2022

Caregiver Perceptions of the Helping Families in Mental Health Crisis Act

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Abstract

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by

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MPA, Pace University, 2011

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Policy and Administration

Walden University

August 2022

Abstract

Caregivers often experience increased stress when raising children who have a mental illness. Awareness of the various challenges caregivers face enables the offering of improved support. The Helping Families in Mental Health Crisis Act of 2016 (HR2646) improves and raises the profile of mental health within the government chart. This qualitative phenomenological study was guided by questions aimed at identifying caregiver perceptions of The Act and understanding caregiver input and opinions on the impact of this policy. Howlett's five stream framework of the policy process and Kingdon's multiple streams model provide the theoretical framework for this study. Individual telephonic interviews were conducted with ten caregivers. The collected data were analyzed through coding and the development of themes to determine the findings of this study. The findings determined that emerging themes such as a lack of funding can be erased through this current policy and areas of lack met. The findings of this study provide awareness for policymakers and help inform more effective public policy by identifying opportunities for improvement based on caregiver lived experiences. This study positively impacts social change by providing insight into areas of potential improvement for public policy regarding children's mental health services.

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Dedication

This dissertation is dedicated to my father, the late Ambassador Lazarus Chigewe, and my mother, Mrs. Chinyere Chigewe. Dad, thank you for all the values you instilled in me over the years and for all the sacrifices you made for my siblings and I. Thank you, Dad, for teaching me the value of education, always providing, and always being present. Even though losing you years ago was challenging, over the years, I have felt that you have always been by my side, guiding me along the way. My desire, dad, was always to make you proud, and I will continue to strive to make you proud. To my mother, Chinyere Chigewe, words can never express the gratitude and thankfulness in my heart towards God for blessing me with a mother like you. Thank you for always encouraging me during this journey and for all the words of motivation that kept me sane. Thank you, mom, for always being present, always being a shoulder to lean on, and always encouraging me along the way. Mom, you have been an outstanding example of what it means to persevere through trials and tribulations to fulfill your dreams. As an immigrant, I watched you arrive in America and start from scratch. I am in awe and inspired by how far you have come. I desire one day to be half the woman you are. I love you, mom and dad.

Most importantly, I dedicate this dissertation to God. I want to thank God for giving me the wisdom and strength to persevere. My prayer is that God will continue to use me to be a positive change agent.

Acknowledgments

Thank you for your insight and guidance through my dissertation process to my committee members, Dr. Melanie Smith and Dr. Deborah Laufersweiler-Dwyer. To my Chair Dr. Melanie Smith, words can never express how grateful I am for you. Thank you for investing in me through this journey. Thank you for teaching me the meaning of self-discipline, accountability, and perseverance. Through your guidance and mentorship, I have accomplished this goal. To Dr. Deborah Laufersweiler- Dwyer, thank you for all your patience and support during this journey and for serving as my committee member. The insight and feedback you provided during this process helped propel me to reach this goal. With humbleness and humility, I admit I would not have come this far without the both of you, so I thank you.

My heart is filled with extreme gratitude to my academic advisor Catherine Heck that we crossed paths and you were assigned, my academic advisor. I will never forget that moment during this journey when I broke down, and you reassured me that I would survive and make it through. I held unto that moment in time, and I always remembered all the words of encouragement you provided to me along the way. I genuinely believe that I would not have made it this far without you. I am forever grateful for your patience, kindness, and being a source of strength that I could continuously tap into through this process.

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Chapter 1: Introduction to the Study

Introduction

Mental illness is a high disease burden across the globe and is primarily developmental with its genesis in childhood experiences. (Roser & Ritchie, 2016). Mental illness refers collectively to all mental disorders-health conditions involving significant changes in thinking, emotion, or behavior (Parekh, 2018). Distress or inability to function is also associated with mental illness (Parekh, 2018). Relatedly, mental disorders are comprised of a broad range of problems, with different symptoms generally characterized by some combination of abnormal thoughts, emotions, behavior, and relationships with others (World Health Organization [WHO], 2018). According to World Health Organization (2018), these issues account for more disabilities in developed countries than any other disorders, including cancer and heart disease. Impacts of childhood-onset mental health disorders are substantial public health concerns because of their prevalence, early onset impact, and associated costs to the child, family, and community (Younger, 2017).

Up to 20% of children and adolescents globally have a debilitating mental illness (Akol, 2018). Early detection and management of child and adolescence mental health disorders reduces the likelihood of long-term ill health and minimizes stress on individuals, families, communities, and health systems (Akol, 2018). It is essential to prioritize mental health, and there must be a moral obligation to address the issues that contribute to mental illness. Parents and guardians play a vital role in the development of children. Children depend on their parents and guardian to provide basic needs and support, such as food, education, shelter, and protection- especially during challenging times. By focusing on the challenges that caregivers face, we will better understand, detect, manage, and reduce any long-term effects of childhood mental illness.

Background

Healthcare, family, and community attributes are associated with increased risk for mental and developmental disorders (Robinson et al., 2017). There is an estimated prevalence rate of 14.4% amongst children and adolescents with mental health disorders, with half of all lifetime mental health disorders emerging before the age of 14 years (Merikangas et al., 2010). The negative impact of poor mental health early in life extends into adulthood; they are predicting poor academic outcomes, increasing the risk of subsequent mental health problems and high rates of mental health service use, reducing life satisfaction, and creating a substantial economic burden for society (Colizzi et al., 2020). In recent decades there has been a rapid growth in the development of evidence-based treatments for mental health disorders in childhood and adolescence, and the lasting benefits of intervening early are established (Creswell, 2017). However, reduced rates of treatment access have been reported, and national surveys in the United States have estimated that only 25%-56% of children and adolescents with mental health disorders access specialists with mental health services (Holbrook, 2016). As background, the HR2646 act was introduced by Tim Murphy (R.PA) and Rep. Eddie Bernice Johnson (D. TX) and focused on provisions related to severe mental illness. This act is meant to raise the profile of mental health in the government chart and ensures that the lead policy official for mental health policy is knowledgeable about mental illness.

The HR2646 act is focused on improving metrics such as suicide attempts, emergency psychiatric hospitalizations, emergency room boarding, arrests, incarcerations, victimization, and homelessness. The bill dramatically tightens the definition of evidence to be used in determining the efficacy of programs. This bill revised the previous block grant requirement, which stated that states must maintain spending on community mental health services. Instead, now under this act, states must use at least a specified amount of block grant to support evidence-based programs for individuals with early serious mental illness.

Problem Statement

Childhood mental illness is an important public health issue in the United States (Centers for Disease Control and Prevention [CDC], 2021). Caregivers often experience an increased level of stress when raising children who suffer from various mental illnesses such as autism spectrum disorder (ASD), bipolar, and mood disorders. The purpose of this research study is to identify caregiver perceptions of the Helping Families in Mental Health Crisis Act of 2016 (HR2646). HR2646 was introduced by Tim Murphy (R.PA) and Rep. Eddie Bernice Johnson (D. TX) and focused on provisions related to severe mental illness. This act is meant to raise the profile of mental health in the government chart and ensures that the lead policy official for mental health policy is knowledgeable about mental illness. The HR2646 act is focused on improving metrics such as suicide attempts, emergency psychiatric hospitalizations, emergency room boarding, arrests, incarcerations, victimization, and homelessness. The bill dramatically tightens the definition of evidence to be used in determining the efficacy of programs.

This primary research question is addressed by examining four different areas of this policy: (a) availability of care plans and resources, (b) medical billing practices, (c) patient rights and protection, and (d) responsible governance of policy and resources. Caregivers have described the mere process of obtaining a mental illness diagnosis for their ill child as stressful and unsatisfactory (Jensen 2016).

Parents have indicated the difficulty associated with coping with children that are mentally ill, and the unpredictable behaviors that follow (Mazur, 2017). They report many headaches and frustrations during the diagnosis process and express their stress and depression of their child's degree of impairment (Stapley & Midgley, 2016). Childhood mental illness impacts the entire family, and researchers have consistently found that parenting children with mental disorders is psychologically distressing (Mazur, 2017). The increased rate of stress and depression in parents of children with a mental illness increases parenting demands, leading to the use of various coping strategies (Cauda-Laufer, 2017). A mental illness diagnosis not only affects the child but also has a profound effect on the caregiver. Parents and guardians are the primary caretakers in the family, and they play a critical role in the lives of children and adolescents. Awareness of the various challenges faced by caregivers in such situations enables improved support offered to such parents.

Stability is an essential factor in how a child responds to mental health services (WHO, 2019). The children must receive appropriate care when they attend appointments and visits to meet their mental health needs. This research has the potential to positively impact social change by providing insight into areas of potential improvement for public policy regarding children's mental health services.

The results of this research may help to improve public policy by identifying parent/caregiver opinions and issues with the current policy.

This research study focuses only on a single policy because the details in the selected policy, HR2646, cover various areas that enhance childhood mental health treatment and provision. Specifically, The Helping Families in Mental Health Crisis Act targets:

1. Improving metrics linked to emergency psychiatric hospitalizations and emergency room boarding. (AAP statement). Retrieved from *H.R.2646 - 114th Congress (2015-2016): Helping Families in Mental Health Crisis Act of 2016*. (2016, July 6). Congress.Gov | Library of Congress. https://www.congress.gov/bill/114th-congress/house-bill/2646
2. Tightening the definition of evidence to be used in determining the efficacy of programs. (AAP statement). Retrieved from *H.R.2646 - 114th Congress (2015-2016): Helping Families in Mental Health Crisis Act of 2016*. (2016, July 6). Congress.Gov | Library of Congress. https://www.congress.gov/bill/114th-congress/house-bill/2646
3. Increasing mental health block grants to address serious mental illness, and does not divert money away from families/children with mental illness. (AAP statement). Retrieved from *H.R.2646 - 114th Congress (2015-2016): Helping Families in Mental Health Crisis Act of 2016*. (2016, July 6). Congress.Gov |

Library of Congress. https://www.congress.gov/bill/114th-congress/house-bill/2646

4. Ensuring states are provided with block grants to include "a separate description of case management services and provide for other programs that lead to the reduction rates of emergency hospitalizations. (AAP statement). *H.R.2646 - 114th Congress (2015-2016): Helping Families in Mental Health Crisis Act of 2016*. (2016, July 6). Congress.Gov | Library of Congress. https://www.congress.gov/bill/114th-congress/house-bill/2646
5. Defining caregivers as an immediate family member and someone who assumes the primary responsibility of providing a basic need, making it clear that the providers may receive information form caregivers. (AAP statement). *H.R.2646 - 114th Congress (2015-2016): Helping Families in Mental Health Crisis Act of 2016*. (2016, July 6). Congress.Gov | Library of Congress. https://www.congress.gov/bill/114th-congress/house-bill/2646
6. Allowing states to obtain Medicaid reimbursement in facilities where the average full length of stay is less than 30 days. Most importantly, this policy eliminates discrimination against people with serious mental illness, including children, and also the barriers that prevent families and caregivers from gaining access to hospital care when needed. (AAP statement). Retrieved from *H.R.2646 - 114th Congress (2015-2016): Helping Families in Mental Health Crisis Act of 2016*. (2016, July 6). Congress.Gov | Library of Congress. https://www.congress.gov/bill/114th-congress/house-bill/2646

