [MPW] existed. I had to give up my job, which threw us in financial hardship. I won't lie, because the things that it was taking to care for her, even though she had a medical card, she had a medical card that was covering her medical costs, thank goodness. We were blessed to have that. But at the same time, we had these other things that she was needing—at the time it was diapers because she wasn't potty-trained. She did become potty-trained during the day, but at night she wasn't. So, we had expenses with diapers. We had expenses with different foods. We had expenses with sensory issues, just things. We have a swing in our house. I mean we put a therapy swing in our home. But things like that that we felt that were something that she needed were coming out of our pocket. Well, we were already down one income, so we were lost.

In sum, for the caregivers interviewed for this study, knowledge of the MPW was

absent, unavailable, or incomplete before having a child of their own with a disability,

and this absence of knowledge contributed to a sense of uncertainty regarding their own

state of medical knowledge, as well as their trust in the systems of health care. Caregivers

eventually found information related to the MPW through meso-level sources, although

there did not seem to be any systematic process through which this occurred. Participants

were surprised, especially given the amount of time that they spent with organizations

and medical professionals that service the disability community, that no one had shared

information about the MPW with their families.

Hidden application and renewal language. The medical sources of uncertainty

observed in this study often involved complexities related to navigating systems of care.

One such complex meso-level system interaction that often contributed to participants'

experience of uncertainty included the process of de-coding or learning the language

required when applying for and annually renewing the MPW. A central function of the

MPW application and renewal process is to establish some systematic rationale or criteria

for determining whether an individual qualifies for government assistance. Unlike most

assistance programs, the income of the parent is not a determining factor of eligibility for

the MPW. Instead, written assessments and questionnaires that are intended to determine

the severity of an illness or disability are used to build a case for eligibility. Participants

reported that they felt (and continue to feel) an expectation to prove that their child is

"disabled enough" or "sick enough" to be worthy of benefits. For Kelli, learning to speak

about the severity of her child's disability was a new and disturbingly uncertain

experience.

> I can remember our first meeting with the case manager, and, now that I look back
> at it, I know she was trying to be sensitive to our feelings, but she was looking for
> the worst possible things about my kid. She would say, "Does he put himself in
> danger or your other child in danger?" And I would be like, "Well, he is only 5, not
> really." She would say, "Can you think of anything?" I would say, "I mean he does
> throw things." He went through a period of banging his head against the ground
> when he was mad, and that is what she would write down.

Taylor described the unexpected burden of proof she felt was placed on caregivers by the

Medicaid system: "However, applying for the Michelle P. is something different, and yes,

there is a secret language. It is like you are on trial. You have to prove without a shadow

of doubt that your kid needs it." Several participants reported that it was through their

interactions with the case manager (i.e., a meso-level source) that they began to learn

what words and information to report on the application and renewal forms. Nancy

discussed the emotional impact that she experienced as a result of a recent renewal

application interaction in which her case manager crossed out an entire list of age-

appropriate milestones on her behalf.

> They'd have these questionnaires, and you'd be like, "No, she's not doing any of
> those things. No, she's not doing any of those things." So, they [the case

managers] literally would cross out the entire page, and it was for things for kids in her age range. . . . But the unrecorded language is very true, because you really, rather than being able to just give facts, you actually have to focus on what your child's not doing, as opposed to what they are doing. And that is brutal for a parent. Because in the midst of things, you want to celebrate. Especially when the accomplishments are spread out.

Perhaps most upsetting for parents is that the conversation and reporting of their child's level of functionality takes place right in front of the child. For Taylor, this was the most heart-wrenching part of the process; she worried about how the conversation would affect her child's feelings about himself.

> Every year, even though we've done this now 10 times, you worry that they will deny you. But yes, I mean we celebrate every milestone at home, but not on that piece of paper. Can't risk it. And I'll tell you another thing that really hurts me and worries me about the process. They make me do it in front of my kid. They make me say the worst possible things right in front of him. I don't think he understands it all, but I mean there will come a day when he does. I hate it. I hate it that he has to be in the room for that. It's not right. If my husband is home when they come, he'll like take him to the other side of the room or the living room and keep him distracted. But like they want to see for themselves that he is disabled— even though he was disabled last year and the year before. You have to keep proving it. I cannot tell you how, just, shaming, humbling the process is. But, unless you are a billionaire, or you just give up on helping your kid, I don't know what else you do.

In sum, many caregivers felt that to have the best chance of obtaining the MPW, they had to learn to effectively utilize clinical and "worst-case scenario" language when reporting about the functional levels of their child. The use of such language was a source of uncertainty for parent caregivers who felt and continue to feel conflicted about portraying their child in the worst possible light.

Medicaid mistakes. For some participants, uncertainty existed because of a lack of confidence in Medicaid. The participants in this study recalled instances of inconsistent instruction and repeated mistakes made by Medicaid staff that threatened the security of their child's MPW benefits. For instance, Rachel, who was interviewed during

her renewal window, talked about being asked for income documentation, even though

the MPW is not based on parental income, and such documentation had never been

requested before. She also commented on what she considers the unprofessional and

discourteous communication behaviors of local Medicaid office staff.

> Oh, Medicaid office. They suck. That's awful, but I don't know how else to put it. Yeah, so even right now, we just did our renewal process for the waiver and we got paperwork in from Medicaid saying we have to fill out all kinds of stuff about our assets and our incomes and our savings accounts, and I called them and said, "She doesn't qualify based on income," and they were like, "You still have to do it." We've never had to do that. She's had the waiver for 4 years. In the end, I was right, and we didn't need all of that. But yes, our local office, they're just rude. Every time I go in, it's just an inconvenience to their life that I'm there. It's awful.

Several caregivers discussed the impact of a Medicaid mistake on their ability to

continue medically relevant treatment for their child. Chelsea, the mother of two

daughters receiving the MPW, worried that the qualified workers that she has worked

diligently to find and train will quit when Medicaid delays their payments.

> When Medicaid has made an error, they're able to absorb that cost without flinching. We have people's salaries that they're depending on, so we have to pay them or they're going to quit. So, it's hard for us to absorb that financially every time there's an error, which is two, three, four times a year at least, for each kid.

John conceded that his child will probably lose the MPW at some point, and he admitted

that he is running out of mental energy to keep up with the ever-changing rules, mistakes,

and requirements of Medicaid.

> And again, that's how bad they are, that they thought they were looking at his eligibility as if he was in a different program. But actually, quite honestly, I just said to my wife, "If they cut us off we'll just, it's almost like"…well, I don't have the mental energy to fight with them. It is almost like, "If I knew your rules, I could follow them. No one knows your rules." And again, it is almost like that there is this sense of fatalism. It is like they're going to do what they're going to do. I have no control over it. I can't stop them. I can't appease them. Whatever will be, will be.

In sum, parents described several sources of meso-level medical uncertainty related to the MPW that challenged their ability to successfully identify and access health resources for their child. Such medical sources of uncertainty often included having a lack of information, skill, and experience in effectively navigating waiver-based care through Medicaid. Perhaps the most prominent theme that emerged in the analysis of this data was that parents most often discovered the MPW, and subsequently learned to communicate with Medicaid and others about the MPW (e.g., application language) through accidental or grassroots communication interactions at the meso level (i.e., churches, happenstance conversations, a random loan officer), and, notably, did not hear about the MPW from medical providers with whom they had regular contact.

RQ2: Appraisal and Management of Uncertainty

The participants utilized various communicative practices to engage with their community to reduce, increase, or maintain their desired level of uncertainty. Specifically, parent caregivers managed their MPW-related uncertainty by employing the following strategies: (a) information seeking, (b) vigilance, (c) avoidance, (d) social support, (e) reframing, and (f) advocacy. These results related to RQ2 are summarized in Table 2. We were unable to consistently and explicitly identify exemplars where participants specifically discussed their appraisal of uncertainty. This finding, or lack thereof, is discussed in detail in Chapter 5.

Information Seeking as Uncertainty Management

As discussed in the previous section, a prominent source of uncertainty reported by participants was a lack of knowledge about the MPW. To effectively reduce their unwanted uncertainty, many caregivers employed information-seeking strategies, which

included efforts to inquire about the MPW from meso-level sources. For instance, Becca was unsuccessful in finding resources on her own and was still unaware of resources like the MPW. To address her feelings of uncertainty, Becca decided to share her story on Facebook in the hopes that someone she knew might be able to point her in the direction of available resources.

> I was like there has to be help for families like us. I kept telling my husband. I was like, there has to be. There has to be a program to help us. Somehow, some way, there has to be. I don't know what it is, but there has to be something to help us. I kept trying and trying and trying. I even posted on Facebook, "I'm looking for help because . . ." and telling my situation. I went public with it. That's when [an employee of a disability-related agency] got ahold of me, and she was like, "Have you tried the Michelle P.?"

For Becca, finding help for her child required reaching out to her community. She first attempted to attain the knowledge on her own (i.e., at the micro level); but as the uncertainty and the threats to her perceived ability to successfully care for her daughter both increased, Becca made a decision to share her story with the broader community via Facebook in hopes of improving her chances of accessing resources and information that could reduce her uncertainty.

For Kelli, it is both her ability to successfully search for information online and her willingness to pose questions to anyone in the community who might have information about the MPW that has been most effective in reducing the information-related uncertainty she experiences regarding the MPW. She stated:

> Anything that I have learned about the Michelle P. has been from my mad Google skills. I think I have a Google degree in the Michelle P., or by word of mouth and by me asking questions. Asking questions with the case manager, asking questions everywhere.

Several participants explained that finding information at the meso level has not been an easy task. The lack of public information—and the ambiguity of available

information at the meso level—played a role in how participants perceived their

uncertainty. For instance, Rachel credited her success in navigating the MPW and thus in

managing (i.e., reducing) her uncertainty to her constant efforts in networking with

members of the disability community:

> The thing is, especially for all the resources—not just the Michelle P. waiver program, but anything that we've gotten—has not been because of there being a hub of information. It's been us networking with other disability parents and finding out from disability networks and learning the best way to go about the things.

Taylor also shared a recent example of the information-seeking process she undertook in

trying to find an answer from multiple meso-level members (e.g., case manager,

Medicaid personnel) to a question about incentives for waiver families who also carry

private insurance. She explained:

> Recently, I learned that if you have private insurance that pays for some of the child's insurance, you can potentially get a kick back for using it. Things are very confusing. I mean, it is nearly impossible to find that information online. I searched and searched. Then I asked my case manager; she wasn't sure either. Then I asked [one of] the Medicaid people during my renewal—she didn't know. Then at a work thing, where there were a lot of people surrounding Medicaid and the waivers at a meeting, I started asking there; and someone finally sent me the details and I am working through that. It is very frustrating. You must be persistent in waiver world.

For Grace, making strategic alliances as a form of information seeking led to her

discovery of the MPW and thus served as an effective mechanism for reducing unwanted

uncertainty:

> I realized this is up to me. I needed to figure this out myself because no one was going to do it for me, so I started asking my friends, "Do you know anyone with a child with a disability?" I didn't know anyone who had a child with a disability. It wasn't my world. I knew nothing about all of this. I had to build my own community. That was hard sometimes, because I worried about reaching out to someone else [who] might be struggling and how that would make them feel. But then I just got to a place where I would just ask, and if they didn't want to talk or help me, I was like, "Next." I hate to say it, but I have to be that way. Everything I

learned, I had to learn by the school of the hard knocks, by hitting the pavement. In that research, I began to find out that there were all these committees looking for parents of children with disabilities to serve on them. So, I joined every committee that would take me, and I kept learning and meeting people. And then, one day I attended a lunch-and-learn, they were talking about the Michelle P. as a part of Medicaid.

In sum, when lacking MPW knowledge (i.e., a medical source of uncertainty), participants in this study were often motivated to reduce their uncertainty. After conducting what research they could on their own, parents engaged with multiple meso-level sources (e.g., social media, case management organizations, disability networks) to find additional information about applying for and utilizing the MPW and to reduce their gap in knowledge and ultimately feel that they were improving their ability to care for their child.

Vigilance as Uncertainty Management

Vigilance is an uncertainty management strategy that includes keeping records, making additional phone calls, and preparing for potential mistakes. Vigilance was often used by participants in the present study to manage uncertainty about potential mistakes made by Medicaid and to prevent waiver loss. In the case of Medicaid mistakes, participants specifically identified local Medicaid personnel as influential storytellers in the community whom contributed to the uncertainty they felt by making mistakes, being unknowledgeable, providing misinformation, and in making the resolution process time-consuming and uncertain. For instance, Megan described the use of vigilance when interacting with the Medicaid office to resolve mistakes and to reduce the threat of additional benefit loss:

> The first year, that was March, they went ahead and cut off our benefits, and we did not get our benefits reinstated until July 1. So, we had no medical benefits until July 1. I went ahead and just paid our copays. But let me tell you, I called

them every day for 30 days. Could not get through. I would be on hold for like 40 minutes, 45 minutes, you know? I could just sit and dictate into my dictation machine while I was waiting on hold. But basically, I would just stay on hold until I got a phone call or had to stand up. And then I started faxing them. I would fax the entire packet with a cover letter. I would strike out yesterday's date and write "second attempt" with today's date, "third attempt" with today's date, "fourth attempt" with today's date. I think I got to 11 or 12 before they finally wrote me and said that we were approved. So now I keep everything and I document everything so that I am prepared when they inevitably screw up again.

Chelsea also described the vigilance that is required in managing the administrative work required to keep the waiver when you are also a caregiver of a vulnerable child. Chelsea reported that keeping up with the demands of the waiver (i.e., the paperwork) compromised her ability to provide attentive care to her child. However, she explained that such administrative vigilance is necessary to keep the waiver and to reduce the possibility of losing access to all the benefits that are offered through the MPW. She shared in the interview about the constant internal tug-of-war she feels in trying to balance the demands of both roles and the insecurity she feels about her life as a result.

> Managing the Michelle P. is work. So much work for people that are also trying to keep their kid alive. I mean, we were not supposed to leave him out of eyesight for like three years; and yet I have to make phone calls and file papers and make appointments and attend meetings. The other option is to rely on the case manager to do it and they know less than we do most of the time. It is so hard, and sometimes so overwhelming to feel insecure about your lives. For a long time, I was losing my mind worrying about what would happen if we lost the waiver or if they didn't approve this or that or whatever.

Becca's daughter lost coverage for an entire year, despite the family's relentless contact and vigilant efforts to work with Medicaid; this further exacerbated the uncertainty that she felt about the potential for system mistakes by Medicaid,

> We didn't get paid one year. Our recertification was in July. They started [the process] in May, and I thought, "Well, they're starting early. They're going to get everything in and everything's going to be fine." By—let's see—it was August, September, three months we went without pay or anything, nothing. Nothing. Even the medical card came up [showing] that she wasn't even on it. I was

furious. I kept telling them, "What is going on?" They were like, "We got a," whatever the—I can't remember the numbers on the—which meant that it was a mistake on their part that they needed to correct. I kept getting the letters in the mail telling them—I was like, "I got this letter in the mail again saying that something's wrong and [child's name] is going to get kicked off the program if we don't get it fixed." "Okay, we'll get it fixed. We'll get it fixed." Well, she got kicked off, and it took us a year of resubmitting documents, talking to Medicaid, to get her back on.

In sum, caregivers often employed vigilant strategies to manage the ongoing uncertainty they felt knowing that a system-level mistake by Medicaid could result in waiver loss, which would compromise their ability to afford their child's health care. To reduce this source of uncertainty, participants discussed using more assertive and persistent communication when interacting with Medicaid personnel, such as documenting their interactions, following-up with Medicaid to ensure that paperwork was processed properly and becoming the plan administrator.

Avoidance as Uncertainty Management

Caregivers who utilized avoidant strategies when managing MPW-specific uncertainty were often motivated to socially withdraw, ignore information, or regulate information or conversations so that unwanted information was minimized. Some participants discussed the personal uncertainty they felt regarding their own competency in being able to sustain the level effort required to keep up with and fulfill the administrative demands required by Medicaid. Rather than trying to reduce their uncertainty, however, participants chose instead to maintain or increase uncertainty by avoiding additional interactions at the meso level (e.g., with Medicaid) as a means to maintain optimism or to improve their own mental health by eliminating an information-seeking task. For example, John discussed his tendency to ignore the letters he receives from Medicaid and to instead hope for the best: "I've almost gotten to the point where it's

almost like, they're too incompetent to figure a problem out. If you ignore them for a while, they'll stop sending letters, and nothing bad will happen." Megan shared that she sometimes avoids responding to letters from Medicaid and instead hopes that things will work out; the thought of trying to figure out a new procedure is too daunting for her. She did admit, though, that she knows she is taking a risk by avoiding communication with Medicaid:

> And it's not just that. It's almost like [Medicaid's] procedure sometimes seems so random. I'm just going to have to hope for the best. I don't think that that monster can be appeased. I'll just take my chances. I have—speaking of communication— I have no idea what they want. I'm not sure they do either. So, it is sometimes just easier to avoid it because otherwise you feel like you're spinning your wheels.

Avoidant strategies allowed participants to distance themselves from uncertainty that felt too emotionally or mentally overwhelming. Specifically, participants discussed how Medicaid's changing policies and lack of procedural consistency is a source of uncertainty for them. To manage the uncertainty they experienced when faced with new or conflicting requirements from Medicaid, participants sometimes elected to ignore or avoid requirements that seemed too overwhelming, complicated, or futile.

Support as Uncertainty Management

Social support is a method of uncertainty management that is particularly useful when individuals prioritize the management of their psychological and social health. Unlike social support received at the micro level—which often includes natural supports from friends, family and close social or peer networks—social support at the meso level involves support from more formal community entities (e.g., churches, disability networks, paid at-home providers, online communities). In the present study, social supporters at the meso level were referenced by parental caregivers as impactful to the

management of their uncertainty related to information needs, oftentimes by taking on the information management role themselves. Layne shared that parents of children with disabilities are given so much information related to their child's care, that it becomes impossible to take it all in at once, which was overwhelming for her.

> I'm sure you've heard this from other parents that you kind of get inundated with a lot of information, and it doesn't always sink in. You kind of have to hear it multiple times before you actually go, "Oh, yeah. I should call on that." So, it was from the small group at my church where I finally began to put it together because I was hearing from people who had been there.

Layne's strategic engagement with the church helped her to effectively address the uncertainty she felt about her lack of knowledge. By networking and meeting regularly with other parents of children with disabilities through the church, Layne felt that she was able to hear about resources multiple times, at her own pace, and that eventually she was able to piece together what options might be best for her child.

Social supporters also provided validation and encouragement, which served to address the identity uncertainties that caregivers encountered as facilitators of their child's MPW. John described how strategic associations with other disability families (i.e., meso-level community members) has provided he and his wife opportunities to discuss openly their experiences and questions related to the MPW, which in turn, has helped shaped their perspective, contributed to their sense of belonging in the community, and encouraged a sense of efficacy as caregivers.

> I think for us, seeking out other autism families [through Autism Speaks] has been really important in how we've managed working with our son. It's helped us set our perspective and made us feel much less isolated than I think some families could be. We've networked mainly with a few other families who are kind of in similar situations, and they have provided an awful lot of our support. I think the way we manage things is we have a few very high-quality people in place.

Similarly, associations with a support group helped Chelsea to more positively manage

the uncertainty she felt about navigating MPW requirements and to feel reassured about

her competency as a caregiver.

> We have a support group here of autism families. When I am having those doubts [about her parenting abilities], those overwhelmed days, I know there's people in the support group that I can communicate that feeling to, that can say to me, "Yep, I get that. I fully understand that, and you're still doing a good job, even though you feel that you're not." Like, they know how we have to be brutally honest about what our lives are to get [MPW] services. Still, it's hard every time you fill out forms and you're going over what your child can and can't do. Having that communication with other people who are going through it has been such a lifesaver for me.

A number of participants explained that the providers they hired through the

MPW (i.e., meso-level members) have been a tremendous source of educational and

personal support for everyone in the home. Accepting social support from paid providers

served as a useful mechanism for reducing the parenting competency-related uncertainty

that Layne felt about not being able to read her child's emotions,

> When the therapists would come into our homes, they would teach us all stuff, and [child's name] is definitely happiest when she is interacting with her brothers. She is a hard one to read, because she doesn't show a lot of emotion; but you can tell she definitely enjoys being with them. Our help has helped all of us learn to connect with her in more meaningful ways and that has been so huge! I would say I was a whole lot more isolated and anxious and depressed [before having the support of providers]. And then suddenly we were able to do things, and I just kind of accepted her where she was.

Layne's narrative illustrates how providers at the meso level play an important role in

building communication skills (i.e., addressing informational needs, a medical source of

uncertainty) for the family as a whole, and how, as parental caregivers begin to feel more

comfortable in knowing how to engage with their child, their uncertainty was reduced.

In sum, when caregivers connected to social support in their communities, they

often found a meso-level network from which they could seek information (i.e.,

uncertainty reduction) by learning from the experiences of others, while also finding validation (i.e., maintaining or increasing uncertainty) for the feelings of uncertainty that they had experienced in learning to care for their child.

Reframing as Uncertainty Management

In the present study, reframing seemed to be an especially useful strategy for parental caregivers when managing their uncertainty related to the use of unfamiliar clinical or derogatory language to describe the abilities of their child when completing application and renewal forms and when answering the interview questions required by Medicaid. Several participants discussed the personal uncertainty and guilt they experienced when speaking negatively about their own child during the application process. Reframing the use of such language as an opportunity to demonstrate parental competence rather than a personal or parental failure served as a useful mechanism for reconciling this personal source of uncertainty. For instance, Kathy recalled, "At first, it was strange and hurtful that I was sitting here telling someone how awful and horrible my son is, but I had to remind myself that the opportunities the waiver would provide were worth it." In a similar example, Taylor shared that by reframing the use of clinical or derogatory language as an opportunity to secure the waiver, she was able to reconcile the personal uncertainty she felt about writing down what she described as "the most horrible things" she could think of in terms of her son's abilities.

> Thankfully, because I knew people working in the disability field, they told me to think about the worst day and write down the ability of your child on that day. It is very hard, very hard. When we applied—and even now when we renew—it breaks my heart. I hate to say it, though, but at some point, you do just get to the point where you are like, "Fine, I will write the most horrible things I can think of because I know we need this card."

Matthew credited his professional training as an engineer as helpful in keeping his use of waiver language in perspective, stating that he knew what he had to do to "get results," meaning that he would be able to secure the waiver and more effectively help his daughter access specialized services. However, he also felt that the conclusions made in the assessments did not show the whole picture of his daughter's capability, which discomforted him during the application process. He stated,

> When I heard that the DSM 5, I believe got modified. I said, All right. We're going back (to get a diagnosis). At that time, that's when she was diagnosed with autism. That set out a nice course for a program of improvements that we can do, including the MPW. It (the diagnosis) has been a God send ever since. When I saw that they defined, re-defined autism and Asperger's. I was like "We're probably in that little window where we could get the MPW. I have no doubt some of my engineering training, and filling out those permits, helped me out in doing the common paperwork, because luckily when we got that second test, and got the assessment. We got to the end of it, where there were conclusions. I mean, it is not easy to only look at your child through the results on an assessment. My wife, well ex-wife couldn't do it. But they (i.e., the assessments) are not wrong, but well let's just say, my daughter is high-functioning enough that even the case manager doubted that we would get approved. But I just copied that language over. I knew that was the professional working language, and code speak that would get results (i.e., access to the waiver). I transferred a lot of that over. Just filled in the blanks…The most important part was about getting privatized services.

By reframing the use of assessment-based language as professional code speak, Matthew was able to normalize, and therefore maintain or accept the uncertainty he felt about describing his daughter in this manner.

To summarize, the use of reframing was described by several participants as an effective strategy for managing their feelings of uncertainty related to the use of clinical or derogatory language when describing the abilities of their child during the application and renewal process. By reframing the use of such language as industry language, or as a necessary formality, caregivers were able to renegotiate the personal uncertainty they felt

about enacting an undesirable parenting behavior (i.e. talking negatively about their child) and to instead view such behavior as an opportunity to showcase their love and competence as a parent.

Advocacy as Uncertainty Management

To manage various social sources of uncertainty (e.g., unpredictable responses from community members, insecure political backing), many caregivers chose to become advocates for the disability community and for the MPW in particular. Advocacy provided caregivers with a platform to share their story with the community despite knowing their message might not be well-received, and also allowed them to redefine their relationship with the community as an advocate, an educator, and a resource for other families in order to manage their uncertainty. Chelsea explained that, in dealing with the unpredictable responses of community members (i.e., a social source of uncertainty), she tries to share her story as often as she can, even though it can feel scary to do so publicly. She hopes that by advocating for waiver services she can change the community's perception of Medicaid in order to reduce the potential for future Medicaid cuts.

> I talk about it as much as I can possibly talk about it, because I think that has to change. People's perception of Medicaid and the people using Medicaid has to change. So, I'm always open to that conversation. It is frightening to put yourself out there, but every time I hear about cuts to Medicaid, I talk about it as much as I can because I feel that the more people who hear the word "Medicaid" can see my son's face and my daughter's face, that maybe it might change their opinion about it. But of course, I don't know. I really don't know.

Andrea, who said she was new to advocacy, also discussed the experience of social threat in becoming an advocate for the MPW:

Well, I'm new to advocacy, and sometimes I'm not popular. And that is kind of

hard for me. I'm not mean, and I know Governor Bevin—we've met with

Governor Bevin when I spoke at the rally and he met with [child's name]. And he

was super nice. I can't say anything bad about him from that perspective. But I've

been very verbal with him about the waivers. I know it's a lot more expensive to

put somebody in a home, and who wants to have their family member spend their

life in a facility somewhere? Nobody would. I get fiery about that. And I have

been run through the mud for it, and I have not had any support, not even from

other disability families, at times. But I know this is important, and that is why I

advocate. I have made advocacy my job.

For Andrea, advocating for Medicaid waivers is worth the risk of unpredictable

community response, because it allows her to reduce the uncertainty she feels about the

potential for waiver loss.

Megan described how becoming an advocate for the MPW has allowed her to

combat the stigma associated with Medicaid and to address her feelings of social

uncertainty in regard to the unpredictable responses of community members by leading

the conversation about Medicaid in the community. She saw advocacy as a way to share

valuable knowledge and perspective with her community, and thus reduce the social

uncertainty she feels:

> It hasn't always been easy to take on the negative stigma associated with
> Medicaid. But, I mean, I think I'm advocacy-motivated anyway. I think I'm a
> natural advocate. So, this is the way I describe it a lot: I'm just really happy that I
> have something to care about now. I remember at Thanksgiving where I had to
> tell everybody about the greatest new invention, [which] was crescent rolls
> without the seams because I could wrap my brie without having to pinch the
> seams together. And, like, nobody cares about that. But people *do* care about

special education, and about Medicaid, and so I now have something to talk about that has value in the community.

In sum, many caregivers expressed that it was important for them to share their stories in a public (i.e., meso-level) way and to advocate on behalf of Medicaid waivers to manage their social uncertainty. Caregivers felt that their communities knew very little about the MPW, which contributed to the apprehension they felt about becoming advocates. However, they recognized that if they could change perceptions about Medicaid in their communities, it might also improve public support for waiver services; thus, it was important for them to talk openly about their experiences as caregivers for children with disabilities receiving the MPW.

RQ2a and RQ2b: Decision Making and Treatment Adherence

For parents negotiating health care decisions and treatment adherence within the context of the MPW, it is vital—and in some cases required—to consult and to coordinate their child's health care not only with the medical community but also with a variety of meso-level entities. This additional work can create more uncertainty for caregivers to manage. In the present study, I found that participants' meso-level experiences played a role in shaping their motivation and strategies of uncertainty management when facing at least three MPW-related decisions, including (a) decisions about the type of plan to choose under the MPW, (b) decisions of whether to adhere to a treatment plan, and (c) decisions about future planning. The results associated with RQ2a and RQ2b are outlined in Table 2.