7. Protecting patients against abuse and neglect. The Helping Families in Mental Health Crisis Act requires those who get PAIMI contracts to agree to refrain from lobbying or retaining lobbyist to influence a Federal, State, or local government entity or officer, and counsel an individual with serious mental illness who lacks insight into their condition on refusing medical treatment or acting against the wishes of such individuals caregiver. (AAP statement). Retrieved from *H.R.2646 - 114th Congress (2015-2016): Helping Families in Mental Health Crisis Act of 2016*. (2016, July 6). Congress.Gov | Library of Congress. https://www.congress.gov/bill/114th-congress/house-bill/2646
8. Eliminating discrimination in Medicare against the mentally ill who need long term care. The Act requires Medicaid to allow two services within the same day(allows payment for two services received in a single day) (AAP statement). *H.R.2646 - 114th Congress (2015-2016): Helping Families in Mental Health Crisis Act of 2016*. (2016, July 6). Congress.Gov | Library of Congress. https://www.congress.gov/bill/114th-congress/house-bill/2646
9. Strengthening hospital discharge procedures by ensuring that the hospital's responsibility does not end in discharge and requires hospitals to prepare discharge plans to facilitate the connection with outpatient treatment for patients that are discharged. (AAP statement). *H.R.2646 - 114th Congress (2015-2016): Helping Families in Mental Health Crisis Act of 2016*. (2016, July 6). Congress.Gov | Library of Congress. https://www.congress.gov/bill/114th-congress/house-bill/2646

Such policies that promote care/treatment of a mental illness are essential to assist caregivers with the support needed. By focusing on the Helping Families in Mental Health Crisis Act, we can see the direct link between mental health and public policy. It is essential to frame relationships between open sound systems and the population to promote mental health in children and youth (National Mental Health Dementia and Neurology Intelligence Network, 2015). Public policies can promote mental health in children and youth by strengthening their families and supporting their capacities (Raphael, 2014). The focus of this research study will facilitate caregivers' identification of barriers/gaps in policy and government social services so that caregivers can become active agents of change in meeting their child's mental health needs.

Purpose Statement

The purpose of this proposed qualitative study is to identify caregiver perceptions of The Helping Families In Mental Health Crisis Act, explicitly their perceptions of policy impacts on: (a) availability of care plans and resources, (b) medical billing practices, (c) patient rights and protection, and (d) responsible governance of policy and resources.

Various implications of this single policy will be explored, and the focus of this study is on the caregiver input in understanding caregiver opinion of the impact of this policy. The effect of the policy is the focus of this study. I will report the results of the data collected, discuss those results within the context of current relevant research, and provide recommendations for future research.

Research Questions

The main research question this study addressed was: What are the caregiver perceptions of the Helping Families In Mental Health Crisis Act (HR2646)? This was done by examining four different areas of this policy: (a) availability of care plans and resources, (b) medical billing practices, (c) patient rights and protection, and (d) responsible governance of policy and resources.

Conceptual Framework

The conceptual framework for this study focused on only one main theory, known as the five-stream framework of the policy process by Howlett et al. (2016). While focusing on Howlett's work I will be using Kingdon's multiple streams model (1984), as part of the development of the theory. Howlett will be the only theory used to provide the framework for this study. It is useful to connect the five-stream framework of the policy process by Howlett et al. with the Kingdon's multiple framework. This can be done by extending Kingdon's streams approach to other stages of policymaking, such as formulation, decision making, implementation, and evaluation (Howlett et al., .2016). Uniting Howlett and Kingdon easily answers the research questions posed in this study, and by combining the strengths of each, we can better describe, understand, and explain policy making.

Howlett argued that to accomplish a reconciliation of the conceptual pillars of the multiple-stage and cycle models, a five stream framework which retains the conceptual architecture and analytical vocabulary developed by Kingdon offers a more comprehensive and capable framework for capturing the full range of policymaking dynamics (Howlett et al. 2016). According to Howlett, it is essential to think about policymaking as a sequence of phases. In the five streams model, each confluence point brings about new actors, new tactics, and new resources, that ultimately join the flow of policymaking events. The first confluence point occurs in agenda setting like Kingdon suggested, when the problem, politics, and policy streams coalesce in a temporary policy window. New policy streams are created that become the main or central pathway upon which other streams subsequently converge (Howlett et al. 2016). Critical junctures have made the future impetus for the policy process, essentially becoming the “choice stream.” After this crucial agenda-setting process has occurred, in many specific sets of the subsystem, actors such as policy analysts and stakeholders organized in advocacy coalition contribute to deliberations and propose policy alternatives (Howlett et al. 2016). The five streams framework explains how and why new actors, ideas, and interests merge into an existing policy flow and explain the various patterns of policymaking that result from a presence or absence of relevant inputs at different critical junctures. The use of a combination of stages, streams, and coalitions provides a more integrated and holistic understanding of policy. Due to its diversity and flexibility, there is room for increased creativity, inventiveness, and focus on policymaking.

A child or adolescents' life can present different issues that create vulnerabilities requiring interventions and policies. (Hagen, 2017). The social determinants of children's mental health correspond to the many factors and living conditions that affect children's lives, particularly their socioemotional, cognitive, and physical development (Moore, 2015). Safe, supportive, tolerant, inclusive, and stimulating environments have a strong positive influence on children's mental health (Moore, 2015). All health policies should address issues that concern children's lives and encourage them to adopt healthy behaviors (Center on the Developing Child at Harvard University, 2015). The implementation of policies can improve living conditions in families and communities; specifically, policies can facilitate the quality of an opportunity for social interactions, enhance the possibilities for social participation, and strengthen individual capabilities (Poissant, 2014). The conceptual framework provides the insight to formulate policies that assist caregivers; we must acknowledge the vital role that policymakers play in developing and implementing policies.

The Kingdon’s multiple streams model is a framework for understanding how issues find their way onto the political agenda, and to determine if a window of opportunity exists for the policy idea (Atupem, 2017). Meier and Atupen provided definitions and interpretations of this framework. Kingdon's multiple streams model is based on policy change coming about when three streams connect: (problems, politics, and policies) (Meier, 1991). Each of the streams in Kingdon's model focuses on the importance of timing and flow of policy actions (Meier, 1991). Each of the streams in Kingdon's model runs independently of the others (Atupem, 2017). Kingdon asserted that the three streams must come together to form a window of opportunity before the policy can have a chance for action (Atupen, 2017). In this study, the policies emerge from perceived problems followed by acknowledging the role policymakers and other stakeholders have in proposing policies and acting on policy options (Meier, 1991).

Obtaining data from the caregivers of their perceptions of this current standing policy (HR2646) can birth the development of more systems (policy stream) that will provide an available solution to any problem related to the standing policy. In acknowledging the role of the policymaker, this potential solution will then go through the political stream, which is the motivation and opportunity to turn any proposed change into policy. As the diagram in figure one states, there is a policy window, which leads to policy adoption/output. In the Kingdon's multiple streams model, the problem stream is filled with perceptions of problems seen as "public," in a sense that government action is needed to resolve it (Beland, 2016). The policy stream is filled with the output of experts and analysts who examine problems and propose solutions. The political stream comprises factors that influence the body politic such as sings in national mood or legislative turnover. (Beland, 2016). In the Kingdon's model, all three streams flow along different channels and remain independent until a specific policy window opens.

When the separate streams of problems, policies, and politics come together at critical times, solutions become joined to problems, and both are joined to favorable political forces (Beland, 2016). Only then that an issue which, through the research question for this study, can be identified by the caregiver, becomes recognized, and the public policy process starts addressing it. So, from identifying caregiver perceptions of the Helping Families In Mental Health Crisis Act, it creates the engine and the movement towards potentially increasing identifying and addressing any public policy issues related to this particular current policy.

Nature of the Study

The qualitative approach explored the caregiver perceptions of The Helping Families In Mental Health Crisis Act. In qualitative methods, the researcher is the instrument (Tracy, 2019). In qualitative research, the description of the research methods often includes the journey of access and flows into the stories, observations, and interactions collected (Tracy, 2019). Qualitative data can be systematically gathered, organized, interpreted, analyzed, and communicated to address pressing concerns and prompt change (Tracey, 2019). The qualitative method is best suited for the goal of my research project, in that this research provides a means to assess the lived experiences of caregivers involved in this study (Hamilton, 2016). Due to the current ongoing pandemic, phone interviews and online surveys were the safest and most effective way of gathering data towards understanding the daily life and affairs of care policy, and the caregiver perception of The Helping Families In Mental Health Crisis Act. Participants were able to choose to participate either via telephonic interviews or Survey Monkey online survey. The goal of the surveys was to obtain a detailed description of the lived experiences of caregivers of mentally ill children who reside in the Bronx, NY.

Definitions

Childhood mental illness: A disease or a condition that influences how a child thinks, feels, behaves, or relates to others or their surroundings. A combination of genetic, biological, psychological, and environmental factors can trigger mental illness. Illnesses that manifest in early childhood include depression and intellectual disabilities and numerous behavioral diagnoses such as anxiety, bipolar, impulse control, and obsessive-compulsive spectrum disorders (McLaughlin, 2011).

Caregiver/stress: A situation that the individual appraises as personally significant and demands that exceed the person's resources to cope (Folkman, 2012). This study will reflect directly on the stress experienced by caregivers.

Emotional or / physical fatigue: Weariness, emotional or physical, that caregivers experience due to the stress and burden of caring for a child with mental illness.

Caregiver depression: The effect of stress and emotional fatigue on the caregiver. This study will specifically focus on caregiver depression. Parental depression is associated with poor health and developmental outcomes for children of all ages (Child Trends Databank, 2015). Depressed mothers are more likely than nondepressed mothers to have poor parenting skills and negative interactions with their children (Child Trends Databank, 2015). These are the essential fundamental concepts and terms within this research study that aims to identify the various challenges experienced by these caregivers and better understand how current policies' provision of resources impact caregivers' coping mechanisms and approach to seeking care for their children with mental illness.

Assumptions

An assumption is defined as a statement that is presumed to be accurate, often only temporarily, or for a specific purpose, such as building theory, and are the conditions under which statistical techniques yield valid results (Wargo, 2015).

Concerning qualitative research, some common assumptions are that participants will truthfully answer the interview questions, the inclusion criteria sample is appropriate. It assures that the participants have all experienced the same or similar phenomenon of the study. Also, concerning qualitative research, an assumption is that participants have a genuine interest in participating in the research study, and there are no other ulterior motives that exit.

This study was based on two different assumptions. The first assumption was that survey respondents would provide truthful feedback. A lack of honestly in participant response can result in an inaccurate date. I ensured that the data was accurate by using purposive sampling. The process of gathering data is crucial in research, being that the data is meant to contribute towards a better understanding of the theoretical framework (Tongco, 2006). Selecting the participants from whom the data will be acquired was done with sound judgment because no amount of analysis can make up for improperly collected data (Etikan, 2016). The purposive sampling technique, also known as judgment sampling, is defined as the deliberate selection of a participant due to the qualities the participant possesses (Etikan, 2016). Purposive sampling involves the identification and selection of individuals or groups of individuals that are proficient, well informed about a phenomenon of interest, knowledgeable, experienced, and have the willingness to participate in the study (Etikan, 2016). Purposive sampling allowed me to concentrate and focus on participants with characteristics that will be better able to assist with the relevant research.

Participants were provided the opportunity to identify any lack of correlation and needed corrections in the transcribed interview data. The second assumption is that the inclusion criteria of the sample are appropriate and therefore assures that the participants have all experienced the same or similar phenomenon of the study. I used the transcripts of the conducted individual interviews to ensure that there is data saturation. To ensure that all participants have experienced the same phenomenon of the study, I provided data saturation. Data saturation is reached when there is enough information to replicate the study (O'Reily & Parker, 2012; Walker, 2012), when the ability to obtain additional new information has been attained (Guest et al., 2006), and when further coding is no longer feasible (Guest et al., 2006). I achieved saturation by having at least a minimum of 10 participants in this qualitative study, and also by gaining an understanding of the phenomenon.

Scope and Delimitations

The purpose of this study will be to identify caregiver perceptions of The Helping Families In Mental Health Crisis Act (H.R 2646) enacted in the year 2016 in Washington, D.C. This study seeks to reveal caregiver's perceptions of this current policy. The results of the study may enable future policies to be developed and implemented to assist caregivers with children who have a mental illness. Also, the results of this study may bring about the implementation of policies that can improve living conditions in families and communities, particularly in the neighborhood of Bronx, NY. When conducting this study, I conducted individual interviews with 10 participants. I used purposive sampling to identify participants who: (a) live in the Bronx, NY, (b) are caregivers of a child that is receiving mental health services and, (c) were interested in sharing their experience. The city of the Bronx is the location chosen because the agency I will be using to recruit participants is located in this town. The transferability of the results of this study can inform future research in this field. The knowledge gained from this study can contribute to the development of additional public policies on a local and federal government level that will improve and increase the resources available to these children and their families.

Limitations

Limitations are aspects of a study beyond a researcher's control (Marshall & Rossman, 2015). The methodology of this study afforded three limitations.

Limitations of the study are the characteristics of design or methodology that impacted or influenced the interpretation of the research (Price et al., 2004). Limitations are the constraints on generalizability and the result of unanticipated challenges that emerged during the study (Price et al., 2004). There are a few limitations afforded in this study.

The first limitation was that I was the single and the only researcher conducting the study. The data were gathered and interpreted through my singular perspective. Also, a second limitation was that in addition to being the only individual conducting the study, I was also the sole analyst, which can create researcher bias. To avoid this bias, reasonable measures were taken to address the study imitations. Notably, interviews were not restricted to specific questions; instead, I examined and guided the research.

Moreover, I addressed these limitations to maintain research quality by developing my research skills to reduce personal bias. The first step towards addressing such barriers was to acknowledge the possible biases that might occur during this research study and prevent them from occurring. Given the volume of information shared by participants during data collection, it was essential to synthesize or simplify after the phone interview instead of during, to limit distractions. I remained aware of high-level points/ direction/ categories the participant was discussing and used it as a guide for more in-depth explanation/data collection.

Due to the current COVID-19 pandemic, all data collection and interviews were conducted remotely over the phone or online surveys. During the phone interviews, I recorded and used notetaking strategies to collect the information for ease of reference. The data was recorded and stored in addition to notetaking for ease of reference later. More importantly, I allowed respondents to review my transcribed data, from their specific interview, to address any inconsistencies/miscommunications they might see in my transcriptions.

I focused on avoiding confirmation bias, which occurs when the researcher forms a hypothesis or belief and selectively uses the respondent's information to confirm that belief (Sarniak, 2015). To avoid confirmation bias, my goal as the researcher was to mentally put aside my hypothesis and approach the methodological process of data collection objectively without judging whether responses confirm my theory. I also avoided question order bias, which is when one question tends to influence answers of the following items (Sarniak, 2015) by asking broad questions before narrowing in on specific issues. Therefore, I asked unaided questions before aided ones and actual questions before negative ones. Overall, during the data collection process, asking quality questions at the right time and remaining focused on the sources of bias gave room for honest responses and ensured I followed high qualitative standards.

Significance

The focus of the study is centered on the caregiver perceptions on the impact of the current policy, The Helping Families In Mental Health Crisis Act. The significance of the course is focused on obtaining the thoughts of this policy from the caregiver's perspective. It is currently unknown the policies or solutions that will result from this study because I do not have any results. Despite this, ultimately, it is hoped that the results of the research will inform policymakers on policy success and opportunities for improvement regarding services and care for children with mental illness, and specifically the children with ADHD.

Summary

The purpose of this study is to examine caregivers' perceptions, either positive or negative, of policy impacts form the Helping Families In Mental Health Cries Act of 2016. Overall the study will explore how this policy is geared towards addressing some of the deficiencies related to the care and medical accessibility for children with mental illness. In this chapter, I outlined my qualitative research study. This chapter covered the research questions that will guide the study, the conceptual framework, and the nature of the study. Key concepts were also defined, including emotional stresses, physical fatigue, and mental health. Further, I outlined assumptions, scope and delimitations, limitations, and the significance of this study, including potential impact and social implication.

Chapter two will provide an overview of the current literature related to establishing the relevance of the research question for this study.

Chapter 2: Literature Review

Introduction

The purpose of this qualitative study was to identify caregiver perceptions of HR2646, based on a phenomenological design study that will gain clear insight into the caregiver perception of policy impacts on: (a) availability of care plans, (b) medical billing practices, (c) patient rights and protection, and (d) responsible governance of policy and resources. A case study of individual interviews conducted with participants who: (a) live in the Bronx, NY, (b) are caregivers of a child who is receiving mental health services and, (c) are interested in sharing their experience. The agency used to recruit participants for this study is located in the Bronx, NY. Childhood mental illness has proven to be the single most important public health challenge in the United States (Bessel, 2017). Furthermore, caregivers often experience an increased level of stress when raising children who suffer from various mental illnesses.

CDC (2017) reported that several disparities in overall health and wellbeing are rooted in early childhood. Stressors in early childhood can disrupt neurologic, metabolic, and immunologic systems, leading to lower developmental outcomes (CDC, 2017; Lancet, 2017). The CDC further reported that the implementation of effective public policy often plays a critical role in both the identification of at-risk children and the integrated systems that can support healthy development. Enacting effective policies can address the disparities by reducing barriers that might prevent children from reaching their full potential. This literature review explores chronic mental health stressors and symptoms of mental illness in early childhood development and other factors that influence and molds the caregiver perception of current policies in place geared towards resolving some of these issues, like the HR2646. The sources reviewed to support the research problem and framework suggests that policies such as the HR2646 promote the health and the development of children by increasing access and integrating support services to children and their families.

Furthermore, public policies such as the HR2646, are aimed towards highlighting the importance of effective interventions and strategies focused on increased access to comprehensive care coordination, early care, education, early identification of children and families in need of services, and promotion of protective factors through family support programs (Pediatrics, 2016). As a researcher, I was neutral/objective in conducting my research. The results of the research may help inform more effective public policy by identifying opportunities for improvement based on caregiver lived experiences. This chapter contains the following: the literature search strategy, the conceptual framework of the study, the literature review related to key variables or Concepts, and finally, a summary/ conclusion of the major themes in the literature.

Literature Search Strategy

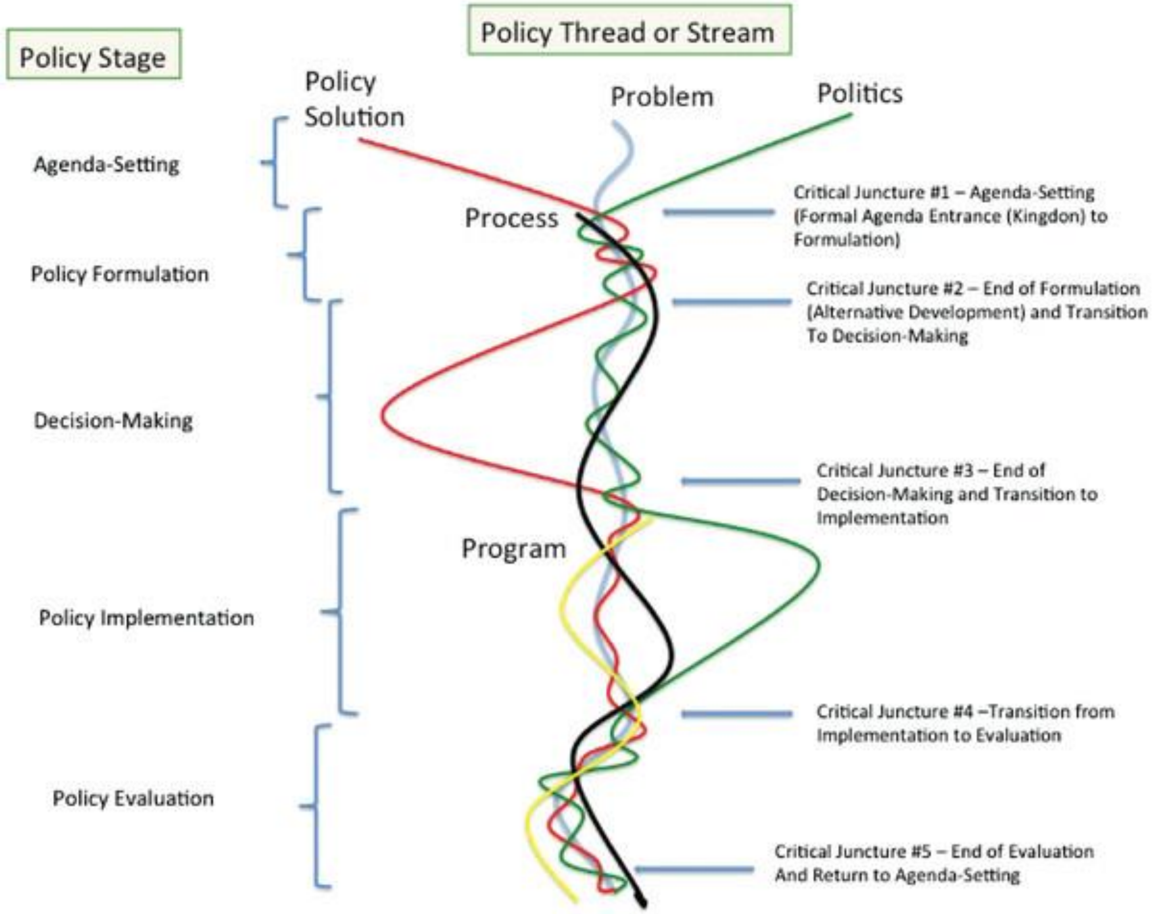
The literature search strategy involved examining scholarly journals, books, peer-reviewed articles, and various monographs using the Walden university library research databases, including-Academic Search Complete, EBSCO Host, ERIC, ProQuest, and Sage. Additionally, Google Scholar was used to supplementing the discovery of peer-reviewed journal articles, along with published dissertations, periodicals, and mental health websites. The search terminology included: *"child and adolescent mental health,* *childhood mental illness and public policy, caregiver/parental distress, caregiver stress, mental diagnosis," Helping Families in Mental Health Crisis Act of 2016."* The timeframe for the literature review is between 2015-2020; however, seminal research and theory associated with this topic were critical in the construction of the conceptual framework.