Choosing the Consumer-Directed Plan

The MPW, like private insurance plans, allows eligible beneficiaries to choose from different plan types, each with different offerings. When considering a plan type

under the MPW, there are several implications for the parental caregiver to consider. Under a traditional plan, the parent caregiver would rely on the management agency to coordinate all paperwork required by the MPW and hire qualified workers to deliver respite care, community-living support, and at-home therapy services to their child. Under a consumer-directed plan (or, in some cases, a blended option), it is the responsibility of the parental caregiver to find workers and manage timesheets and other MPW-related paperwork. Caregivers often opt into a traditional plan at first, desiring the administrative support. However, for a variety of reasons (e.g., competency concerns, difficulty in securing qualified workers), most participants in the present study reported that they eventually lost confidence in the quality and effectiveness of traditional case management and chose a consumer-directed option (CDO) to address this source of medical uncertainty—thus managing their uncertainty through vigilance, which included efforts to control processes and decision making about the child's health care by taking a more active role in the selection and facilitation of services. For example, Kelli explained her decision to opt into a CDO to have better control over her child's care:

> We started with an agency. The appeal [of] the agency is that they help you keep up on your paperwork, they check in with you on things, they sometimes know of providers that you might not think to contact because they work with so many families. But working through an agency has its challenges, especially when your child needs in-home therapies. [Child's name] was eligible for 20 hours of ABA therapy; he has autism. So, we were like, "Great, the agency set it up, scheduled the therapists." But then we started to notice it was a different therapist every time, and some of them—well, I would say, [some] were more qualified than others. And for autism, routine is a big part of effective therapy. So, I thought that was strange; and sometimes, I felt like it was just glorified babysitting and not ABA therapy at all. So, then we began to experiment with [a] consumer option. We began seeking out students at [local colleges] that were training to work with kids with disabilities, and then having them trained to do the ABA therapies in our home. This way, we could have that consistency that we wanted, and we have really liked that. We can personally vet and build a relationship with the people working with our child.

Kelli felt that by relying on the traditional agency (i.e., a meso-level source), which had been inconsistent in addressing her child's needs, her daughter's care was compromised and this further stimulated Kelli's feelings of uncertainty in navigating her daughter's care effectively. To manage this uncertainty, Kelli utilized a vigilance strategy, assuming the role of an at-home caregiver through the CDO, so that she could control and provide better and more consistent care and thereby reduce the level of uncertainty she felt.

Some participants spoke about the challenges faced in accessing providers through the traditional model due to their residence in a rural area. For instance, Stacie shared her concerns about the quality of the providers chosen by the agency, which she perceived as compromising her child's health care. Stacie also made the decision to switch to a CDO option, and to employ vigilant strategies in order to reduce the uncertainty she experienced when trying to find qualified providers to work with her child.

> With my older daughter, this is awful. They'd always say, "Oh, we don't have anyone that comes out to your area. You live out in a rural area. We're sorry." And then, "Oh, we've got someone we can send," and then they would send somebody that I didn't feel comfortable leaving her with. So that became a problem. If you can't send someone that looks presentable in the health care field to care for my daughter, I didn't feel good about leaving. And they didn't really know her—and that was a huge problem. With [child's name], our younger daughter we already about the CDO option, or participant director options. We started there, because we knew better than to try to do any traditional services.

Taylor also felt uncertain about the quality of care her child received under the traditional plan, describing her medical uncertainty as a safety issue, especially given that her child was nonverbal. According to Taylor, in choosing the CDO plan, she could hire her own workers within the community (and therefore reduce the insecurity she felt as a parent

about placing her child in a potentially unsafe situation), even though it created additional work for her.

> My child was nonverbal for a long time. I was afraid somebody was going to hurt him. That was my fear. And he wouldn't be able to tell me or wouldn't remember why it happened. I'd better be able to trust you if I am going to leave my child, who cannot tell me what you do. Bringing someone into your home [puts you in] a really vulnerable position. That person gets to know your family in a different way, and I just never felt comfortable, and in some cases safe, leaving my child with the people sent from the agency. I'll also say, knowing what I know now, being able to hire and train someone from my community to be his worker has also improved his ability to learn social skills and to be a better community member. As you might imagine, when you have a kid with complex health needs, it can be easy to just never leave the house. But as we began to hire people from our community and they would take him places, or we would see them in the community when they were not working for us, it felt really good to see welcoming and knowing faces in his community. That is what this waiver is supposed to be about: Integrating people with their community, not hiding them away or servicing them with the lowest level of care workers that you can find.

In sum, caregivers were motivated to employ a vigilance strategy by choosing the CDO option, which allowed them to control and direct care to reduce their uncertainty about the quality and consistency of their child's treatment.

Nonadherence Decisions

Nonadherence decisions commonly occurred when caregivers faced obstacles to receiving care within the community, such as push back from the school. Several caregivers discussed the personal uncertainty they felt about choosing not to adhere to behavioral therapy despite knowing how valuable the treatment is for the child. To reconcile this uncertainty, participants avoided information or solution-seeking efforts and further distanced themselves from ownership of the child's behavioral outcomes. Instead, parents discussed hoping for the best and not knowing whether the choice to give up access to behavioral therapy would work out in the end. Jenny explained that there is only so much time in a day and that because the school refuses to accommodate her

child's need for behavioral therapy, which bothers her, she feels that hoping for the best

is all she can do.

> We also have to maneuver on therapists, because there's only so many hours in the day, and so many hours in the week. When are you going to throw in an extra therapy session? He also gets behavior therapy, and they won't allow—his schools don't have behavior therapists on staff. They have occupational therapy, physical therapy, and speech therapy; they have psychological resources; but they don't have behavior therapists. They have psychological resources, but they don't have behavior therapists. They will not allow an external behavioral therapist into the school to work with the child on behavior issues that may happen at the school. It is my biggest pet peeve. I've got a behavior therapist through the MPW, who is more than willing to go into the school to work with him, and the principal says, "No, they can't." We're like, "But he's pooping in his pants every day at a certain time. This is a behavior issue. What are we going to do about it?" So, I just bring him extra clothes and hope for the best.

Jessica also discussed the difficulty she faced when trying to adhere to her child's

therapeutic treatment regimen and the resistance she encountered from the school system.

Initially, Jessica tried to be vigilant, attempting to persuade the school to allow for an

outside behavioral therapist to work with her child. However, after realizing that there

were limits to her control, and despite greatly valuing the benefits of behavioral therapy,

she ultimately chose to ignore the recommendations of the child's behavioral therapist to

incorporate behavioral therapy into the child's curriculum because working with the

school was too hard and she wanted her child to have a school-based education.

> I tried to get her [an MPW-paid behavioral therapist]into the school system. Well, that's been hell because they're [the school] like, "Well, it takes our time and it costs money," and every excuse you can think of. And then, I was like, "Well, no, you wouldn't be responsible financially. She could just come in like a volunteer." They want to tell us all these excuses and really, it's like, "Why would you not want more help if it is offered?" I told them, "I don't want [child's name] pulled out of class. I want him in a class setting, with his behavioral therapist explaining what is socially acceptable that he's supposed to be doing." I said, "Do you not realize what ABA therapy is? ABA therapy is behavioral therapy for everything. Not just home. It's for living skills." And I said, "Right now, this school is [child's name]'s community. His behaviors are more intense in the school setting than [when] he is around me." So, why wouldn't I want help for him? I've been

more than happy with the school and how they treat [child's name], but it's like any sort of change, they want to fight. So I do what I can do with the therapy, but I am not taking him out of school. They don't understand that I have to worry about his functional skills because I can't be with him every day of his life when he gets older.

According to Meredith, even after a scary incident where her daughter ran away from school, the school still resisted and discouraged the use of a behavioral therapist; she feels this resistance poses a safety risk, but has not removed her child from the school because she also feels that her child needs to have social interaction at school. After several efforts to challenge the school's decision to not allow for the child's behavioral therapist to come in, Meredith now chooses to hope for the best and to avoid continued altercations, even though her child continues to suffer behavioral challenges at school that could be addressed with behavioral therapy.

> All of a sudden, she didn't want to go to school. She was really having a hard time. That's the year that she ran away from school. She got out of the school four times, but the last time she got away, she was found wandering in the woods by a man who was home from work sick and called 911. I knew something was wrong, and I wanted my behavioral therapist to go into school to watch [child's name]'s behavior because they were telling me she was having behavior issues that year and she never had before. They treated her terribly. They made it very impossible for her to get in. What am I supposed to do? I don't know what to do about it other than take her out; and then it is just me and her in the house all the time, and she needs social interaction. And I don't have enough hours [MPW paid provider hours] to cover that too. I've had to hire lawyers. I've gone through hell. So she is in school now, has behavioral issues, but doesn't use her behavioral therapy hours. It's just ridiculous, I've accepted that there is nothing I can do about it.

In short, for many caregivers in this study, utilizing the approved MPW-services that they had fought so hard to have was often much more complex than they had expected and thus heightened their experience of uncertainty. Working with school administrators was especially challenging for many caregivers in this study. Although parents were not satisfied with their decisions to forfeit behavioral therapy, they also

discussed feeling helpless to control the outcome and therefore defaulted to avoidant strategies to manage the uncertainty they felt. Avoiding feelings of uncertainty included hoping for the best in terms of their child's ability to overcome behavioral challenges on their own and also placing blame and responsibility for the child's behavioral health outcomes on meso-level members [the school], rather than themselves.

Future Planning Decisions

      Avoiding future care decisions. Caregivers varied widely in their preparedness and engagement with the meso-level storytelling network when making plans for the future care of their children. Future care decisions included considerations of potential future waivers—particularly those with residential benefits, which would require switching from the MPW into another program—and emergency planning, which required making formal and legal plans about guardianship should something catastrophic happen to the caregiver him- or herself. There are some services under the MPW that become unavailable at the child's 21st birthday. Alternate waivers (i.e., the Supports for Community Living waiver) also have long waitlists, sometimes over ten years. Finally, if a parent caregiver does not formalize a future plan through the means of a will or an advanced directive, and can no longer serve as a caregiver due to death or incapacity, the court system will step in to assign guardianship for the child. Therefore, future planning has significant and consequential implications in terms of health access and the quality of care for children with disabilities. Participants reported feeling unprepared and uncertain about making future planning decisions because they lacked knowledge about the future functionality of their child, had received limited information about the waiver from case managers, or felt overwhelmed by the thought of learning

another system of care in addition to managing the daily needs of their child. Caregivers often described feeling unready to formalize a future care plan, and therefore employed avoidant decision-making strategies, which meant ignoring information, discussion, and opportunities to put a plan in place, to manage their uncertainty. For example, Missy shared that her plan is to simply outlive her child:.

> No, that is not something we have really tackled with our case manager at this point. I don't think that has even come up; but we do think about it all of the time. I think [child's name] will probably be with us for the long haul. My plan is to outlive him. But you don't know what's going to happen. There are a lot of individuals with [child's particular disability] who do end up in a group-living facility at some point in time. While I always said, "I would never do that to my child, I would never put them in a group home, it sounds so horrible," I've actually talked to adults with [disability type] that live in a group facility and [they] love it. It's still is hard for me to imagine not having him with me. But I think only time will tell. You don't know what all he's going to be capable of doing and so on and so forth.

In this example, Missy discussed the uncertainty she feels about the possibility of a group-living facility arrangement for her child in the future, describing the decision as hard for her to imagine. Missy also expressed her desire to wait until she has a better understanding of the child's functionality before making a decision. By utilizing an avoidant decision-making strategy, Missy is able to maintain or increase the level of uncertainty she feels about the possibility of her child receiving care in a group-living facility, while also preserving hope for positive future outcomes in terms of her child's functional and living skills. When asked if this subject had been discussed with a case manager, Missy did not recall any discussion of future care planning, nor had she asked her case manager about future planning despite thinking about it "all of the time."

Rachel also discussed planning to outlive her child, and her intention to prevent sending her daughter to an institution (e.g., a home), explaining that the level of care she

provides as her daughter's caregiver is optimal (compared to institutional care). Still, no

formal plans have been implemented to guard against the possibility of

institutionalization. She stated,

> We don't have any type of will set out yet, but we've [she and her husband] been
> in the process of talking about those things. I'm assuming that we will outlive her.
> And I'm really hoping that we outlive her, as bad as that sounds. Because she's
> well taken care of right now, and I don't want her to be in a home. So that's my
> goal—to outlive her. …I just keep thinking the healthier I can be, the stronger I
> can be, the longer I can take care of her. So that is my goal.

Like many participants, Rachel described the use of avoidance strategies, such as

not taking the necessary steps to formalize a will and by prioritizing a different goal

(outliving the child), which served as useful mechanisms for managing the uncertainty

she associated with the lack of a future plan, especially in hoping that her daughter is

never institutionalized.

Proactive future care decision making. Not all caregivers in the study were

unwilling to make future health care plans for their child. In fact, some parental

caregivers have already gone to great lengths to prepare for their child's future health

care needs by seeking information and formalizing plans at the meso level. Chelsea's

family had already begun taking steps to put plans in place for the future care of their

child (i.e., information seeking), including researching a different waiver that would

allow for 24-hour residential care. However, she acknowledged that switching waivers

requires her to acquire a whole new body of knowledge, which she finds confusing but

wants to learn more about:

> Yes, we have. I mean, that's the thing that keeps me up at night, worrying about
> the future. But we have made some plans, the plans that we feel we can control.
> They have a special needs trust, they have some things in place. But as far as the
> waiver, this is something we're actively pursuing right now, trying to figure it out;
> because we heard that the Supports for Community Living waiver right now has

an 8 to 10-year wait list, and they just really don't know funding-wise how it's going to go. We obviously want to keep [our child] on the MPW as long as possible, but when I'm old and can no longer care for him, I need to know that that's an option, because it does have that residential component. We don't understand the inner workings of that waiver, because we're not in it. We know that's probably the next step for him. We have a fantastic case manager; we talked with him about this, and he really doesn't know all the answers either. But we are working on it.

Similarly, Megan explained that she is learning everything she can (an information-seeking management strategy) about future planning, including meeting with financial advisors (i.e., a meso-level member). Megan described the uncertainty she has about protecting her son's future financial and health care needs and how actively planning for the future manages this uncertainty by ensuring that there is plan in place for him.

I just finished up a special-needs estate planning meeting. That's what I did this morning. And my God! I mean, there's so many ways for the government to bust up your trust and to take money that you've saved and pay back Medicaid on [child's name]'s debt. Part of me is like, "I don't even want to deal with it. I don't want to deal with the government, I don't want them to take my money. He's gonna live in either my house or a duplex that I buy for him, and I'll get him a little job and that way he can earn as much as he wants." But then I'm smart enough to know that anything can happen and my God, if he gets leukemia then we're shot, so I can't take that risk, or Alzheimer's. And that is why you would want to keep some kind of waiver. Those are his two biggest risk factors. But yes, this is something that I am doing everything I can to figure out, so that he is protected.