Theoretical Framework

The theoretical framework for this study is Howlett's five stream framework of the policy process. The five stream framework of the policy process by Howlett et al.,2016 shows the usefulness in connecting it with the Kingdon's multiple framework. However, the three-stream framework developed by Kingdon is suited to understand the specific stage of policymaking; it requires augmentation to effectively encamp variables and activities affecting deliberations, action, and outcomes that occur over multiple stages or phases of policymaking.

Figure 1

The Five Stream Framework of the Policy Process Diagram



Howlett stated that it is essential to reformulate the various streams approach and take it beyond the agenda-setting. Developing an enriched policy stream framework can fully engage with policy cycle thinking while overcoming limitations of both constructs and creating a more robust conceptual apparatus for advancing the understanding of policymaking (Howlett et al., 2016). Howlett believed in the approach of not layering, but instead refining, adapting, and blending. Howlett also recalled that earlier authors like Cohen, March, and Olsen had noted the existence of four, and not three streams.

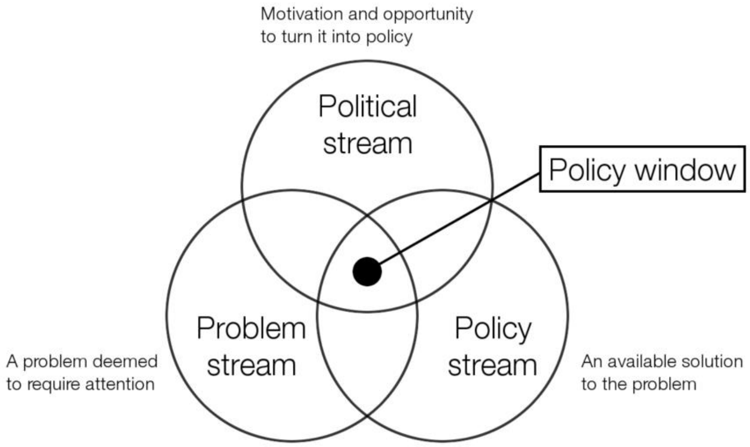
Howlett argued that a version of the streams framework involves thinking about policymaking as a sequence of phases. Various tributaries to a river merge at different points into the river as it makes its way down the stream. Howlett's framework begins with the classic Kingdonian articulation of the problem, policy, and political streams that affect agenda setting. Still, it adds new processes and program streams that feed into specific conjunctures where the existing streams intersect or coalesce as the policy process unfolds (Howlett et al., 2016). In the five-stream framework, each confluence point introduces new action, new tactics, and new resources. These new actors join the flow of policymaking events. Within each intersecting stream, there is a merger point representing a 'window' which Kingdon described. This yields a difference in the configuration of policy inputs that generate distinct policy patterns through each juncture, much as the rounds style of policymaking theories suggested (Howlett et al. 2016).

In the five streams framework of policy process, Howlett states that the issue with Kingdon's model is that the framework was not used to interpret all aspects of policymaking. Howlett argued that the multiple streams framework is narrow and only seeks to explain how issues moved onto government agendas, becoming targets of action, rather than how the solutions were decided upon, implemented, and put into action. Another framework worth mentioning is the advocacy coalition framework (ACF) developed by Paul Sabatier and Jenkins-Smith. Paul Sabatier criticized Kingdon's policy cycle framework. He stated that the framework lacked a casual theory because it contained no coherent assumptions about what forces drive the process from stage to stage and very few falsifiable hypotheses (Howlett et al., 2016). The ACF model stated that focusing on beliefs and motivating collective acting with a subsystem would generate a superior understanding of the conflict inherent within policymaking by comparing the actor less vision of the Kingdoms staged approach (Howlett et al., 2016).

Sabatier's focus was on political actors being the drivers of policy development. The ACF framework was strengthened by the ignoring of the decision-making process and melding together the inputs formulated by a successful coalition to produce policy outcomes. Howlett wrote about the usefulness in connecting the Kingdon’s multiple frameworks and the advocacy coalition framework. Howlett added that this could be accomplished by extending Kingdon’s streams approach to the other stages of policymaking, such as formulation, decision-making, implementation, and evaluation (Howlett et al., 2016). The existence of only three streams makes it impossible to apply other stages of policymaking that go beyond agenda setting and implanting or evaluating when other central actors are active. Howlett’s primary argument was that a five stream framework would retain the conceptual architecture and analytical vocabulary developed by Kingdon while offering a more comprehensive and capable framework for capturing the full range of policy-making dynamics (Howlett et al. 2016). Howlett also argued that this can be the reconciliation of the conceptual pillars of the multiple stages and cycle models would develop a five stream framework. The multiple streams framework provides an understanding as to how issues find their way to the political agenda, and to determine if a window of opportunity exists for the policy idea (Atupem, 2017).

Figure 2

The Kingdon's Multiple Streams Model



The Kingdon's multiple streams model is based on policy change coming about when three streams (i.e., problems, politics, and policies) connect (Meier, 1991). Each of the streams in Kingdon's model runs independently of the others and focuses on the importance of timing and flow of policy actions (Atupem, 2017). In Kingdon's multiple streams models, three streams must come together to form a window of opportunity before the policy can have a chance for action (Atupem, 2017). In this study, the policies emerge from perceived problems, followed by the acknowledgment of the role of policymakers and other stakeholders have in proposing policies and acting on policy options (Meier,1991).

The use of the Kingdon's multiple streams model in this study will be one method for exploring and obtaining data on caregiver perception of the current standing policy HR2646. The development of more policies (policy stream) will provide an available solution to any problem related to the standing policy. The potential solution will then go through the political stream, which will be the opportunity to turn a proposed change into policy. In the Kingdon's Multiple Streams Model, the problem stream is filled with the perception of the problems seen as "public," in a sense that government action is needed to resolve it (Beland,2016). The policy stream is filled with the output of experts and analysts who examine problems and propose solutions. The political stream comprises factors that influence the body politic, such as signs in national mood or legislative turnover (Beland,2016). In the Kingdon's Model, all three streams flow along different channels and remain independent until a specific policy window opens. The Kingdon's Multiple Streams Model emphasizes agenda setting and includes three independent streams that, when joined together, open a window of opportunity(Beland, 2016).

The first part of the Kingdon's Multiple Streams Model is referred to as the problem stream and is related to the issues and challenges that have attracted the attention of society. The problem stream is filled with perceptions of problems seen as "public" in the sense that government action is needed to resolve them (Jones, 2016). Policymakers become aware of such issues due to events such as crisis or through feedback from existing public programs.

In the second part of the conceptual framework, the Kingdon's Multiple Streams Model is the policy stream. The policy stream comprises the output of experts and analysts who examine the problems and propose solutions (Ravaghi, 2019). In the policy stream, the range and possibility for policy action are identified, assessed, and narrowed down to possible options towards solutions.

The third part of this framework is the political stream. The political stream comprises factors that influence the body politic, such as swings in national mood, executive or legislative turnover, and interest group advocacy campaigns (Howlett, 2017). The approach of shaping the political stream involves political stability, political will, and the contribution of legislation from key persons (Ravaghi, 2019). According to Kingdon (1984), these three streams flow along different channels. They remain more or less independent of one another until, at a specific point in time, a policy window opens, which is the only moment that the streams cross (Howlett et al.2016).

In assessing the Kingdoms Multiple Streams Models and Howlett’s Five Stream Framework of the Policy Process, there are a few studies that stand out. In a study done by Mauti, Gautier, Tosun, and Jahn (2019), HiAp (Health in All Policies) is an approach that facilitated the decision making amongst policymakers in Kenya, with the intent to maximize positive health impacts of other policies. Mauti et al. (2019) examined the HiAP program in Kenya by conducting a qualitative case study review of the relevant policy documents. Also, interviews of various key informants with diverse backgrounds in government, UN agencies and development agencies, and civil societies was conducted as part of the study. This analysis was performed using the Kingdon's Multiple Streams Approach (problems, policy, and politics). The study also aimed to investigate how HiAp rose to the agenda-setting level and its adoption in Kenya, using the Kingdon framework (Mauti, 2019). The authors of this study examined the three streams in the context of HiAp in Kenya:

Problem stream- What were the issues that led to HiAp being sought as the policy solution in Kenya? Policy Stream- How has HiAp been, or is Hiap being adopted in Kenya?

Politics stream- What were the political factors for or against the adoption of HiAp in Kenya? Ultimately, the results of this particular study showed that under the political stream. There was an increased potential for increased budgeting, and also for sustainable development goals.

Another example of Kingdon's Multiple Streams Model in policy analysis is in a study conducted by Behzadifar, Goji, Rezapour, and Luigi (2019). This study focused on investigating the hepatitis C infection in Iran, a policy analysis of agenda-setting using the Kingdon's multiple streams frameworks. The study examined Hepatitis C related issues as a priority for the Iranian healthcare system using the Kingdon's various streams frameworks. The hepatitis C virus infection causes many deaths in Iran annually, becoming a key healthcare challenge, leading to the high cost of treatment drugs. Also, there is a limited capacity of laboratories and a lack of financial resources in the health sector. More importantly, the lack of support for many policies and decision-makers in low- middle-income countries (Behzadifar, Goji, Rezapour & Luigi, 2019) Behzadifar et al. (2019) found that various national and international factors may play a role and influence the process of agenda-setting. Through Kingdon's model, Hepatitis C was placed on policy and the decision-makers agenda. Kingdon's Multiple Streams frameworks guided the data analysis during the study. Ultimately, this resulted in researchers identifying that some of the factors that have influenced the hepatitis C outbreak were primarily a lack of proper information of hepatitis C before the 1990s (Behzadifar, 2019). The results of the study were also various national and international factors that play a role in shaping Hepetatities C related policies (Behzadifar et al., 2019). Researchers concluded that the aspects related to the policy were effective treatment methods, drug production inside of Iran, and positive changes in government and parliamentary support (Behzadifar et al., 2019).

Lastly, Wals et al. (2019) discovered that the Kingdon's Multiple Streams Framework could be used to analyze how and why governmental policies were adopted. Wals found the ideas that would end up in a proposal to establish a new immunization program would develop along three main streams. In this study, the problem stream focused on a particular vaccine-preventable disease and its stakeholders (Wals et al., 2019). The policy stream was centered on experts' views on the available vaccines (Wals et al., 2019). The politics stream consisted of the sociopolitical factors, such as budgetary constraints and ideas shaped by policy personnel into a proposal with concrete implementation strategies (Wals et al., 2019). Wals et al. discovered that the three streams would converge within a policy window, where it is likely that adoption would occur. Due to the timing of the policy window being unusually predictable and short in duration, the authors discovered that for the policy to survive, the proposed program would have to be feasible in operation, financially affordable, and consistent with mainstream social values. In summary, in this particular study, an idea on new immunization programs developed along three main streams: (a) The problem: the disease; (b) the solution: the vaccine and a program; and (c) the politics: sociopolitical factors including budgetary constraints (Wals et al., 2019).

Howlett analyzed the limitations of both the ACF and the policy cycle model and suggested that the limitations of each could be taken by combining key elements within an overall cycle rubric. When the three problems, politics and policy streams coalesce temporarily, as Kingdon suggested, in the policy window, this intersection creates a new policy process stream, which becomes the main central pathway upon which other streams subsequently converge. The choice stream written by the author's Cohen, March, and Olsen, occurs when the critical junctures are created and set up the future impetus for policy deliberations, establishing the initial conditions, which animate subsequent policy process (Howlett et al. 2016) The political stream then separates from the problem and policy stream, and specific sets of subsystem actors such as policy analysts and stakeholders will deliberate and propose policy alternatives. The ideas are mobilized, policy problems and solutions are blended, and a configuration or alternative possibilities are created. The contents of this range of choices provide a basis for a new phase when the politics stream returns to connect with the process stream creating momentum toward a decision (Howlett et al. 2016). The third critical point in this framework occurs if the policy is acquired and then requires implementation. Howlett writes that during this point, the ‘policy’ stream separates from the main flow, which includes the process, politics, and problem streams. These three streams are now joined by a program stream composed of the actors and interests working on calibrating new program instruments while integrating or alternating them with established ones to generate new outputs

(Howlett et al. 2016). When the evaluation occurs, the ‘policy’ stream rejoins the other streams. According to Howlett, the connection between streams and cycle frameworks can encompass qualitatively different kinds of policymaking, which occurs at each intersection point. This also depends on the inputs that each stream brings to a particular moment in the policymaking process (Howlett et al. 2016).

Whether addressing mental health or publicly funded programs such as immunization programs, the Kingdon's Multiple Streams Model has played a significant role in understanding how separate streaks of problems, policies, and politics can come together at critical times and form solutions. Despite this, in the Five Streams Model, there is an openness that diverse inputs offer the kind of insight into policymaking that draws upon the analytical strength and persistence of the stage cycle idea, although escaping the limitation that the absence of program policy feedback streams, created for earlier efforts to link the framework of the stage with ‘streams’ thinking (Howlett et al. 2016). The Five Streams Framework explains how and why new actors, ideas, and interests merge into the existing policy flow but also explains the different patterns of policymaking that result from the presence or absence of relevant inputs at various critical junctures (Howlett et al. 2016). This framework integrates the actors and behaviors that the author Kingdon identifies but also goes beyond the task of policymaking by addressing the concerns to Sabatiers (1991) of ‘actor less’ or ‘agentless.’ Expanding the ACF and cycle stream framework to explain each stage of policymaking, ads further insight into policy process and outcomes.

Overview of the Issue/ Childhood Mental Illness

According to WHO (2004), mental illness accounts for more increased disability in developed countries than any other disorder, including cancer and heart disease. Health has been defined as a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity (WHO, 2016). Mental illness refers to all diagnosed mental disorders characterized by sustained, abnormal alterations in thinking, mood, or behavior associated with distress and impaired functioning (Younger, 2016). Mental illness is associated with a lifelong risk of anxiety, depression, and suicide in children (Younger, 2017). Younger investigated understanding mental health promotion, prevention, and treatment of mental illness in children in the United States. The objective of the study conducted by Younger (2017) was to do a review of current national survey data of mental health in children over the past decade and to review the implications of childhood mental illness. Younger showed that 13%-20% of children experienced a mental health disorder from 1994-2011(Younger,2017). The results of this study showed depression was prevalent amongst children between the ages of 3-17 years old, and the major depressive episodes were 12.8% amongst adolescents between 12-17 years old (Younger, 2017). Younger concluded that mental illness hinders the expected cognitive, social, and emotional development in children. Younger found that an effective way to manage mental illness would be by ensuring that there is adequate access to treatment services that reduce its associated morbidity and mortality

Like Younger, Patalay and Fitzsimons focused their research on understanding the complete framework of childhood mental illness, its issues, and its impacts on caregivers and families. Patalay and Fitzsimmons's research focused on implementing interventions that treat or prevent symptoms of childhood mental illness. The works of Patalay and Fitzsimons (2016) provided an overview of the data. They found that, apart from the focus being primarily on childhood mental illness, there is a need to investigate both a framework that correlates both mental illness and wellbeing. Mental disease harms a range of domains through the life course, including economic activity, relationships, and physical health (Copeland, Wolke, Shanahan, & Costello, 2015). The objective of the study conducted by Patalay and Fitzsimmons was to investigate a framework that correlates both mental illness and wellbeing in a large, current, nationally representative sample of children in the United Kingdom (Patalay & Fitzsimmons, 2016). The study was conducted using an ecologic framework of correlates, individual sociodemographic/human capital, family, social, and broader environmental factors (Patalay & Fitzsimmons, 2016).

All these were examined in 12,347 children of the age of 11 years old from the U.K. The results of this study showed that it is essential to implement interventions that not only focus on preventing or treating symptoms of mental illness but also on improving a child's wellbeing. In examining the two studies, Younger spoke about managing mental illness by ensuring that there is adequate access to services and also taking increased preventive measures. Both studies highlighted the importance of prevention, treatment, and overall understanding of childhood mental illness. The works of the Patalay and Fitzsimmons related to the Younger research show the importance of having adequate and effective treatment services to reduce childhood mental illness.

Both studies cover similar aspects of mental health issues in children and looked at the correlation of both mental health and wellbeing. Both studies also establish that childhood mental illness is harmful and affects a range of domains through life. Both studies showed it is essential to improve a child's wellbeing by focusing on the prevention and treatment of symptoms. The works of Younger and Patalay & Fitzsimmons showed that improved access to treatment reduces childhood mental illness.

Naughton et al. (2017) focused on childhood mental illness within families. Naughton et al. examined the extent of mental illness within families of 152 children attending a regional child and adolescent mental health service. Cross-sectional study design was conducted. A case record review and a clinician completed a questionnaire of the children attending this mental health service. The study by Naughton et al. (2017) highlighted the extent of both mental illness and the scares support available for children and parents in the same family. The findings in this study conducted by Naughton et al. (2017), indicated that there is a need for coordinated multiservice delivery and appropriate, consistent family-focused interventions that respond to both mental illness and social supports for children and parents. The authors concluded that there is a need for further research that examines specific components of family need and support as seen through the eyes of the child and the family (Naughton et al., 2017)

Similarly, Garrido et al. (2019) also identified that there are a need and a significant challenge in making mental health interventions accessible to children and families in need. Unlike Naughton et al. (2017), who only identified that there is a need for family-focused interventions, Garrido et al. focused on the market for coordinated multiservice delivery by using a mixed-method approach to compare the use of digital intervention to provide mental health services to children. By identifying a child and family need, the authors were able to analyze the effect of digital interventions. Garrido et al., 2019 found that digital interventions and interactive content with a game-like feel increased adolescent engagement during mental health treatment. Both studies are different because Naughton et al. only identified the need for coordinated multiservice delivery. Still, the second study by Garrido et al. identified and analyzed the effect of a particular intervention strategy in improving the deliverance of treatment towards childhood mental illness.

Prevalence of childhood Mental Illness in the United States

Revisiting the article by Younger, the author reports that the diagnostic terminology used to describe mental illness diagnostic categories may vary. In this study, Youngers findings were that childhood mental disorders include several types, some of which are primary mental illness while others have a close association with a mental disorder (Younger, 2017). Attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), conduct disorder, is characterized by developmentally inappropriate levels of inattention, hyperactivity, impulsivity, or a combination thereof, which impairs functioning in a multiple setting (Younger, 2017). This study by Younger showed that the prevalence of depression amongst children age 3 -17 years was 3%. The prevalence of lifetime and past year major depressive episode. 28.5% of high school students age 14-18 years reported feeling sad or hopeless every day for two weeks or more in a row that they stopped doing usual activities (Younger, 2017). Parents reported that 4.7% of children between the age of 2-17 years old of having anxiety (Younger, 2017). Data showed that 8.3% of self-reported adolescents age 12-17 years had 14 or more mentally unhealthy days in the preceding month as a marker of mental illness (Younger, 2017). Younger also reported that the data gathered amongst 16 U.S states noted an overall suicide rate among children age 10-19 years of 4.5 per 100,000, with 4.2 suicides per 100,000(Younger,2017). White non-Hispanic children had higher rates of suicide than black non-Hispanic and Hispanic children (Younger,2017). Amongst suicides reported, 29.5% disclosed the intent to die by suicide before the act; In comparison, 35.5% had a diagnosed mental disorder at the time of death, and 26.4% were under treatment for a current psychiatric disorder the time of death (Younger,2017).

Youngers findings supported the study conducted by Miranda & Patel (2005), which concluded that mental illness is among the most important causes of sickness, disability, and in certain age groups premature mortality in developing countries. Poor and marginalized people are at higher risk, and about 30% of the population globally are affected by mental health disorders, and more than two-thirds do not receive need care (Kessler, 2005). Roughly 10% to 20% of children are affected by one or more mental or behavioral problems (Murthy et al., 2001)

A study by Devitt (2019) found that one in six children in the United States has a mental illness. One in six children in the United States between the ages of 6 and 17 has a treatable mental health disorder such as depression, anxiety, or attention-deficit/hyperactivity disorder (ADHD). According to this study, nearly half the children diagnosed with mental health disorders did not receive counseling or treatment from a mental health professional such as a psychiatrist, psychologist, or clinical social worker. The study gathered an initial sample of more than 50,000 surveys of children between the ages of 0 to 17 years of age and analysis based on parents' responses to questions. The questions were on if parents were informed, their child had a mental health illness, and if their child currently has a condition. The parents who indicated that their child did have a disease were asked to specify the type. Parents were also asked if their child had received any treatment or counseling from a mental health professional within the past 12 months. The researchers calculated prevalence estimates by adjusting the survey design and excluding children without health insurance coverage and those under six years (Devitt, 2019). Through this study, it was estimated that 16.5 percent of U.S children between the ages of 6 and 17 (about 7.7 million) have at least one treatable mental health disorder (Devitt,2019). Devitt asserts that, through this data, there is indeed a prevalence of childhood mental illness in the United States.