Jessica credited her case management team for encouraging her to set up a special needs trust for her child to protect his future financial security. Jessica described her uncertainty about what would happen if she died and how her case managers have introduced her to possibilities that she would have never otherwise considered, which gives her a sense of confidence about her ability to work with the team to establish effective plans for her child, and thus reduce the uncertainty she felt about her child's future.

I have had really good case managers though all this. They've all been willing to help. And another thing I'm trying to get done is a special-needs trust. Because I

found out [that] if I die and I don't have [child's name]'s will protected, or my will protected for [child's name], then Medicaid can come take everything for medical bills. So I found out there's a thing called a special-needs trust that'll protect the estate I'll leave [child's name] and my life insurance, and they can't take nothing from him until he dies.

In short, to mitigate their concerns about the future financial and health care security of their children, many caregivers reported actively seeking out information and formalizing legal documents that would protect the money and assets they wanted to leave for that purpose. To acquire this information (which allowed them to reduce their uncertainty), caregivers conducted personal research and engaged with members of their communities by attending estate-planning workshops, discussing future planning in meetings with their case managers, and seeking advice from financial advisors.

RQ3: Barriers and Facilitators to UMT in the Communication Action Context

The CAC plays a critical role in connecting individuals to resources that can impact health behavior. Data analysis identified several physical and psychosocial barriers of the CAC that constrained communication between parental caregivers and their meso-level community—namely, (a) lack of systematic entry, (b) poor case management, and (c) constraints due to social control—and that thus also challenged caregivers' ability to adaptively manage their MPW-related uncertainty. In addition, several features of the CAC enabled communication at the meso level—in particular, (a) online neighborhoods and (b) disability networks—by connecting caregivers to resources, support, or information that helped parental caregivers to effectively manage their MPW-related uncertainty. These results related to RQ3 are summarized in Table 3 and are illustrated in Figure 1.

Barriers to Uncertainty Management in the CAC

Analysis of participants' narratives revealed three meso-level barriers (i.e., lack of systematic entry, poor case management, and social control through Medicaid) within caregivers' built and psychosocial environments that shaped parental caregivers' management of their MPW-related uncertainty.

No systematic entry point. Perhaps the most consistent theme in the data was the lack of systematic entry into the MPW. Each participant learned about the waiver from a different community source, often years after learning the diagnosis of their child. Taylor explained, "There is nowhere to find information in our little town, unless you are getting it from me or someone else that has it. Ninety-five percent of people have no idea what a waiver is." Becca felt that there is no easy way to for caregivers to learn about the MPW at the meso level. She was especially frustrated that medical providers—whom most people learn to rely on for health-related information—do not suggest the MPW, and she blamed this lack of a systemic process for introducing families to the MPW for her child's delayed access to the program.

> I do think, in my opinion, that it is something that needs to be put out there, even if it's just a suggestion; to say, "Listen, we offer this to all of our patients that have a child with a mental disability. There is a program called MPW." Maybe even have a brochure or a handout to say, "Here, this is what the program is, and if you're interested, you need to contact blah blah blah." That would have helped me. It really would have. But I ran around looking for an answer and had to find it the hard way years down the line. If we had gotten on this program years ago when we first got her, it probably would have worked out even better.

Several caregivers also expressed their surprise and frustration in learning that pediatricians and other health care providers do not have information related to the MPW to share with disability families. For instance, Nancy said:

> I think it starts with the pediatrician. I think that has to be the first point of contact for most individuals who will need a referral for a diagnostic battery. Yeah, I think the pediatrician is the most important first contact. And I think that—for

example, we go to [provider name] and they knew nothing about it [the MPW]. Every pediatrician should have information if they're making a referral right there about what waivered services are available for family. I don't know why it doesn't happen. Maybe it's just not seen as a priority. It would have made things [finding and applying for the MPW] a lot easier.

Mary also wishes that the medical community were more knowledgeable about the MPW so that the finding about the waiver was a more straightforward process.

I wish there was a better way, that I don't know, the doctor, or hospital, social worker, somebody who says, "Okay, you got this diagnosis, here's things that we're going to do to help you. Here's the Michelle P. waiver if you need it." Instead of just saying, "Here's the diagnosis, have fun with your autistic child."

In sum, caregivers expected information about the MPW to come from a medical source (e.g., pediatrician) and were surprised that there was no systematic process in place to alert potential candidates about it. This absence of a systematic entry was particularly problematic for caregivers who desired to reduce their medical uncertainty (i.e., absence of waiver knowledge), but who struggled to find information from the medical community.

Low-quality case management. Poor or unavailable case management arose as a barrier to many families' ease in accessing waiver information or other related health services; this proved to be a source of unwanted uncertainty for most caregivers. In the context of home- and community-based care such as the MPW, parental caregivers are required to seek input from non-medical meso-level sources. Participants often discussed their lack of confidence in (and thus uncertainty about) the validity of information provided by case management agencies because of past incidences wherein they received inaccurate information. Andrea shared how the incorrect information provided by a past case manager regarding the possibility of maintaining private insurance (in addition to MPW benefits) led to their daughter losing access to a specialty doctor:

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Her case worker told us she couldn't have other insurance and stay eligible for the MPW. So for a year-and-a-half I was told that, and it's not true. And we lost her doctor in Baltimore because a case worker in Kentucky did not know what they were talking about.

Although Stacie was already working with a case manager, at no point in time did the case manager—someone Stacie assumed should know about resources like the MPW—actually recommend the waiver. Stacie blamed her case managers' lack of knowledge about the MPW for her delay in finding out about it and ultimately applying for it. She shared,

When we asked our case manager about it, they were like, "No, no, there's no way you can hire, no." They just shut us down. But then a friend said we could. We really had to fight for it. We had said to her, "We don't understand why, when we asked you if there was anything out there to help us, you told us no. But there was something else out there to help us. There was the MPW." And she was quickly not our case manager any longer. We got a new one after that. But yeah, I mean, some of the case workers act like the services are coming out of their pocket sometimes. They don't want to get services for you, because—I don't know if it's the agency or if it's the case manager, you know what I mean? They feel like you're getting something you don't deserve.

Some participants talked about case manager turnover as an issue that considerably reduces their trust in their management team. For instance, Taylor explained: "We've been through five case managers, I think. That is a hard job. They leave." According to Andrea, when case managers moved on, she never knew what to expect regarding the quality of their replacements:

I've had a couple of caseworkers that have been really good and have given me suggestions about places to take [child's name] for physical therapy. But then I've had some, and they don't know anything. I've had some great ones and some really horrible ones.

Taylor is currently working with her fifth case manager since her child became waiver-eligible seven years ago. In Taylor's experience, she is usually better off finding answers

to her questions about the MPW from her own sources because the case managers'

knowledge is usually limited:

> It wasn't that we had anyone that was particularly bad, but we definitely had case managers that only knew the basics. I find it hard to rely on case managers. Like I said, I feel like they try; but I will get better information if I poke around myself.

The lack of quality case management is a community-level barrier that

contributed to parents' uncertainty about where and from whom to find accurate

information to manage their unwanted uncertainty regarding the MPW. The inability of

case managers to relay accurate information about the MPW effectively is a problematic

constraint to uncertainty management related to information needs within the CAC.

Social control in accessing the waiver. Many participants discussed the stringent

processes and rules imposed by various meso-level authorities that made it difficult to

effectively manage their uncertainty about the MPW. Participants felt that inconsistent

instructions from Medicaid created an obstacle to their child's access to health care by

inhibiting open communication, and this condition was described by caregivers as

uncertainty-producing. For example, Nancy spoke about the indirect paper trail and the

redundancy of work required by Medicaid as factors that delayed her access child's

access to care.

> I had to provide all the documentation and sign releases of information for every doctor we'd ever seen, write down every medication, every procedure that had been done. It was ridiculous; I literally carried my entire tub of paperwork from the first two years of her life to the Medicaid office, never knowing what they might need. And then, even though I [had] just jumped through the hoops of Michelle P., I had to jump through the hoops again with Medicaid.

Madeline also discussed feeling that the complexity of Medicaid (i.e., a meso-level

source of medical uncertainty) was a barrier to access care for her child. It took Madeline

almost three years of persistence to apply for the waiver successfully.

I got bounced around a lot. I mean, I would go to the Social Security office and they would say, "Oh, no, you're at the wrong office, you've gotta go to Cabinet for Families and Children." And I remember this one day in particular, this happened to me. I drove to Lexington, had an appointment with Social Security because that's where I thought I was supposed to go. Sat there and waited for however long—an hour or plus. And then I finally got my appointment, sat down for literally 30 seconds, [and] she said, "You don't need to be here. You need to be at Cabinet for Families and Children." And I was like, "What the heck? And where is that?" I would say, and I'm guessing, probably it took us two-and-a-half to three years to go from starting the process to being accepted. And that was before the waitlist was what it is now.

June wondered if the process of applying for the waiver was purposely complex to discourage people from accessing it, acknowledging that she knew several families that had given up on trying to access the waiver for their children:

I know tons of families that started the process that gave up, even knowing that their child was going to benefit greatly from the program. Gave up because of the work. They were like, "I had a job. I cannot do another job, and this is a job. Literally. The paperwork, the connections, the criteria that we have to meet. It is a job." That is the truth. I mean it probably is that way so that less people do it. It is a job. There are hundreds and hundreds of research hours required.

In sum, findings revealed three elements of the CAC (i.e., lack of systematic entry, poor case management, and social control through Medicaid) were major barriers for parental caregivers when seeking information about the MPW. Participants shared several instances in which they felt frustrated with the meso-level processes required to successfully navigate the waiver and communicate with Medicaid, and that contributed to their experience and management of uncertainty. Such frustrations often stemmed from restricted or ambiguous information flow at the meso level regarding the MPW.

Facilitators of Uncertainty Management in the CAC

A CAC can enhance communication within a community by establishing communication hotspots—places where community members tend to engage with one another in dialogue. In the present study, participants' narratives revealed two

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communication hotspots within the CAC of parental caregivers that facilitated communication (and therefore uncertainty management) about the MPW: online neighborhoods and disability networks/nonprofits.

Online communities. Several caregivers discussed the importance of connecting with other waiver families through social media outlets, which also allowed them to reduce their uncertainty by accessing information related to finding health care-related resources for their children. In some cases, it was through their engagement with online communities that caregivers first learned about the MPW. For example, Nancy recalled: "I didn't know about the waiver, other than through the community, the Facebook community of the Down Syndrome Association of Central Kentucky (DSACK), where I heard rumors of waivers." Taylor also discussed the impact of joining online communities, which she considers her most trusted source of MPW-related information:

> Everything that we've ever been able to get for our daughter—the reimbursement of insurance, the waiver programs, figuring out how to do timesheets, all the things that we do, everything I've learned that actually helped us—we have learned from parents through Facebook support groups, or just by polling parents.

Reece discussed how social media has made it easier to connect with other families and share resources at a pace that feels is best for her and her family, thereby facilitating her use of information-seeking as an uncertainty management strategy.

> When [child's name] is having a particular issue, I go look online for information. There is Autism Speaks, there are all kinds of support groups on Facebook. I mean, there's just anything you want support on in Facebook, and you can go in there and just read people's comments. Even for the waiver itself, I pretty much get all my information from other people that are in those communities that are on the program. When he would develop new issues and stuff, I would research online. I do more of the Autism Speaks, like the big groups, and it has been really helpful.

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In summary, online communities enable the sharing of resources among parents by providing a space where caregivers could talk openly about their experiences. These forums also served as a form of informational and social support that aided the management of MPW-related uncertainty.

Membership in disability networks. Membership in disability networks (e.g., Human Development Institute, Down Syndrome Association, Autism Speaks) also facilitated MPW-related communication among caregivers. These nonprofit entities, whether by hosting a meeting, a website, or a Facebook page, were instrumental in creating opportunities for families to communicate with each other and with knowledgeable advocates who could help them reduce unwanted uncertainty about the MPW. For example, Rachel described how her membership in state and international disability networks had recently led to an opportunity to be an ambassador for one of the networks. This facilitated her use of advocacy to manage her uncertainty. In this new role, Rachel has been asked to help disseminate diagnosis and resource information, such as a list of programs—like the MPW—for which families might be eligible:

> Once we did the [disability specific] page, then we found there's a central Kentucky special-needs parent page, and then we found there's a [treatment type] support page. So, as everything has come up, we found different groups, if that makes sense. We met one other kid that has [child's name] diagnosis, and the rest of them are spread all over the world. It's crazy, because people just don't get it if they're not going through it—and they shouldn't have to get it, because it's awful. Even our friends and family, they don't understand to the [full] extent, because we don't tell them when we have bad days. It's isolating. But the [disability specific] foundation is working on an ambassador program, so they're seeking out people in each state that can collect all the resources, like stuff about the waivers in each state, and to put it in one place so that as people are diagnosed, we can literally hand them a sheet and say, "Here are the things in Kentucky your kid will automatically qualify for." Or, "Here's the way these are processed, do this."

For Jenny, it was through her membership with a disability network that she finally

learned how to successfully apply for the MPW, thus reducing her uncertainty by

securing access to quality health care for her child:

> The Commission for Children with Special Health care Needs, they work a network, and it's a kind of a governmental job. I started going there. I emailed them. I was Googling something, and I found them, and I was like, "Hey, this is what my kid has. Can you guys serve him?" They said yes. I started going there for his orthopedics. They have a parent organization, which I'm just starting to become a part of, where we go out there and talk to parents and say, "Hey, you need any support?" They will ask you, "Do you have this? Have you tried this? Have you heard of this?" And they will go through the entire list. They pushed me to apply for Michelle P. again. He goes, "You've asked the wrong questions when you've gone in there." He goes, "You have to apply, and you will get it." And we did get it, which was huge for us.

When asked "Can you think of a time where you learned something that helped you

navigate the MPW better or differently?" Madeline shared an example of an important

connection she was able to make through her association with a disability network.