Similar to the study conducted by Devitt (2019), the works of Bitsko, Holbrook, Ghandour, Blumberg, Visser, Perou, and Walkup (2018) provided an overview of data, which points to the fact that there is a prevalence and impact mental illness such as anxiety and depression in U.S. children, based on the parent report of health care provider diagnosis. Bitsko et al. (2018) analyzed data from the National Survey of Children's Health, from the years 2003, 2007, 2011, and 2012. In an article by Bitsko et al. (2018). the authors conducted a cross-sectional random digit dial telephone survey of parents and guardians, with the analysis restricted to children between the ages of 6- 17 years, with valid data on anxiety and depression questions. Bitsko et al. (2018) research study found that the lifetime diagnosis of anxiety depression among children between the age of 6- 17 years old increased from 5.4 % in 2003 to 8.4% between 2011-2012 in the United States. More than 1 in 20 U.S. children had current anxiety or depression, and the findings may inform efforts to improve the health and well being of children with internalizing disorders(Bitsko et al.,2018).

According to the American Academy of Pediatrics (AAP), 50% of children are diagnosed with mental illness before becoming adults, with many adolescents never receiving treatment. There is a need to identify patients with risk factors such as depression (personal or family history of depression), bipolar disorder, suicide-related behavior, substance abuse, and other psychiatric illness and major psychological stressors (AFP,2018). According to the CDC, ADHD, behavior problems, anxiety, and depression are the most commonly diagnosed mental disorders in children. In the United States, children aged 2-17 years (6.1 million children) have received an ADHD diagnosis (CDC, 2020). Approximately 4.4 million children between the ages of 3-17 years have been diagnosed with anxiety (CDC,2020). 1.9 million children between the ages of 3-17 years have been diagnosed with depression in the U.S(CDC, 2020).

Impact of Mental Illness in Children on Families/Caregivers

Mayberry and Heflinger (2018) asserted that family caregivers' conceptualizations of their child's emotional and behavioral problems influence help-seeking for the child and the caregiver strain. Mayberry and Heflinger noted that caregivers' recognition or understanding of their child's mental illness influences the resources that they mobilize to address the problem, which in turn affects help-seeking commitment to treatment.

Experiences with the mental health system and other families shape whether caregivers believe that the problem is caused by a chemical imbalance or other biological mechanisms, a response to a stressful environment, or a combination of all these factors (Mayberry & Heflinger, 2018). In this study, Mayberry and Heflinger (2018) examined how caregivers conceptualized their child's mental illness, how they reported their caregiver strain, how they felt about seeking help for their child, and what type of supports they activated to cope with their emotional response to their child mental illness. Mayberry and Heflinger (2018) analyzed interviews with caregivers of children with mental illness who lived in rural areas enrolled in their state Medicaid program. The authors examined how the caregivers conceptualized the children's problems, how they reported their strain, how they felt about seeking help for their child. The types of supports they activated to cope with their emotional response to their children's problems. The results of this study were caregivers conceptualized their experience with their children with mental illness as a stressful event or as a response to a previous stressful event. This conceptualization was characterized by the belief that the disease occurred unexpectedly, with the child's problems being caused by the disorder. Caregivers with a stressful event conceptualization were also more likely to indicate or experience high levels of a strain than caregivers with a response conceptualization (Mayberry &Heflinger, 2018). In response to the interview questions during the study, caregivers unanimously indicated and agreed that they need support groups for caregivers to assist them in coping with the stress. Also, caregivers thought that support groups for parents/

caregivers would be a forum for sharing ideas and problem-solving techniques (Mayberry & Heflinger, 2018).

Mwei (2015) examined the caregiver experience while raising a child with mental illness. Mwei demonstrated that caring for a child with a diagnosed mental health condition not only affects the child but also impacts the caregivers in a variety of ways. While children with mental health conditions need to receive proper treatment, it is also essential to look at the caregiver's experience of raising a child with a mental health condition (Mwei,2015). Similar to the study conducted by Mayberry & Heflinger (2018), the author explored the supports and the services available to caregivers, the usage of the supports, and the various challenges encountered by the caregiver. Mwei (2015) conducted the study using a qualitative design, where six participants were selected and interviewed regarding their experiences raising a child with a mental health condition. The results showed that caregivers experienced challenges raising a child with mental illness. Also, Mwei (2015) indicated that there are supports available to caregivers, but there were often barriers reaching such support services. Both articles illustrate and defined caregiver stress associated with raising and caring for a child with mental illness. Both authors identified the barriers caregivers experienced in obtaining assistance, in addition to their perceptions of support systems they need to receive relief.

Ntsayagea et al. (2019) used a qualitative phenomenological survey to create a comprehensive chronicle of family caregivers' experiences caring for relatives living with mental illness. Ntsyagea et al. obtained an in-depth view of the caregiver's lived experiences. The family's caregiver experiences were characterized under four themes:

perceived responsibility of caregiving, experiences of emotional effect, backgrounds of support needs, and experiences of changed perceptive (Ntsyagea et al., 2019). The results showed a lack of emotional coping among the family caregivers, which called for a robust family caregiver interventions to facilitate their mental health (Ntsyagea et al.,2019). Also, some of the results showed that the caregivers experienced the physical exhaustion, encountered frustration when their mentally ill child refused medication or food; caregivers had to alter their responsibilities and combine caregiving with attending to their everyday role. Also, the results showed that caregivers experienced feelings of shame and fear, feelings of hopelessness, and helplessness. Caregivers expressed that they felt helpless when they could do nothing about their relative's aggressive behavior. Both studies correlate because all participants/ caregivers expressed that they felt overwhelmed and burdened, and also expressed the need for programs towards providing caregiver relief and a network of support. Both studies show the impact of mental illness of children on families and caregivers.

Ngibise, Doku, Asante, and Agyei (2015), examined the experience of caregivers of people living with severe mental disorders. The authors evidenced that the interplay of caregiving consequences included: poverty, discrimination, stigma, lack of support from others, diminished social relationships, depression, emotional trauma, and poor interrupted sleep, are all associated with caregiver burden (Ngibise et al.,2015). In this study, the authors assessed the burden of care on caregivers of individuals living with mental illness and the coping strategies and additional support available. The study was conducted qualitatively and involved 75 caregivers and participants. Data gathered from these caregivers on their experiences providing care for their family members. The authors found that caregivers reported various degrees of stress, including financial, social exclusion, emotional depression, and inadequate time for other social responsibilities (Ngibise et a.,2015).

According to the Anxiety and Depression Association of America 2020, 40% to 70% of caregivers meet the diagnostic criteria for major depression. The AADAA reports that being a caregiver can be physically and emotionally stressful. When raising a loved one, caregivers often put their needs before their own (ADAA,2020). In conclusion, the studies included in this portion of the literature review showed evidence of burden and stress in caregivers' lives. This evidence consists of emotional distress, stigma, financial hardship, social exclusion, and, most importantly, the absence of support services geared towards alleviating caregiver burden. More importantly, the studies showed a need for policy development and implementation to offer psychosocial support for caregivers and relieve emotional burden.

Services of availability for children with mental illness in the U.S

According to the Centers for Disease Control and Prevention (CDC), nearly 1 in 5 children have a mental, emotional, or behavioral disorder, such as anxiety or depression, attention-deficit/ hyperactivity disorder,(ADHD), disruptive behavior disorder, and Tourette Syndrome. About 20% of children with mental, emotional, or behavioral disorders receive care from a specialized mental health provider (Centers for Disease Control and Prevention). According to the CDC, there are various barriers hindering families from obtaining mental health care. Such restrictions include a lack of mental health providers in their specific region, the cost of insurance coverage, and the time and effort it takes the parent to obtain mental health services for their child. The CDC reports that they work towards identifying policies and practices that may help children access psychiatric health care.

So, McCord and Kaminski (2019) conducted a systematic review of evaluations of select policy levers geared towards promoting, accessibility, affordability, acceptability, availability, or utilization of children's mental and behavioral health services. Although the proportion of uninsured families has declined over time, access to mental health care has mostly not improved since 2000 (So et al., 2019). The authors found that children, in particular, are more likely to have an unmet need for mental health services and face difficulty obtaining services. So, McCord and Kaminski (2019) began by identifying four policy levers for children's behavioral healthcare to consider in targeted searches. The author's used search terms for integrated care models, geared towards evaluating the quality of delivery psychological services in medical settings.

The author's selected search terms geared towards capturing the provisions of delivery of mental health support services within schools and educational institutions in the U.S. Telehealth / Telemedicine search terms in this study to identify the evaluations of policies that allow technology-assisted assessments and treatments of children. The findings of the study were that policy levers can help families overcome barriers to obtaining mental health care for their children. This study uncovered evidence that location-based policy levers (i.e., school-based services and integrated care models) have significant effects on utilization and acceptability (So et al., 2019). The authors also concluded that the impact of mental health accessibility might be depending on other factors, such as if there are sufficient non-school based services that already exist in this area (So et al., 2019).

Several authors have studied the availability of services for children with mental illness in the United States. In their work, Robinson, McCord, Russel, Cloud, and Kaminski (2020) examined the availability and the amount of SSI and State supplementary payment program benefits geared towards supporting families and children with disabilities. Nearly 1.2 million children with disabilities received federally administered Supplementary Security Income (SSI) payments in 2017 (Robinson et al., 2020). According to the National Academies of Sciences, identified modifications to SSI, such as increasing the federal SSI benefit maximum by one or two-thirds, are strategies that could reduce the U.S child poverty rate and improve child health and well being on a population level.

The objective of the study was to examine the availability and the amount of SSI program benefit payments that support families of children with disabilities. The authors designed their research using public health law research methods. They looked at statues and state agency regulations that govern the federal SSI and SSP programs in all 50 U.S states, including the District of Columbia, between 1996-2018 (Robinson et al., 2020). The results of this study showed that the states with SSP payments amounts in their codified laws, the SSP monthly benefit amount ranged from $8 to $64.35 in 1996, and $3.13 to $60.43 in 2018 (Robinson et al.,2020). This study showed that the number was stable if jurisdictions that were offering SSP programs between 1996 and 1998.

The number of jurisdictions offering SSP benefits to eligible families increased from 39 jurisdictions in 1996 to 45 by the end of 2018 (Robinson et al., 2020). The authors concluded that despite SSI's availability in all jurisdictions as a federal law that governs the entire United States, there had not been an increase in SSP availability for children in the last 20 years. The authors initially began by exploring SSI related policies as a tool for improving the economic stability of children with disabilities and their families. The results of this study showed the current SSP's in combination with SSI, is not yet aligned with evidence that increased SSI amounts by one to two thirds could offset some of the additional financial costs caring for a child with disabilities living in poverty. The SSI and SSP are one type of program that supports children at economic health risk; understanding more about how this program reaches children and works in combination with other federal and state income security programs may help identify policies and strategies that further support children with disabilities in low-income households (Robinson et al., 2020).

Cummings, Case, Ji, and Marcus (2016) conducted a study on the availability of youth services in U.S mental health treatment facilities. As per Cummings et al. (2016), although on in five youth have suffered from a mental health disorder resulting in severe impairment at some point of their lifetime, less than half have ever received any mental health treatment. Due to the concern from policymakers, researchers, and practitioners, the focus has been on the availability of youth mental health services as an impediment to care. The authors indicated that developing strategies towards achieving the goal of children getting mental health treatment requires a thorough understanding of the current mental health treatment system.

Cummings, Case, Ji, and Marcus (2016) found that youth-serving hospital – and community- based mental health facilities commonly provide an array of psychotherapeutic and psychosocial services in addition to psychotropic medication management and that the vast majority of these facilities offer assistance to low-income populations. The authors conducted the study by using national data to examine which types of mental health treatment facilities (hospital- and community-based) were most likely to offer youth services, and which kinds of communities were most likely to have this infrastructure. The authors observed a systematic difference in the types of facilities that provide youth services- with more extensive, privately-owned being most likely to service this population. When examining the types of facilities that were most likely to serve youth, results indicate that privately owned for-profit and nonprofit mental health treatment facilities were more likely to serve this population than publicly owned facilities (Cummings et al., 2016). Authors indicated that there had been reports of increased investment in privately held, for-profit corporations expanding their role in organization and delivery of mental health services. Still, the role of the public sector in the organization and the delivery of services has declined. Rural counties in which most residents were nonwhite and or counties with a higher percentage of uninsured residents were less likely to have a community-based mental health treatment facility that served youth (Cummings et al., 2016).

State mental health agencies experienced more than $4.4 billion in budget reductions between the year 2008 and 2013, resulting in an estimated 9% reduction in the number of states psychiatric hospital beds, the closure of state psychiatric hospitals, and a reduction of community-based mental health programs (Cummings et al., 2016). Additionally, and per Cummings et al. (2016), when examining the geographic availability of specialty mental health treatment facilities, only 12% of counties have a hospital-based mental health treatment facility that serves youth compared to one-fourth of counties that have any hospital-based mental health treatment facility. The author's findings provide essential information that examines the ongoing trends in the behavioral health care system and significantly how consolidation may affect the geographic accessibility of hospital-based mental health services for youth in the coming years. The authors conclude their study by stating that the consolidation of multiple hospital-based mental health facilities into fewer facilities could reduce the geographic accessibility of youth services. Therefore future studies should assess the extent to which geographic access to youth services in hospital-based facilities has diminished due to the ongoing consolidation of facilities and organizations (Cummings et al., 2016).

Prevalence of childhood mental illness in the Bronx, NY

The next portion of the literature review provides a better understanding of the prevalence of childhood mental illness in Bronx, NY, through statistical analysis of data. According to the Citizens Committee for Children's 2020 report, more than 18,000 children received public mental health services weekly, according to the New York State Patient Characteristic Survey. 26% of the children receiving public mental health services reside in the Bronx (CCC, 2020). The prevalence analysis conducted by the CCC revealed that there are a significant number of children within New York City with a mental health need, and for whom there are a considerable number of treatment slots(CCC, 2020). The CCC conducted a prevalence of mental health analysis in the Bronx, NY, which showed that there are 108,204 children in the Bronx between the ages of 0-4 and 8,981 children ages 0-4 Bronx are estimated to have a behavioral problem (CCC,2020). Four thousand four children between the ages 0-4 in the Bronx, NY, are expected to have an externalizing behavioral problem (CCC,2020). Three thousand five hundred seventy-one children between the ages of 0-4 in the Bronx are estimated to have a comorbid (internalizing and externalizing) behavioral problem(CCC,2020). There are 281 629 children in the Bronx between the ages of 5-17: 56, 326 children ages 5-17 in the Bronx are estimated to have any mental health disorder, and   28,163 children ages 5-17 Bronx are having severe emotional disturbance(CCC,2020).

The prevalence analysis conducted by the CCC revealed that there is a significant amount of children who do not have access to mental health treatment due to the lack of availability of treatment slots. CCC, through their study, discovered that there is an insufficient slot capacity to serve children in need of mental health treatment.

Details about HR 2646- intended improvement of prior policy

The next portion of the literature review provides details of the HR 2646, in addition to the intended improvement of the prior policy. HR2646 is a bipartisan bill introduced to Congress which proposed to resolve many issues within our mental health care system and improve the treatment of people with mental illness. A study by Pruchno (2015) presented a history of what it was like before the introduction to this bill. Pruchno (2015) noted that for decades in the United States, there was an occurrence of deinstitutionalization that occurred without a comprehensive plan. The author states that this resulted in an ineffective state and community programs that existed across the country. HR2646 is a substantive piece of legislation that proposes to improve the treatment of individuals with mental illness.

According to Pruchno (2015), one of the values of the HR2646 legislation would be to reform HIPAA so that families and caregivers have access to necessary protected health information to care for their loved ones. Also, ensure oversight so that funds are used to treat and prioritize those with the most severe mental health diseases; provide funding for assisted outpatient treatment; increase the number of psychiatric beds for crisis treatment; emphasize evidence-based treatments, and more (Pruchno,2015). The author Pruchno, indicated various provisions of the bill, which included increased funding for assisted outpatient treatment centers in underserved urban communities have the access needed mental health care.

The HR2646 covers various areas that enhance childhood mental health provision. Howlett’s five stream framework of the policy process and the Kingdon’s multiple streams model can be tied into each of these provisions/ topics found within the HR2646. The HR2646 is focused on improving metrics linked to emergency room boarding and psychiatric hospitalization. The framework starts with the classic Kingdon’s articulation of the problem, policy, and political stream. When a policy window of opportunity opens, we witness policymakers become proactive and quickly seize those opportunities to formulating policies before the window closes.

The HR2646 was proposed during the Obama presidency, and President Obama was welcomed into the discussion on mental health policy. It had been stated by Chairman Fred Upton (R-MI) at the time that mental health reform continued to be a priority for 2016. Before this, the Health Subcommittee had passed Rep Murphy's bipartisan HR2646 ACT, and several concerns that were raised during the subcommittee debate were being addressed continuously at the member level (Jauregui, 2016). The focus of H.R. 2646 was to make psychiatric, psychological, and supportive services available to individuals who have mental illness and their families (Jauregui,2016). The bill included provisions for early childhood intervention and treatment, in addition to several reforms to Medicare and Medicaid, and, most importantly, enhanced coverage for certain mental health services. Also, there was increased access to prescription drugs and eliminating the 190-day lifetime limit on inpatient psychiatric hospital services for Medicare patients (Jauregui, 2016).

The HR2646 Act attracted high public interest and political attention due to the failure of The Substance Abuse and Mental Health Services Administration (SAMHSA) ability to focus its efforts on serious mental illness. The SAMHSA also failed to use existing science to develop policy and hire employees with medical expertise. SAMHSA also was unable to reduce rising trends and rates of homelessness, arrests, incarcerations, suicide, violence, and the hospitalization of people with mental illness. As a background, SAMHSA is a branch of the U.S Department of Health and Human Services, charged with improving the quality and availability of treatment and rehabilitative services to reduce illness, death, disability, and the cost to society resulting from substance abuse and mental illness. The Administrator of SAMHSA reports directly to the Secretary of the U.S Department of Health and Human Services.

As the problem, policy, and political streams began to converge, the resulting policy window was seized. Favorable policy windows opened in both the problem issue and the politics streams when various events such as the decrease in the quality and availability of mental health treatment and rehabilitative services and a need for increased early intervention programs, that will allow people to get the right mental health care at the right time. Another event was the increase in the incarceration of mentally ill individuals and the fight to keep them out of jail but in treatment—identifying the decrease in the mental health workforce and a lack of trained professionals. Also, there was a weakness of the enforcement of the mental health party law, which ensured that health plans were held accountable for the coverage people paid for.

The favorable policy window opened in both the problem and politics stream when two things occurred. The failure of the SAMHSA to improve and develop effective mental health policies, and the Assistant Secretary of Mental Health and Substance Use Disorders are replacing SAMHSA. With SAMHSA being replaced, the policy window was seized, and the streams were successfully converged. Kingdon (2011) pointed out that solutions become joined to problems, joined to favorable political forces. This coupling is more likely to occur when opportunities for pushing conceptions of problems are open. According to Kingdon, success is more likely to happen when all three streams are coupled, depending on the type of window that opens.

To open a policy window, the three streams needed to the couple, and as Kingdon points out, the separate streams come together during a critical time. This occurs when a problem is recognized; then, a solution becomes available. The political climate is also a factor that makes the time right for a change, where constraints do not prohibit action. In HR2646, the streams converged because there was a focusing event, which is the failure of the SAMHSA to focus its efforts on serious mental illness. This resulted in the SAMHSA being replaced by an Assistant Secretary of Mental Health and Substance Use Disorders, who is a psychiatrist or clinical psychologist, and the HR2646 Act being introduced at a time where common interests towards the solution predisposed politics streams.

Window of opportunity

The three streams work along with different, mostly, independent channels until a particular time, they then become a policy window, and they flow together or intersect (Beland & Howlett, 2016). This is the policy window or the window of opportunity that delivers change and moves items onto the government's formal agenda. The problem, the politics steam, and the failure of the SAMHSA to focus its efforts on severe mental illness combined to open up a policy window raising the issue of U.S mental health reform on the nation’s high priority agenda. According to Kingdon, policy windows are short-lived opportunists for advocates to focus political attention on a problem and promote their preferred solutions.

The importance of the window of opportunity is that once there is a problem that is recognized, in addition to an articulation of a solution, this is when the political climate serves as the right time for change. In addition, when this occurs when there are no other constraints that oppose this action that a new policy can be implemented. The coupling of the following three streams in this case is an example of a “window of opportunity” through which behavioral health policy is being implemented.

The window of opportunity: the problem stream

The Substance Abuse and Mental Health Services Administration (SAMHSA) failed to focus their efforts on serious mental illness. This resulted in a decline and a weakening of the U.S mental and behavioral health system. The U.S behavioral health policy was mired in post-crisis, there was an abundance of resources that have been spent on mental illness in courtrooms, jails, and prisons, but despite this, there was an increased revolving door of routine hospitalization, frequent incarceration, and chronic homelessness. There was not enough effort and time invested in the prevention, intervention, early identification, and integrated behavioral health services that promote recovery and change trajectories of lives for the better.

The problem stream refers to the moment that the policy issue requires attention and action. As mentioned, the increased revolving door of routine hospitalization, incarceration and homelessness showed the persistent disparities in behavioral health outcomes. This problem motivated policymakers to focus on a social determinant behavioral health approach. The ongoing developments also played a role in the increase of attention and focus on the existing disparities with behavioral health and other social determinants.

The window of opportunity: the politics stream

Government officials are sensitive and responsive to shifts in public opinion concerning an issue (Henstra, 2015). A problem is more likely to come under active consideration by policymakers and put to decision-makers for resolution if it is perceived that the balance of public opinion is supportive of government intervention (Henstra,2015). With the failure of the SAMHSA to improve the U.S. mental health system, and the need for improved behavioral health policies, increased and frequent hospitalizations, incarcerations, and less investment in prevention and early identification of integrated behavioral health services, all three streams- the problems, the politics, and the policy stream-converged and created a window of opportunity for the creation of a comprehensive policy for the U.S behavioral and mental health population. As Kingdon states, policy changes flow out of coupling problems, policy proposals, and politics. This policy would take the form of the HR2646 Act. The failure of the SAMHSA to improve the U.S mental health system contributed to both the problem and political streams that led to the solution found in the policy stream.