According to Madeline, she gained access to both social support and important resources

as a result of the association, which served to alleviate some the uncertainty she

experienced related to the MPW:

> I think probably the biggest thing is that it [connecting to a disability network] makes you feel like you've got support. So that if you do feel like you're in a spot where things are not completely known, or you don't know where to go or where to turn, at least you have resources to reach out to. And some of those resources are nationally known people that do this every day.

In summary, participants' narratives illustrated several ways in which the CAC

thwarts access to or connects parental caregivers to resources that can shape the health

decisions parental caregivers make on behalf of their children. Some aspects of the CAC

constrained communication between parental caregivers and their meso-level community,

challenging caregivers' ability to adaptively manage their MPW-related uncertainty.

Other features of the CAC enabled communication at the meso level and thereby facilitated caregivers' uncertainty management through information seeking, social support, and advocacy strategies.

Table 1: Meso-Level Sources of Uncertainty

Main finding: Parent caregivers experienced unique sources of uncertainty related to the MPW.

I. *Personal sources* of uncertainty involved complex or competing roles or identity dilemmas related to the child's use of the MPW, which were often shaped by parents' interactions at the meso level.

    A. Parents felt uncertain about their parenting competency.

        1. The process of verbalizing the child's behavioral challenges to a meso-level entity often contributed to parents question their own abilities in parenting and providing care for their child.
        2. The process of applying for specialized health care for their child sometimes prompted parents' questioning of their parenting competency.

    B. Parents felt uncertain about sacrificing their previous careers to become paid at-home care providers for their children.

        1. The lack of adequate community support (e.g., schools) compromised their ability to work outside of the home, which created feelings of unwanted uncertainty.
        2. Some participants were uncertain about depending on the MPW for income rather than their own career, knowing that it is not guaranteed to always be there.

    C. Parents reported feeling uncertain about what it meant as members of society to be Medicaid recipients.

        1. Some participants expressed a sense of stigma against or a sense of personal failure associated with requiring assistance through the MPW.
        2. Personal bias against Medicaid sometimes delayed participants' willingness to seek meso-level resources, including the MPW as they tried to reconcile the uncertainty they felt.

II. *Social sources* of uncertainty included unpredictable interpersonal responses from members in the community and perceptions of unclear community backing of Medicaid waivers.

    A. Parents felt uncertain about disclosing their child's waiver status to members of the meso-level community.

        1. Parents felt that their community possessed a limited understanding of Medicaid, which then challenged their ability to have meaningful conversations about the MPW.
        2. Parents perceived that their communities did not prioritize the care of

persons with disabilities who rely on Medicaid waivers and also undervalued the work involved in caring for a child with a disability through the MPW, and therefore chose to keep their child's MPW status private because of the risk of negative responses from others.

3. Participants felt particularly uncertain having conversations about MPW at doctors' offices because of potential stigma from medical personnel.

B. Parents felt uncertain about whether the community supported the future of the MPW.

1. Participants' knowledge about the scarcity of waivers contributed to their willingness to discuss the MPW with other members of the disability community.

2. Several participants experienced uncertainty about the sustainability of the MPW, acknowledging that the waiver program is not a guaranteed benefit and that their child could lose the waiver at any time.

III. *Medical sources* of uncertainty were related to insufficient knowledge, hidden application and renewal language, and system-level mistakes by Medicaid.

A. Parents reported having no knowledge of the MPW prior to their children's diagnoses, which contributed to their experience of uncertainty.

1. Parents often found out about the MPW by chance from meso-level community members.

2. Parents reported that, after facing financial insecurity in trying to afford the treatments required for their child, they sought advice from meso-level agents, but they did not know to ask about the MPW.

B. Parents felt uncertain when learning to use clinical and unfavorable language about their children's developmental status when applying for and renewing the MPW.

1. Participants felt an expectation to prove and provide evidence that their child was "disabled enough" to be worthy of MPW benefits.

2. Parents were especially uncomfortable with reporting negatively about their children in the children's presence.

C. Parents felt uncertain about the potential for system-level mistakes by Medicaid that could lead to a loss of benefits for their children.

1. The participants in this study recalled instances of inconsistent instruction and repeated mistakes made by Medicaid staff that threatened the security of their child's MPW benefits.

2. Several caregivers discussed the impact of a Medicaid mistake on their ability to continue medically relevant treatment for their child.

Table 2: Appraisal and Management of Uncertainty and Decision Making and Adherence

Main finding: Parent caregivers managed their MPW-related uncertainty using a variety of strategies based on their appraisal of uncertainty.

I. Participants utilized a variety of uncertainty management styles to manage the uncertainty they experienced in regard to the MPW.

    A. Parents used *information-seeking* strategies to reduce their uncertainty about the MPW.

        1. Caregivers shared their story publicly (often online) in order to access information to reduce uncertainty.
        2. Some parents engaged with case managers to seek information to reduce unwanted uncertainty about the MPW.
        3. Networking with members of the disability community was a useful method for finding information related to the MPW, and thus for reducing unwanted uncertainty.

    B. Parents used *vigilance* as a strategy to reduce uncertainty related to their MPW experience.

        1. Vigilant strategies allowed caregivers to reduce uncertainty through communication aimed at gaining control over the child's care (e.g., record-keeping, persistent contact with the meso level) or by applying oversight in order to reduce uncertainty.
        2. Vigilance was often used by participants to reduce uncertainty about potential mistakes made by Medicaid.
        3. Some caregivers reported that they had lost coverage for their child in the past, which negatively impacted the child's care and the family's finances, and thus inspired their use of vigilance to reduce their uncertainty about future compromises to care.

    C. Parents used *avoidant* strategies to increase or maintain their uncertainty when managing the MPW.

        1. Some participants opted to increase or maintain their level of uncertainty through avoidance by ignoring communication (i.e., letters and required correspondence) from Medicaid, and instead held out hope for the best outcome to occur on its own.

Table 2 (continued): Appraisal and Management of Uncertainty and Decision Making and Adherence

D. Parents utilized *social support* strategies to reduce their uncertainty about the MPW.

1. Interactions with social supporters at the meso level often assisted caregivers' in managing the uncertainty they experienced related to their information needs by taking on the information management role themselves.
2. Social supporters provided validation and encouragement, which served to address the identity uncertainties that caregivers encountered as facilitators of their child's MPW.
3. Accepting social support from paid providers helped reduce the unwanted uncertainty they experienced about their parenting competency, who could help them to build the skills they felt they lacked.

E. Parents used *reframing* strategies to manage their uncertainty about the MPW.

1. Reframing allowed parents to reconcile their unwanted uncertainty related to the use of clinical or derogatory language to describe the abilities of their child and their unwanted uncertainty about their parenting competency.

F. Parents used *advocacy* strategies to manage their social uncertainty about the MPW.

1. Advocacy provided caregivers with a platform to share their story with community despite knowing their message might not be well-received and also allowed them to redefine their relationship with the community as an advocate for a greater cause.
2. Some parents felt that sharing their story in the community was a way to increase the community's support for the waiver, even though it felt threatening to do so publicly given the stigma associated with Medicaid use.

II. Participants' management of their uncertainty impacted decision making and adherence related to MPW.

A. Parents employed *vigilant strategies* to manage their uncertainty related to the quality of their child's care provided under the traditional plan, which ultimately contributed to their decision to elect into a consumer-directed plan type.

1. Caregivers expressed a desire to opt into a traditional plan at first, desiring the administrative support. However, most participants lost confidence in the quality and effectiveness of traditional case management

and chose a consumer-directed option to better control the quality of their child's care.

2. Some caregivers expressed concern about the unavailability of providers or the lack of trustworthy providers through the traditional plan, especially those participants in rural regions. In order to better control access, consistency, and quality in providers, caregivers elected into the CDO plan to reduce this unwanted uncertainty.

B. Parents employed *avoidant strategies* to manage nonadherence decisions related to the child's behavioral therapy.

1. Parents felt forced to choose between a public education for their child and the child's behavioral therapy, and they often prioritized the public education over the behavioral therapy.

C: Parents employed *avoidant and information-seeking strategies* to manage their uncertainty regarding future planning decisions for their children.

1. Caregivers used avoidance to manage their uncertainty about the future (that is, their hope for what might be functionally possible for their child and their perception of limited financial resources or limited knowledge about other waivers) by avoiding future planning.

2. Some participants used information seeking to proactively prepare for their child's future health care needs

Table 3: Barriers to and Facilitators of Uncertainty Management

Main finding: Parent caregivers' uncertainty management is both constrained and enabled by physical and psychosocial barriers in their communication action context

I. Parents described several meso-level conditions that challenged their ability to adaptively manage their MPW-related uncertainty.

A. Parents reported that the *lack of a systematic entry* to the MPW made finding information and applying for the MPW a difficult and uncertainty-producing experience.

1. Parents were surprised that a more formal system in the meso-level community was not in place to more efficiently alert families of children with disabilities about the MPW.
2. Many caregivers felt that pediatricians and medical providers should be equipped to share MPW information with potentially eligible families of children with disabilities.

B. Parents felt uncertain about their ability to rely on information and support from *low-quality case managers*.

1. The variability in the quality and experience of case managers (i.e., a meso- level member) in the community contributed to parents receiving inaccurate information about the MPW.
2. Parents perceived that low-quality or inconsistent case management due to case manager turnover was a barrier to seeking MPW information to reduce their uncertainty.

C. Parents discussed *social control processes* that made applying or renewing a waiver a difficult and uncertain process.

1. Participants felt that inconsistent instructions from Medicaid created an obstacle to their child's access to health care by inhibiting open communication, and this condition was uncertainty-producing for many caregivers.
2. Participants saw the complexity of Medicaid as a barrier to access and thus a source of unwanted uncertainty.

II. Parents described meso-level conditions that facilitated their ability to adaptively manage their MPW-related uncertainty.

A. Parents reported that access to *online communities* provided a space, which facilitated their uncertainty management strategies of information seeking and social support.

Table 3 (continued): Barriers to and Facilitators of Uncertainty Management

        1. Online communities allowed caregivers to reduce their uncertainty by accessing information related to health care-related resources for their children.

        2. Online communities also allowed parents to connect with other waiver families in ways that were validating to their experiences regarding the MPW.

B. Parents discussed their membership in disability networks as a key facilitator in their management of MPW-related uncertainty.

        1. Nonprofit entities created opportunities for families to seek information and to advocate for other families with children with disabilities, which helped them reduce unwanted uncertainty about the MPW.
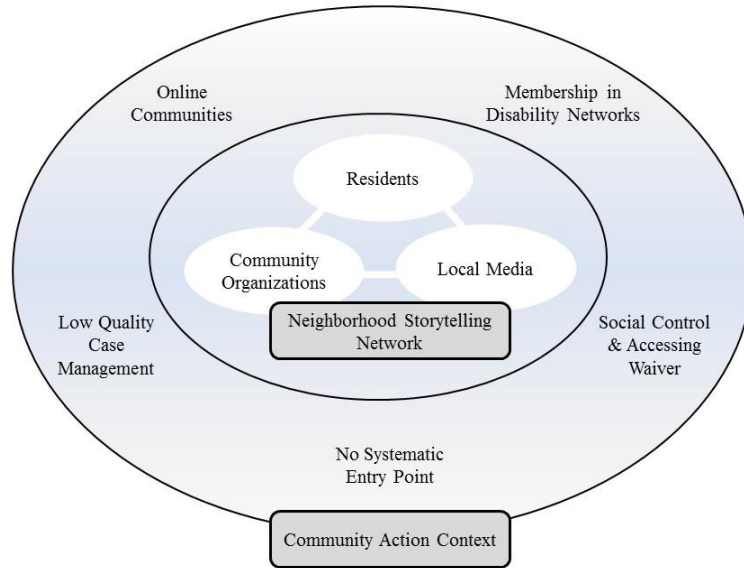
Figure 4-1: Communication Infrastructure: Barriers to and Facilitators of Uncertainty Management Within the Communication Action Context

CHAPTER FIVE: DISCUSSION

The objective of the current study was to examine how parents' interactions within the meso level of their community shaped their MPW-related uncertainty, appraisals, and management, including the impact on decision making and treatment adherence. I conducted 31 narrative interviews with parent caregivers of children under the age of 18 who were currently receiving health benefits through the MPW program. I used thematic narrative analysis to identify parents' meso-level sources of uncertainty (i.e., personal, social, and medical) when navigating the MPW on behalf of their child (RQ1), to explain how these sources of uncertainty were subsequently appraised and managed (RQ2), and to examine how that uncertainty appraisal and management affected the key outcomes of treatment decision making and adherence (RQ2a/b). I also identified various barriers to and facilitators of uncertainty management in the parental caregivers' communication action context (CAC) (RQ3).

Although 33 states offer some form of a Medicaid Home and Community Based (HCBS) waiver to meet the unique health care needs of individuals with disabilities, few research studies have explored patients' experiences and decision making when navigating such programs. The MPW is one of only two home- and community-based waivers available to young children with disabilities in the state of Kentucky. For children with disabilities to gain access to the MPW program and its extensive health care offerings, their parents must apply for the waiver, navigate a complex web of rules and regulations, and make both immediate and long-term health care decisions on their behalf. Parents commonly enter this role lacking any previous experience with waivers. Additionally, as paid providers through the MPW, parental caregivers become primarily

responsible not only for coordinating their child's care in the community but also for providing health care services themselves in the home and community; therefore, parental caregivers play a key role in the child's adherence to treatment.

There has been little research about how parental caregivers meet these demands and navigate the uncertainties inherent in the MPW process. In this dissertation, I focused on meso-level influences that contributed to caregivers' experiences of uncertainty. This focus allowed me to expand understandings of the illness experience beyond the individual/micro-level of the communication ecology and to draw conclusions with a number of theoretical and practical implications, which I summarize in this chapter. I conclude this dissertation with a description of directions for future research and a discussion of the current study's limitations.

Theoretical Implications

An emerging body of research suggests that current uncertainty management theories and decision-making models do not adequately address the unique experiences and dilemmas faced by parent caregivers of children who require complex care, despite the known potential for heightened uncertainty in this specific caregiving population (Clarke-Steffen, 1993; Kerr & Hass, 2014). Further, health communication research in general has given limited attention to the broader forces of communication, such as the community's influence on health behavior and health outcomes (Ball-Rokeach et al., 2001; Niederdeppe et al., 2013; Wilkin, 2013). The results of the current study offer several contributions that address these gaps in extant theorizing about communication.

Theoretical implications related to the sources of uncertainty. First, the findings of this dissertation demonstrate that parental caregivers experience identity-related

uncertainty in several unique ways. For example, parental caregivers experienced uncertainty related to their child's illness, not their own illness. Most studies that explore identity in illness have focused on the experiences of individuals who have been diagnosed or have lived with an unfavorable or undesirable characteristic or health condition. Findings from the current study illustrate that many parental caregivers experienced uncertainty related to the "courtesy" illness identity that they assumed as the facilitator of the MPW on behalf of their child (Goffman, 1963). Courtesy illness identity has been hinted at in previous work—mainly through a few studies that have confirmed the occurrence of courtesy stigma (Gray, 1993; Macrae, 1999)—but remains relatively unexplicated as a distinct construct. The present study represents a key first step toward more fully understanding this theoretical construct.

Goffman (1963) argued that there is a "tendency for stigma to spread from the stigmatized individual to his or her close connections" (p. 30). Although courtesy stigma has not been *explicitly* described or identified in studies of uncertainty management to date, Babrow et al. (1998) do account for the possibility, reporting that illness uncertainty also affects caregivers. In the current study, courtesy stigma was experienced as a personal and social source of uncertainty for parental caregivers facilitating the MPW waiver on behalf of their children; which then inspired the communication strategies they enacted in order to strategically control or manage their own and others feelings of uncertainty. Brashers et al. (2003) posited that individuals who live with stigmatizing illnesses are often motivated to manage the uncertainty of others with whom they desire to have a relationship. This behavior was observed when parents described their desire to justify their child's use of the medical card as a form of health care payment at doctors'

offices, and also when caregivers explained their reservations about disclosing their child's waiver status with other families in the disability community. This connection between Goffman's courtesy stigma and Brashers's (2001) conceptualization of uncertainty management extends current theoretical understandings of social uncertainty which currently defines social uncertainty as the possibility for unpredictable interpersonal reactions—including stigma and unclear relational implications (Brashers et al., 2003)—by recognizing courtesy stigma as a specific form of social uncertainty.

Building off of this recognition of courtesy stigma, I also found that parental caregivers experience identity-related uncertainty regarding their *means* of health care provision (i.e., Medicaid). Previous research on uncertainty in illness has not identified the meso-level systems of health care provision as a factor in identity uncertainty; but for many caregivers in this study, it was the use of the MPW through Medicaid—rather than the child's illness itself—that most severely threatened their personal and social identities. In some cases, caregivers were initially reluctant to apply for the waiver due to their inability to take on the Medicaid identity, which they felt was undesirable and disdained by members of their community. This finding about identity-related uncertainty related to health care means extends Brashers's (2001) conceptualization of uncertainty by reconsidering the scope of the uncertainty in illness experience. Tracing and documenting new dimensions of uncertainty related to the type of treatment plan or insurance an individual holds could produce valuable insight for improving the conversations surrounding alternative forms of health care, and may also explain delays in preventive care and health care access among populations that benefit from non-traditional forms of health care such as the MPW.

The current findings also expand conceptualization of credible authorities as posited by Brashers et al. (2004), which holds that an individual's support network can influence his or her experience, appraisal, and management of uncertainty in illness. The influence of credible authorities has been given less attention than other variables related to uncertainty in illness (Mishel, 1999; Brashers, Hsieh et al., 2006). Recent studies have expanded initial understandings of credible authorities to include medical providers. For instance, Brashers, Hsieh et al. (2006) found that credible medical authorities were often the preferred and primary sources of information and support for patients living with HIV. Most recently, Kerr et al. (2019) reported that medical providers' communication with parents facilitated their adaptive management of uncertainty through reappraisal. However, these current findings suggest that rather than looking to personal or medical authorities for information or support that could reduce their uncertainty related to the MPW, parents were more likely to engage strategically with meso-level connections such as disability networks, disability families, church groups, or service providers accessed through the MPW.

Oftentimes, parents shifted their perception of whom they considered to be a credible authority after losing trust in the competency of medical authorities. For instance, several caregivers explained that the medical community was unable to offer them guidance about the MPW because they lacked waiver-specific knowledge, which further hindered their ability to find information about the MPW in order to reduce their uncertainty. According to Brashers, Hsieh, et al. (2006), when healthcare providers fail to meet patient expectations, especially in regard to their information needs, they can exacerbate feelings of uncertainty for the patient. This willingness of parental caregivers

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to reevaluate their dependence on medical credible authorities also showcases the experiential nature of information seeking as a strategy of uncertainty management (Brashers, 2001). Participants shared that they have learned to first ask members of their online communities (i.e., Facebook groups) or members of their disability networks when seeking information about the MPW. Brashers, Hsieh et al. (2006) observed a similar behavior in their study of the HIV illness experience. They stated, "Participants in our study developed a complicated understanding of spheres of knowledge and their corresponding authorities. Participants reported that they came to understand that medical professionals could not have access to all illness-related knowledge" (p. 234). Little scholarly attention has been given to the corresponding authorities that contribute to the uncertainty management experience of parental caregivers. Thus the present study extends the conceptualization of credible authorities, in this case, to include non-medical authorities at the meso level.

A further theoretical contribution of this study involves a reconceptualization of Brashers et al.'s (2003) criteria for identifying medical sources of uncertainty. Mishel (1988) first recognized *lack of familiarity or knowledge* as a source of illness uncertainty, suggesting that when this occurs, individuals cannot call upon an available cognitive schema to interpret an event—and ultimately solve the problem—which heightens their sensitivity to uncertainty. Building on Mishel's conceptualization, Brashers et al. (2003) discussed *insufficient information* as a form of medical uncertainty, which encompassed conditions where individuals experience an ambiguous diagnosis and when there is an unknown probability of disease, combined with unfamiliar symptom patterns. However, in this study, sources of medical uncertainty were described by participants as (a) a lack

of knowledge about the Medicaid waiver in general, (b) the unknown probability of being initially accepted into or approved for the MPW program each year, (c) a lack of familiarity about the inner workings of the MPW program, such as the hidden application and renewal language, and (d) the ambiguity or complexity involved in interpreting the rules and regulations of Medicaid and correcting systemic mistakes. This expanded conceptualization of insufficient information in the context of navigating the MPW is consistent with Brashers et al.'s (2003) argument that "different illnesses may have specific features and characteristics that generate different forms of uncertainty" (p. 515). Therefore, by identifying the forms of medical uncertainty relevant to the MPW, this work provides a new structure from which to explore uncertainty related to the means of health care, rather than from experiencing an illness firsthand.

Theoretical implications related to uncertainty appraisal. In this current study, I was unable to sufficiently capture data that could showcase individuals' appraisal of their uncertainty, despite intentionally probing on the topic and in collecting rich and robust narratives. One reason for the difficulty in capturing uncertainty appraisal is the fact that appraisals are so closely tied to an individual's emotional state, which can be dynamic, varied in intensity, and complex (Brashers, 2000). Past studies have shown that, in general, individuals are often limited in their ability to identify and understand their own emotions (Booth-Butterfield & Booth-Butterfield, 1998; Samter & Burleson, 2005). To capture appraisal through interviews using Brashers' (2001) conceptualization would require that the participants themselves possess an adequate emotional vocabulary that could be used to explain how the uncertainty made them feel, and how they interpreted those feelings as either an opportunity, threat, or neutral experience in the MPW context.

It may be the case that to encourage such a deep reflection from participants requires an adjustment in the interview protocol, including an explanation of appraisal by the interviewer within the interview, or perhaps a re-examining of the appraisal construct and what constitutes evidence of appraisal.

To better explore uncertainty appraisals in future studies, future researchers may reflect on how insights posited by Babrow (1992, 1995) may be integrated into an uncertainty management model. Babrow's Problematic Integration Theory (PIT) (1992, 1995) described the appraisal process as an assessment of probability (i.e., how likely something is to occur) and evaluation (i.e., how negative or positive something is), rather than an evaluation of uncertainty as something good or opportunistic versus bad or threatening. Babrow (1992, 1995) suggested that the relationship between the assessment of probability and the evaluation of an event is often contentious and that an individual interprets (i.e., appraises) and must find a way to settle (i.e., manage) the tension they feel, often through communication. In this way, UMT and PIT hold similar assumptions. However, unlike UMT, PIT dives deeper into the different forms that the appraisal interpretation can take, which may be helpful in gaining insights and in building a more robust and nuanced theoretical coding scheme to capture appraisal. Particularly helpful is the idea that when uncertainty is evaluated as ambiguous or inconclusive, meaning that the individual does not know what to make of the experience or feels conflicted about their state of uncertainty itself, the person will often shift focus to the potentially negative or positive outcomes that are associated with their uncertainty and will assess the probability of that more concrete idea or outcome in considering the appropriate management strategy.

In the current study, I attempted to probe parents about how they felt about being uncertain. It was difficult in both the interview and in the analysis to identify in-depth discussion from participants' narratives about their appraisal and evaluation of their uncertainty itself. Instead, I found that parents naturally narrated how their feelings or experiences of uncertainty contributed to their perceptions of their ability to achieve desired goals or life conditions for themselves, their family, or their child. In other words, parents described their appraisal of uncertainty in terms of the possible outcomes of the uncertainty. For instance, in some exemplars parents expressed their desire to reduce uncertain conditions (e.g., potential for waiver loss). Whereas in other exemplars, caregivers described their desire to increase uncertain conditions (e.g., ignoring Medicaid notifications). Exploring appraisal through participants' assessment of probability and outcome more closely follows Babrow's (1992, 1995) view of uncertainty appraisal, but is not accounted for in Brashers's (2001) conceptualization of appraisal and therefore could not be utilized in providing evidence for answering questions about the appraisal process (RQ2) in the current study.

By integrating Babrow's (1992, 1995) explanation of the appraisal process, especially in terms of recording participants' assessment of possible outcomes of uncertainty as threats or opportunities that shaped their uncertainty management and decision making, I would be able to analyze this current data in a different light, showcasing robust participant narratives wherein parents explained their assessment of the probability of a direct outcome (e.g., waiver loss), why that outcome might be detrimental or advantageous (e.g., the child would lose access to life-saving care), and what they chose to do about it (management) when interacting at the meso level.

In sum, appraisals are the most understudied but perhaps most important component of UMT. By prioritizing the theoretical construction and focus on understanding appraisal, and perhaps incorporating understandings from other theoretical models such as PIT, future researchers can offer a more holistic explanation of uncertainty as its role in shaping outcomes in health contexts.

Theoretical implications related to uncertainty management. In addition, the present study raised the possibility of two additional strategies of uncertainty management, including advocacy and vigilance. The *advocacy* uncertainty management strategy served as a means for parental caregivers to combat their feelings of helplessness in regard to the perceived insecure political backing of the waivers by actively participating in collective action efforts, thus reducing uncertainty raised by the threat of waiver loss. In addition, parents' efforts to advocate in the community also allowed them to reduce their own personal biases about Medicaid, and to make sense of their uncertainty regarding their position in society by storytelling, and sharing resources and information to help other families. Brashers, Hass et al. (2000) first recognized the multiple functions and potential purposes of an individual's engagement in advocacy or activist behavior, suggesting that advocacy may be useful in connecting an individual with others like themselves, and by providing a collective purpose. Brashers, Rintamaki, Hsieh and Peterson (2006) then made a theoretical distinction between self-advocacy (that is, persuasive communication behavior intended to benefit oneself at the micro level) and social advocacy or activism (persuasive communication intended to improve the conditions of the broader community at the meso or macro level). Most studies in health communication have emphasized self-advocacy behaviors, particularly in the

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context of patient-provider communication (Brashers, Rintamaki, et al., 2006). However, the current study provides evidence that parental caregivers were motivated to do both in order to reduce the uncertainty they experienced from multiple sources, which extends Brashers, Hass et al.'s (2000) theoretical understanding of the role of advocacy in uncertainty management.

Vigilant strategies allowed caregivers to reduce uncertainty through communication aimed at gaining control over the child's care (e.g., record-keeping, persistent contact with the meso level) or by applying oversight in order to reduce uncertainty. Brashers (2001) has discussed vigilance as a potential social condition that contributes *to* uncertainty but not as a strategy of uncertainty, he stated: "Perhaps greater awareness and greater vigilance about health risks over the years have increased anxiety about disease and illness" (p. 487). Although vigilance is a term often used in communication literature, is has not been clearly delineated as a distinct construct. In this study, I find that vigilant strategies did not fall neatly under the previously defined domains of uncertainty management (i.e., information seeking, avoidance, social support, reframing), and therefore offers the potential for future theoretical expansion.

Theoretical implications related to decision making and adherence. The current findings demonstrate that medical decision making and treatment adherence in waiver-based care are more complex than what is considered in most current decision-making models. Specifically, the decision-making process that parental caregivers undertook when opting into one of the three plan types under the MPW is theoretically unique and thus far unexplored in current research. Plan type decisions under the MPW are conceptually comparable to the process of selecting a plan type through an employer-

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based insurance company wherein the consumer is asked to evaluate the trade-offs (that is, the pros and cons) of each option and ultimately decide which is best for them. In employer-based insurance planning, the consumer might select a plan option because of an attractive feature such as low co-payments, access to doctors that are in or out of network, or additional coverages for prescription medications. What is unique about choosing a plan type under the MPW is that the monetary cost of care is not the focal point of the decision. Instead, caregivers assess the value that a case management agency can provide to them in terms of access to information, resources, support, and insider knowledge about the inner workings of the MPW. From a health communication research perspective, the differences between these plans lie in the interpersonal value offered by each. This nuanced understanding of the plan type decision in the context of the MPW expands current theoretical understandings of the costs of care (which focus on monetary costs) as a determinant of parental caregivers treatment decisions and adherence (Iuga & McQuire, 2014) by explicating the non-monetary interpersonal costs that contribute to caregiver selection of a MPW plan.

Theoretical implications related to communication infrastructure. This study also demonstrated that conceptualizations of *community* through CIT, specifically in terms of belongingness, residency, and connectedness, should be expanded to account for parental caregivers' influential memberships with specialized community groups (e.g., disability networks, diagnosis-specific entities, online communities). Most research in CIT has explored health behaviors and communication storytelling among ethnic communities that lived together in identifiable and proximal parts of a city or neighborhood (Ball-Rokeach et al., 2001). This approach to exploring community

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communication was too focused on shared geography to account for the current findings, given that members of the disability community are unlikely to share the same level of geographical proximity.

Instead, the current findings expand upon the arguments of Ball-Rokeach et al. (2001), which suggest that the strongest predictor of belongingness is participation in a storytelling system and that evaluating connectedness requires understanding the direct and indirect paths that link individuals with members of the storytelling network (e.g., neighbors, organization, or media). Several parental caregivers in the present study discussed the informational and support value of their membership and engagement in extended networks, such as disability networks, online communities, churches, social media pages, or other disability-specific groups. By extending the conceptualization of community to include online communities and disability networks—even when those networks were not residentially local—the present study sheds light on how participants' involvement in meso-level storytelling networks contributed to their sense of belongingness and connectedness, which also positively impacted their ability to manage MPW waiver-related uncertainty and decision making. CIT proposes that when social actors are more connected to local resources at each level, they are more likely to be knowledgeable about diseases, outcomes, and resources (Kim, Moran, Wilkin, & Ball-Rokeach, 2011) and will show more interest in actively seeking health information (Kim & Kang, 2010). The current findings challenge CIT's current conceptualization of community, which is determined by residency, belongingness, and connectivity. These current findings suggest that the criteria for community is likely context-specific,

especially in cases related to the illness experience, wherein the diagnosis or means of healthcare—rather than geography—is the primary criterion for establishing locality.

Theoretical implications for using an integrated theoretical approach. A final theoretical strength of this study is its complementary use of two ecological approaches to health communication research: Brashers's (2001) UMT and Ball-Rokeach et al.'s (2001) CIT. Brashers (2001) acknowledged that "theories of uncertainty need to examine the ways in which uncertainties are interconnected" (p. 480). Utilizing the CIT framework provided a means for the exploration of the interrelationship between personal, social, and medical sources of parental caregiver uncertainty in accessing and utilizing the MPW, and the various meso-level interactions that shaped their experiences (Wilkin, 2013). Further, the CIT framework posits that each level of the communication infrastructure (i.e., micro, meso, macro) is made up of critical storytellers that can be identified and called upon to improve health messages to target populations (Kim & Ball-Rokeach, 2006). This study more fully captures the uncertainty that parental caregivers faced in trying to access, navigate, and make decisions about the MPW at the meso level because of the lack of an integrated storytelling network at the meso level. Combining these two theories allowed me to take a novel approach to analyzing and explaining parental caregivers' uncertainty in navigating the MPW. This theoretical integration brings a level of understanding and nuance to the findings that is not possible when uncertainty experiences are studied independently of one another or through one theoretical conceptualization alone.

Practical Implications

There are several important practical implications that can be gleaned from this study. I have outlined several takeaways to be considered by current and future parent caregivers of children with disabilities navigating the MPW, as well as the various community-level stakeholders identified by participants in this study as significant to their experiences of uncertainty.

Implications for parents. This study provides a starting point for understanding the strategies parents have used to navigate the MPW environment and the inherent uncertainty that accompanies the accessing and utilization of healthcare through Medicaid and related services for children with disabilities in the state of Kentucky. A strength and implication of this current study is that, through a process of social scientific inquiry, method, and rigor, for perhaps the first time, the experiences of parental caregivers managing waiver-based care through the MPW has been collected and analyzed for consideration and dissemination. Therefore, the findings and analysis of this dissertation can be shared with parents who are navigating waiver-based care in Kentucky as a source of vetted research that is potentially informative to their experience.

Several of the sources of uncertainty reported by participants in this study involved gaps in personal and community knowledge about the MPW, which then stymied parents' ability to overcome some early obstacles to accessing care, such as successfully applying for the MPW. I found that parents were able to reduce the uncertainty they felt regarding their knowledge gaps (a) by engaging in active information-seeking strategies, (b) by becoming more organized in their record-keeping, and (c) by building social support networks at the meso level. For instance, when parents

were able to learn the secret language of the MPW, became willing to ask questions at the meso level and found safe spaces to hear and share stories within the community, they reported feeling that their ability to navigate the system, to overcome new challenges, and to cope with their own uncertainties improved. Therefore, the current findings suggest that in order to manage MPW-related uncertainty, parents must develop a willingness to engage with the meso level.

Implications for medical providers. Perhaps one of the most consistent and addressable findings when identifying barriers within the CAC was the lack of knowledge held by medical professionals (pediatricians in particular) about the MPW. Participants were surprised and disappointed that pediatricians' offices were not better equipped to refer patient families to information about the MPW. According to the National Institute for Children's Health Quality (NICHQ) (2019), the early ages (i.e., birth through age three) is a unique time and opportunity for pediatricians to work closely with parents of all children to build a foundation for healthy development. During this time, children are seen more regularly, and parents are often more motivated to learn about healthy habits and resources (NICHQ, 2019). Traisman (2015) discussed the types of knowledge that pediatricians must prepare themselves with to better serve children with disabilities and their families, which includes knowing the services and insurances available to them:

> Know what services are available to the family and child: is the child enrolled in an early intervention program; does the child have an individual service plan, or an individual education plan for school; is the child homeschooled; and is there a school or at-home nurse. Respite planning is also important to ask about. The

health insurance status is important to know due to insurance network procedures

for subspecialty care, hospitalization, emergency department visits, and

prescribing medications. The families of children with special needs have large

financial responsibilities, so limiting costs is critical (p. 523).

In sum, meeting parents' needs for information about MPW services at

pediatricians' offices is a clear practical step that can be taken to improve parents'

experiences navigating the waiver.

Implications for disability networks and non-profits. The results of this study

also offer important practical insights for improving the conditions of the CAC as sites of

communication intervention so that information and support related to the MPW are more

easily discovered and accessed by parental caregivers. Disability networks and non-

profits were referenced by several participants in this study as members of the

community that were most helpful in providing information about the MPW and its

offerings. Therefore, it makes sense to focus efforts on equipping frontline service

providers with information and opportunities to introduce parents to the MPW sooner.

Past studies have demonstrated that when individuals are supported by a strong and

integrated STN, wherein meso- and micro-level storytellers work together to share

information and resources, individuals are more likely to achieve higher levels of

information-sharing, neighborhood belonging, and health literacy (Kim & Ball-Rokeach,

2006; Kim & Kang, 2010). This can occur in the current context by developing a

coordinated effort to first identify potential families who would benefit from the waiver

at initial diagnosis, and then by formally connecting them to established networks (e.g.,

First Steps), thereby improving parental access to knowledgeable storytellers in the community.

Implications for case managers. Finally, most parental caregivers in the current study expressed concern about the future care of their children, yet few had taken official steps (e.g., applied for another waiver, formalized plans, or prepared legal documents) to address this concern. Caregivers often discussed the renewal period as a time when they were required to check in with a case manager or support broker each year. Building upon this systematic process already required by Medicaid could offer a natural starting point within the CAC to explore opportunities to ensure that future care conversations occur and that parents are given opportunities to ask questions and formalize their plans. In a study of policy issues related to end-of-life care models in the United States, Wiener and Tilly (2003) concluded the following: "The challenge for the future will be to harness the purchasing power of public programs [Medicaid and Medicare] to improve the services that dying beneficiaries receive. Up to now, they have been the sleeping giants of end-of-life care financing" (p. 10). In other words, as the main sources of end-of-life care financing for many persons with disabilities in the United States, there is an opportunity to improve the services provided by Medicaid and Medicare, including the quality of future-planning services. Such efforts could potentially reduce costs to the program in general, while also improving the quality of life and decision making for beneficiaries and their families.

Implications for school systems. Findings from the present analysis illustrate that parental caregivers often have a difficult time integrating their child's therapeutic treatment into school-based settings. Therapeutic adherence is especially important in

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this population (i.e.,, children with disabilities receiving waiver-based care), given that

failures to participate in early interventions threaten the ability of the family and the child

to be fully involved in their community and to achieve important health milestones.

Literat and Chen (2013) discussed the importance of community organizations in health

discussions, stating, "Of particular importance are the businesses and community

institutions to which residents feel closely connected" (p. 94).

School systems occupy a unique and significant position as the educational leaders of the

community and have historically embraced opportunities to eliminate barriers to

children's educational progress. Schools must demonstrate their commitment to inclusive

education for children with disabilities by creating learning environments that take into

account students' unique needs. This could be done by reevaluating polices that

compromise children's ability to receive a public education and participate fully in the

school community, including policies that deny children access to prescribed behavioral

services in school-based settings.

Implications for Kentucky's Cabinet for Health and Family Services.

Kentucky's Cabinet for Health and Family Services (CHFS) must prioritize the

publication and dissemination of complete, accurate, and transparent information about

the MPW on its website. Several participants interviewed for this study revealed that it

was difficult for them to find information about the MPW on the state's website. In fact,

at the time of this manuscript's writing, several pages on the CHFS website offered no

content other than a note stating that the website was currently "under construction." To

overcome this informational barrier, parent caregivers in the present study reported

relying on grassroots-level networks and anecdotal information to answer their questions

about the MPW, such as asking other MPW parents. For example, several parents discussed how they initially chose a traditional MPW plan because they did not know about or understand the CDO. Oftentimes, it was other parents or community members who helped caregivers to understand their plan options under the MPW. Additionally, parents shared that they often learned about plan incentives (e.g., kickbacks for parents who maintained employer-based insurance) through word of mouth sources rather than the CHFS website or Medicaid personnel. It has been well established that most Americans use the Internet when seeking health information. Therefore, the CHFS could easily and effectively meet the needs of persons seeking information about the MPW and other waivers by providing credible, accurate, comprehensive, and understandable information online.

Limitations and Directions for Future Research

Like any study, this dissertation had limitations. In the following section, I acknowledge the constraints of the study, and I point out opportunities for future research related to parental caregiving for children with disabilities.

First, a sample of 31 parental caregivers in the state of Kentucky is too small a sample on which to base generalizations about waiver-based care, and thus the sample necessarily constrains the transferability of the present findings. However, as I discussed in Chapter 3, the coding team felt that saturation was reached in collecting a rich and thick account of uncertainty experiences related to the MPW and that we had exhausted the coding process and had displayed transparency and congruency in describing the research design, methodology, and analysis. I also conducted member checks to confirm that the findings were representative of parental experiences managing the MPW in

Kentucky on their child's behalf. A second limitation of the sample was the wide range of children's diagnoses. Decision making and treatment adherence across diagnoses can vary greatly, which limited my ability to provide diagnosis-specific nuance regarding some of the more specific issues related to administering treatment at home or navigating specific services within the community. Lastly, the final sample was not diverse in terms of gender, race, and culture. For instance, only four participants (12.9% of the sample) were fathers to children with disabilities receiving health care through the MPW. Additionally, all of the participants but one reported their ethnicity as white. In this way, the sample may not reflect the actual population of parental caregivers of children with disabilities in Kentucky. Further, cultural differences beyond geographic region were not explicitly explored in the current study.

Many of these same limitations related to a lack of sample representation have persisted in past studies of parental caregiving (Boss, 2002), and therefore, new and innovative recruitment methods for future research should be carefully brainstormed and examined to improve the potential for accessing hard-to-reach populations. In terms of the present study, improving recruitment methods may also reveal differences among various population groups in their perceived sources and strategies of uncertainty and in their experiences at the meso level when navigating the MPW.

Beyond the limitations identified thus far, which are related to the sample itself, some methodological limitations should also be acknowledged when considering the results of this study. First, my own involvement in the collection of data as the researcher likely shaped participants' responses to some degree. According to Hammersley and Gomm (2008),

what people say in an interview will indeed be shaped, to some degree, by the

questions they are asked; the conventions about what can be spoken about . . . by

what they think the interviewer wants; by what they believe he/she would approve

or disapprove of. (p. 100)

In future studies, the use of interviews could be combined with additional data collection

methods, such as observations of interactions at the meso level, to improve confidence in

the validity of the findings.

Second, although all participants were parental caregivers of children currently

receiving MPW services, some of the interview questions required participants to think

about experiences that occurred several years prior to the interview (e.g., "Can you tell

me about the first time you heard about the MPW?"). Although some parental caregivers

were among the first to access the waiver more than 10 years ago, others were newly

approved, and this difference in timing likely affected the narratives they offered. Recall

bias is a factor to consider when interpreting participants' stories. However, using a

narrative lens does mitigate some (but not all) of the risks associated with recall bias due

to the importance placed on participants' subjectivity versus objectivity in storytelling

(Riessman, 2008). The lifespan communication approach could be a useful theory for

framing future research in this area. The theory assumes that as individuals

chronologically progress through life, their communication experiences evolve and

change (Harwood, 2007; Nussbaum, Pecchioni, Baringer, & Kindrat, 2002), and thus the

theory can provide a useful lens through which to reduce recall bias. For example,

researchers could refine the recruitment of participants and more strategically focus on

the specific uncertainty experiences and communication infrastructures of parents who

are perhaps raising children of different ages or who are themselves at different stages as caregivers in the MPW trajectory. As evidenced in the current study, parents of school-aged children experienced a great deal of uncertainty in negotiating their children's access to behavioral therapy, whereas parents of toddlers receiving the MPW may not have encountered these same meso-level constraints. Furthermore, Brashers (2001) noted that uncertainty is temporal, meaning that sources, appraisals, and management of uncertainty can change over time, but I did not have the chance to explore the temporal dimension of uncertainty in this study. Additional research is needed to further parse out these differences, which can then inform interventions for parental caregivers at different stages of utilization of the waiver.

The present study is the first to integrate UMT and CIT to examine the challenges of waiver-based care from a communication perspective, and this theoretical integration raises a number of opportunities for future research, both in terms of developing theories that can account for the inherent fragmentation parents face when making health-care decisions through the MPW and in addressing the potential for competing uncertainties at various levels of the communication ecology. The fragmented delivery of health care services provided through the MPW to children with disabilities challenges parental caregivers' ability to coordinate communication among all members of their care teams (i.e., patients, caregivers, medical providers, and community providers). Given that sound decision making in a health care context requires effective communication among members of the entire care team (Sparks & Villagran, 2010), it is plausible that compromises in the care of the child occur because of this fragmentation and the systematic overreliance on the caregiver to translate among all members of the care team.

This translational burden on parental caregivers contributes to their level of uncertainty (as demonstrated in the current findings), which is consistent with research exploring "illness-related work" proposed by Corbin and Strauss (1985). Accounting for all of the variables that might have influenced caregivers' translational burden (e.g., cognitive capacity, language, culture) was beyond the scope of this dissertation, but investigating the specific translational "work" and the variables that constrain or enable such work when navigating the MPW is a potentially fruitful direction for future studies in health communication.

Furthermore, there has been little conceptual development with respect to alternative forms or definitions of the multidisciplinary care team beyond a clinical context. The findings of this study show that making decisions within the regulations of the MPW requires an expanded definition of the healthcare team for children with disabilities. For instance, past research exploring parental decision making in multidisciplinary care settings typically identifies the care team as the parent, the child, the doctors, and (in some cases) the nursing staff (Kerr & Haas, 2014). However, parental caregivers who coordinate the complex treatment and needs of children receiving care through the MPW must also manage the input of their case managers and their child's school system in accommodating therapeutic care—while also locating (and sometimes training) their own in-home and community living providers (Medicaid.gov, 2018). Studies have shown that as more professionals are added to the decision-making process, it becomes increasingly difficult for parent caregivers to manage their children's care and make satisfying decisions (Kerr & Haas, 2014). The fact that a care team for children with disabilities reaches beyond the family and the clinical context is not accounted for in

the existing communication literature. The current findings show that future research is needed to expand existing models and decision making to account for the influences of potential team members across the caregivers' communication ecology (i.e., micro, meso, macro).

Finally, future studies should consider the impact of uncertainty experienced at multiple levels of the system at once (e.g., MPW stigma) and how the manipulation or response to one ecological level of uncertainty might impact the uncertainty experienced and the management strategies used at other levels. For instance, how might addressing meso-level social uncertainty regarding Medicaid bias in the community through self- and social advocacy affect social uncertainty at the micro or macro levels? Both Brashers (2001) and Ball-Rokeach et al. (2001) argued for the continued exploration of the interconnectedness of levels (i.e., micro, meso, macro) of individuals' communication environments. Brashers (2001) noted, "because uncertainty is multilayered, interconnected, and temporal, the appropriateness and effectiveness of responses used to manage it are likely to vary across contexts and situations" (p. 481). Given the potential for competing uncertainty at each level of the ecology, future research related to waiver-based care should explore how parental caregivers prioritize their management and attainment of their interconnected health goals.

Conclusion

To conclude, by recognizing the community-level impact of communication on the everyday lives and decisions of parental caregivers, community partners can begin to address the barriers to uncertainty management created by ambiguous processes and non-existent points of access to information. The present findings have important implications

for improving health in the context of caregiving and waiver-based care, which is a primary means of access to health care for thousands of people with disabilities in the United States. More specifically, studies such as the current one can inform policymakers at the state and community level about the impact of waiver programs (e.g., the MPW) for children with disabilities, and the support needs of the parental caregivers who provide and coordinate their services. It is important for community partners such as health professionals, case management agencies, disability networks, schools, and local Medicaid offices to understand the complexities surrounding the navigational experience of the MPW and the burden placed on parental caregivers that may contribute to poor uncertainty management, delayed decision making, and treatment nonadherence. Such understanding positions researchers and practitioners to eliminate health disparities for this population.

APPENDICES

APPENDIX A: Consent Letter

To Whom it May Concern,

Researchers at the University of Kentucky are inviting you to take part in a phone interview and brief questionnaire about your experience as a caregiver for a child with an intellectual or developmental disability who is currently receiving a Michelle P. waiver.

Although you may not get personal benefit from taking part in this research study, your responses may help us understand more about how caregivers navigate waiver requirements. Some volunteers experience satisfaction from knowing they have contributed to research that may possibly benefit others in the future.

You will be paid by in the form of a $20 Visa gift card for taking part in this study. If you do not want to participate in the interview, there are other no other choices for participation at this time.

The questionnaire and interview will take about 45 minutes to complete.

Although we have tried to minimize this, some questions may make you upset or feel uncomfortable and you may choose not to answer them. If some questions do upset you, we can tell you about some people who may be able to help you with these feelings.

Your response to the survey will be kept confidential to the extent allowed by law. When we write about the study you will not be identified.

Identifiable information such as your name, clinical record number, or date of birth may be removed from the information collected in this study. After removal, the information may be used for future research or shared with other researchers without your additional informed consent.

We hope to receive completed questionnaires and interviews from about 40 people, so your answers are important to us. Of course, you have a choice about whether or not to complete the interview/questionnaire, but if you do participate, you are free to skip any questions or discontinue at any time.

If you have questions about the study, please feel free to ask; my contact information is given below. If you have complaints, suggestions, or questions about your rights as a research volunteer, contact the staff in the University of Kentucky Office of Research Integrity at 859-257-9428 or toll-free at 1-866-400-9428.

Thank you in advance for your assistance with this important project.

Sincerely,

Whittney H. Darnell
Department of Communication and Information Studies, University of Kentucky
PHONE: 859-620-0175
E-MAIL: whemmi0@g.uky.edu

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APPENDIX B: Demographic Questionnaire

Before we begin the interview, I would like to find out more about you and the person for whom you provide care.

Part I.

Please answer the following questions about <u>yourself.</u>

1. What is your age?

    _____

2. Where do you live (city/state)?

    _____

3. What is your sex?

    ❑Male
    ❑Female
    ❑Prefer not to answer

4. What is your racial/ethnic background? (Select all that apply)

    ❑American Indian/Alaskan Native
    ❑Asian
    ❑Black/African American
    ❑Native Hawaiian/Pacific Islander
    ❑White/Caucasian
    ❑Hispanic/Latino
    ❑Other, please specify _____
    ❑Prefer not to answer

5. What is your relationship status? (Select one)

    ❑Single, never married
    ❑Serious relationship
    ❑Married
    ❑Separated
    ❑Divorced
    ❑Widowed/Widower

6. What is the highest level of education you have completed? (Select one)

❑Some high school
❑High school degree/GED
❑Some college
❑Two-year degree (Associate Degree)
❑Four-year degree (Bachelor's Degree)
❑Master's degree
❑Doctoral degree
❑Professional degree (MD, JD)

7. What is your employment status? (Select all that apply)

❑Full-time
❑Part-time
❑Full time at-home caregiver
❑Seeking employment
❑Student full-time
❑Student part-time

8. What is your average yearly household income? (Select one)

❑Under $20,000
❑$20,000–$39,999
❑$40,000–$59,999
❑$60,000–$79,999
❑$80,000–$99,999
❑$100,000 or more
❑Prefer not to answer

9. What is your relationship to the person for whom you are caregiving?

❑Mother
❑Father
❑Grandparent
❑Family friend
❑Sibling
❑Other, please specify
_____

10. How many years have you been caregiving for this person?
_____

Part II.

Next, I would like to ask a few questions about <u>the person for whom you provide care.</u>

1. What is his/her current age?

   _____

2. How long has he/she had access to the MPW?

   _____

3. What is his/her primary diagnosis?

   _____

4. Does the patient have any secondary

   diagnoses?_____

5. What is his/her sex?

   ❑Male
   ❑Female
   ❑Prefer not to answer

6. What is his/her racial/ethnic background? (select all that apply)

   ❑American Indian/Alaskan Native
   ❑Asian
   ❑Black/African American
   ❑Native Hawaiian/Pacific Islander
   ❑White/Caucasian
   ❑Hispanic/Latino
   ❑Other, please specify _____
   ❑Prefer not to answer

APPENDIX C: Interview Protocol

Origin of the Story: Accessing the Waiver

1. Please begin by telling me the story of how you first found out about the ID/DD diagnosis of your child.
2. Can you tell me the story of how you first heard about the MPW? (Probe: What do you remember feeling about the MPW when you first heard about it? How did you manage those thoughts and feelings at the time?)
3. When you think about how you felt about applying for Medicaid initially, was Medicaid something that you associated with being a good thing or a bad thing? (Probe: Where do you think those feelings came from? If negative, how did you reconcile those feelings?)
4. Some caregivers have discussed a secret code or language that they felt was essential when applying for the MPW. Is this something that you felt you had to learn? (Probe: Can you tell me about how you were able to obtain that knowledge? How did you feel about using this language to describe your child?)

Meso-Level Storytelling Network as a Source of Uncertainty

1. Can you tell me about a time when you reached out to another family with a disability to learn about the MPW? (Probe: Can you tell me if that interaction was helpful/unhelpful and what steps, if any, it led you to take?)
2. Can you tell me about an interaction that you have had, if any, with a local non-profit network related to disabilities and disability services in your community? (Probe: If at all, how did this experience help you find information or support related to the MPW?)
3. Can you think of a time when you heard about the MPW or waiver services in general discussed on the local news, Facebook, a newsletter, a flyer in the library, or some other public venue? (Probe: If yes, did you consider this information good, bad, or accurate/inaccurate? Tell me about the usefulness of that experience.)
5. Overall, how easy or hard has it been to negotiate waiver services in your community (e.g., behavioral therapy, finding at-home providers)? (Probe: Can you think of a service or a treatment that was especially hard to access? How did you resolve this issue?)
6. Are there situations, instances, or people that you avoid discussing the MPW with in the community, and what motivates that decision? For example, some caregivers have discussed their choice to keep their children's status on the waiver private because of the unclear or the unpredictable responses they have experienced (e.g., stereotypes about Medicaid) from people in the community.

Making Treatment Decisions/Future Planning

1. Can you tell me about your choice to use a traditional agency plan or consumer-directed care option? (Probe: Whom did you consult when making this decision? If consumer directed, how do you go about finding qualified people to work with

your child? Is this easy or hard to do? How do you overcome the challenges in finding quality care providers?)

2. Can you tell me about one specific treatment or service decision provided through the waiver that was hard to make? For example, maybe services were not available in your area. (Probe: What community-level resources were either available or unavailable that made this decision more or less difficult?)
3. Sometimes caregivers report that they have doubts about their own ability to perform certain aspects of caregiving (e.g., therapies). Can you remember feeling this way at any time? How did you manage this worry?
4. Can you recall an example of a time when something went wrong with your MPW? (What were your feelings about this mistake? How did you reconcile this issue?)
5. A major concern for many MPW family caregivers is the future care of their children. Can you tell me about the support that you have received from your case manager or other organizations, maybe a disability network in your community, in regard to planning for the future care of your child (e.g., emergency, financial, housing)?
6. In what ways has your caregiver role, especially those functions related to the MPW, either challenged or improved your own overall health? (Probe: What decisions have you made about your own health since becoming a caregiver through the MPW?)

Connection, Belongingness, and Engagement in the Community

1. Can you tell me a story or provide an example of how access to health care through the MPW has improved your ability to do things in your community with your child (children)? (Probe: Can you tell me about a meaningful relationship you have built with a community organization or member related to your child's use of the MPW?)
2. Similarly, can you tell me a story of how your access to health care through the MPW has been limited or constrained because of a community barrier to care? (Probe: How have you managed this issue or adjusted your child's treatment based on the availability of resources in your community?)
3. In what ways have you been able to share your story, concerns, and thoughts about the MPW in your community? (Probe: If yes, with whom do you share your story? How does this make you feel? How has sharing your story in the community influenced your MPW experience?)
4. What political conversations surrounding Medicaid for persons with disabilities do you hear in your community? (Probe: Where do you hear about these stories? Do you worry or feel hopeful about the future of the MPW? How do you cope with this worry?)

APPENDIX D: Member Checking

1. Please review the summary of results provided. In thinking about the "sources" of uncertainty that I have described in **Table 1**, what sources of uncertainty are most and least important from your experience? Do you disagree with any of the sources that I have listed in this analysis? Please add your comments below.

2. Next, please review the findings reported in **Table 2**. In studies of uncertainty, researchers are interested in how individuals feel about the uncertainty they experience, and then subsequently, how they manage those feelings. I have described my interpretation of the strategies that parental caregivers used to manage their various sources of uncertainty related the Michelle P. waiver. What rings true or untrue for you in considering these findings?

3. In thinking about the findings related to decision making as reported in **Table 2**, are there other decisions that I have not touched on in the summary of results that cause you to feel uncertain and that should be included in the findings?

4. Finally, in the analysis of the data, findings showed that the lack of a systematic entry point into the MPW, low quality case management, and social control processes that discourage waiver access compromised their ability to seek information about the MPW effectively and further exacerbated their experience of uncertainty. In addition, I also sensed that as parental caregivers were able to find other families using the waiver or had established a meaningful connection with a disability network or online community, they were then able to navigate the Michelle P. waiver more effectively. Please share with me your level of agreement or insight into these findings. These results are outlined in **Table 3.**

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VITA

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ACADEMIC APPOINTMENTS

2018-present	Lecturer, College of Communication and Informatics, Northern Kentucky University
2015-2018	Instructor, College of Communication, University of Kentucky
2009-2018	Adjunct Instructor, College of Communication and Informatics, Northern Kentucky University
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2009-2015	Adjunct Instructor, College of Communication, Gateway Community College
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AWARDS & HONORS

2018	Human Development Institute Research Grant Recipient
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2016	Top Graduate Student Paper, Kentucky Communication Association
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PROFESSIONAL PUBLICATIONS & RESEARCH

Van Scoy, L., **Darnell, W. H.,** Chinchilli, V., Wasserman, W., Thompson, B., Hopkins, M., Wolpaw, D., Scott, A. M., Volpe, R. (2018). Adapting a small group communication quality assessment to new contexts. *International Research in Higher Education, 3*(2), 61-75.

Darnell, W. H., Buckley, A. N., & Scott, A. M. (In Press). "It's not something you expect a 15-year-old to be sad about": Sources of uncertainty and strategies of uncertainty management among adolescent women who have experienced miscarriage. *Health Communication*.

Adams, E. T., Cohen, E. L., Bernard, A., **Darnell, W.H**. & Helme, D. (In Press). Can opioid gatekeepers demonstrate patient-centered care?: A concept viability assessment in surgery and trauma care. *Health Qualitative Research*.

Darnell, W. H., Real, K. & Bernard, A. (Revise and resubmit). Family refusal: A normative approach to understating third party organ donation conversations during imminent death. *Qualitative Health Research.*

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