The politics stream refers to situations where there is availability of resources as well as motivation towards solving a problem. Funding became available to address these issues within behavior health services, and there was also an increased service coordination amongst health and behavioral health agencies. The three streams came together , to create this window of opportunity.

The window of opportunity: the policy stream

For a proposal to survive the vetting process, the members must regard an idea as technically feasible, meaning it is likely to achieve what it is intended to accomplish, and must also be compatible with the dominant values of the policy community (Henstra, 2015). The politics and the problem provided the policy window opening. The ideas about improving and laying down a new foundation for comprehensive mental health services and supports during childhood and continuing through the life span were debated in congress. This was a bipartisan action of congress, was backed with the support of the president at the time, and the commitment of the elected officials, towards improving mental health services and supports in the U.S. The steams eventually converge with this bipartisan action.

The policy stream usually occurs when a solution to the problem becomes available. We can see here, that during the debates in Congress, there was a bipartisan solution and action, which was supported by the President. This bipartisan support was triggered by a solution being available. All elected officials were on the same page, and agreed on their commitment towards improving the mental health services and supports in the U.S.

The window of opportunity: coupling of the streams

The focusing event, which was the failure of the SAMHSA to effectively lead and support the mental and behavioral health of the U.S population, opened a policy window of opportunity. According to Kingdon, both the problem and political streams occur during the agenda-setting. The convergence of streams occurred through the passage of the HR2646 Act. Policymakers seized the opening of the policy window of opportunity through the focusing event of the initial failure of the SAMHSA as the lead federal agency to support the behavioral health of the population, which prompted the enhancement and establishment of a new Assistance Secretary level leader. Policy entrepreneurs take advantage of a policy window to persuade newly receptive political decision-makers to address a current problem by choosing a policy proposal that has been previously endorsed by the policy community (Henstra, 2015).The problem of behavioral and mental health policy mired in crisis, to both the policy stream (HR2646) and the political stream, the appointing of a new administrator, the Assistant Secretary for Mental Health and Substance Abuse Treatment, who must be a licensed Psychiatrist or Clinical psychologist. The convergence of these streams led to the emergence of policy change toward mental and behavioral health in the U.S. The 2016 Helping Families in Mental Health Crisis Act was passed through a bipartisan vote. The bill was sponsored by Representative Tim Murphy and co-sponsored by Representative Eddie Bernice Johnson.

Summary

The literature reviewed in this chapter contributed valuable information to study the prevalence of childhood mental illness in the United States. Also, the literature reviewed in this chapter contributed to exploring the contents of the HR2646 and the intended improvement towards the current public policy. As previously noted, exploring the caregiver perceptions of this act, it is hoped that the results of this research study will inform policymakers on policy success and opportunities for improvement regarding services and care for children with mental illness.

As noted, nearly 1 in 5 children have mental, emotional, or behavioral disorders, such as anxiety, depression, ADHD, disruptive behavior disorder, and Tourette Syndrome. There have various barriers that hinder families from obtaining mental health care. In this manner, the literature review for this study identified a gap in understanding by focusing specifically on the prevalence of childhood mental illness in the U.S, the overview of the issue of childhood mental illness, the impact of childhood mental illness on families and caregivers, the services of availability to caregivers and children with mental illness, and finally the details about the HR 2646, and it's intended improvement towards current policy regarding mental illness. As previously noted, although research does identify the issues regarding childhood mental illness and the lapse in the provision of services, only a limited number of studies existed which explored the prevalence and impact of mental illness in the Bronx, NY, making this a critical literature review. Ultimately the literature review focused on providing significant insights on the prevalence of childhood mental illness and asserting that policies and laws will be useful in improving service provision to all children. In Chapter 3, I will be discussing the chosen methodology design for this study, the selected population of interest, how I plan to recruit and protect participants, and how I will be obtaining and analyzing data to answer the research questions.

There have also been a few subsequent bills or resolutions that have impacted the HR2646, such as the HR 5462. is a slight enhancement to the HR2646 Act, in that it amends the title of the Social Security Act in order to provide for a state Medicaid option that enhances administrative matching funds, towards statewide behavioral health access programs for children under 21 years of age. The HR 5462 expands the capacity of pediatric primary care providers to include, child and adolescent psychiatrists, psychologists, social workers, nurse practitioners, substance abuse counselors, and nurse practitioners. In the HR 5462 there is an increased monitoring of child and adolescent behavioral health activities by pediatric primary care providers.

Chapter 3: Research Method

Introduction

The purpose of this qualitative study is to explore and identify caregiver perceptions of The Helping Families in Mental Health Crisis Act (H.R. 2646) enacted in the year 2016. A phenomenological design was used to provide insight into this study. Individual telephonic interviews were conducted with participants living in the Bronx, New York. They are caregivers of a child receiving mental health services, interested in sharing their experience and insight on this existing policy. The completed study could bring about social change by enabling future systems to be developed and implemented to assist caregivers in the Bronx, New York, and other areas of the United States. Results from this study may reveal the effectiveness of the current policy H.R. 2646 and potentially inform additional guidelines that will meet the demand in areas of lack. This chapter outlines the setting, research method, design, and the role of the researcher. The methodology and procedures for data collection will be presented. Also, I will be discussing the data analysis, the strengths, and limitations of the study, issues of trustworthiness, and ethical procedures.

Research Design and Rationale

The primary research question that guided this study was: What are the caregiver perceptions of the Helping Families in Mental Health Crisis Act (HR2646)? Using the framework of the Kingdon's multiple streams model (2016), this research question was addressed, including an overview of the issue of childhood mental illness, the prevalence of childhood mental illness in the United States and the Bronx, NY, the impact of mental illness in children/ families of caregivers, services of availability for children with mental illness in the U.S, and details about the HR2646. The Kingdon's multiple streams model allowed me to gain a clear understanding of what caregiver's perspectives are on the HR2646 policy and how this policy impacts caregivers. By conducting this study, it is hoped that this research will inform policymakers of policy success and opportunities for improvement regarding services and care for children with mental illness.

For this study, I used the qualitative method to explore caregiver perceptions of the H.R 2646. The Qualitative approach is structured by the concerns of those who are the research (Henderson,2015). Qualitative research refers to the meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of things (Lune&Berg2017). Qualitative research is designed to reveal the substance that forms the action or outcomes typically measured (Crossman, 2020). Qualitative research investigates meanings, interpretations, symbols, and the process and relations of life (Crossman, 2020). In the upcoming paragraphs, I outlined the chosen method of this research (qualitative); I also provided a rationale for choosing this method over quantitative or mixed methods, and finally provided additional detail about using the qualitative approach with my study.

The qualitative approach to data collections differs from the quantitative methods of research. Qualitative research is an approach for exploring and understanding the meaning of individuals or groups ascribed to a social or human problem (Creswell, 2019). In other words, qualitative research refers to the process of research that involves emerging questions and procedures of data that is typically collected in the participants setting and data analysis built from general themes and the researcher making interpretations of the meaning of the data. Hammargerg et al. (2016) referred to qualitative research as a method used to answer questions about experience, meaning, perspective, most often from the standpoint of the participant. Hammargerg et al. noted that qualitative research techniques include small group discussions for investigated beliefs, attitudes, and concepts of normative behavior. Semi-structured interviews seek views on a focused topic, or with critical informants, for background information or an institutional perspective, and 'analysis of texts and documents, 'such as government reports, media articles, websites, or diaries (Hammargerg et al., 2016).

There are several advantages to qualitative research. First, it is more targeted and can capture changing attitudes within a target group. Also, qualitative research provides a much more flexible approach. If useful insights are not being obtained, researchers can quickly adapt questions, change the setting, or any other variables to improve responses (Crossman, 2020).

Qualitative researchers are interested in understanding how people interpret their experiences, construct their worlds, and what meaning they attribute to their experiences (Butina et al., 2015). The primary characteristics of qualitative research include: (a) the focus on understanding peoples' experiences with the intent to convey experiences into meaning, (b) the researcher is the critical instrument for data collection and analysis, (c) the research process is inductive, not deductive and (d) the product of qualitative research is richly descriptive (Butina et al., 2015). Other characteristics of qualitative research are that the study design is often emergent and flexible, data is often collected in a natural setting, multiple forms of data may be collected, and sample selection is usually purposeful and small (Butina et al., 2015).

A mixed-method approach is a combination of a collection of qualitative and quantitative data. A mixed-method study requires a larger team to conduct more extensive research and qualitative experts who are comfortable discussing quantitative analysis and vice versa (Cresswell, 2014). This may be difficult to find, given that each method must adhere to its standards for rigor, and ensuring the appropriate quality of each component of a mixed-method study can be challenging (Cresswell, 2014). As such, neither a quantitative nor a mixed-method approach will be appropriate for this study. By choosing a qualitative research method, over a mixed or quantitative, will be able to describe the complexity, breadth, or range of occurrences or phenomena (Curry et al., 2009).

Qualitative research is defined as a broad approach encompassing many research methods and the systematic collection, organization, and interpretation of textual information (Young & Hren,2016). Qualitative research generates a comprehensive description of processes, mechanisms, or settings and characterizes participants' perspectives and experiences (Young & Hren,2016). While gathering data sets, the qualitative method allows for increased interaction between participants and the researcher. Qualitative method is used to answer questions about experience, meaning, and perspective, most often from the participant (Hamarberg et al., 2016). Qualitative research techniques include 'small -group discussions' for investigating beliefs, attitudes, and concepts of normative behavior; 'semi-structured interviews,' to seek views on a focused topic or, with critical informants for background information or an institutional perspective; 'in-depth interviews' to understand a condition, experience, or event from a personal perspective; and 'analysis of texts and documents,' such as government reports, media articles, websites or diaries, to learn about distributed or private knowledge (Hamarberg et al., 2016). Description of qualitative research is useful because it can reach people who do not usually volunteer for research and reveal (for example, in this study) the caregiver perceptions of the HR2646 legislation. Quantitative studies generally involve the systematic collection of data about a phenomenon, using standardized measures and statistical analysis (Hamarberg et al., 2016). In contrast, qualitative studies suggest the systematic collection, organization, description, and interpretation of textual, verbal, or visual data (Hamarberg et al., 2016).

There are various distinctions between qualitative and quantitative research. Quantitative research searches for facts, such for example, the number of people the number of percentage of people that prefer a product over another, and measures the phenomena (Barnham, 2015). In contrast, qualitative research is used to obtain a more in-depth understanding of individual attitudes and is associated with "why" questions (Barnham,2015). Barnham noted that even though qualitative research seeks to understand what people think and why they behave a certain way, it also identifies what people think and do.

This study is a detailed qualitative study using interviews as data collection design. I have conducted a comprehensive examination of several qualitative approaches to determine the most suitable method to be used in this study. This research is a simple generic qualitative study that will allow for the gathering of data in answering such questions as to how and why. In this study, to justify the qualitative design approach, the objective is to ask both how and why. Using the form of qualitative research to explore the caregiver perceptions of the HR2646 Act will produce the best results.

This is simply a qualitative study, and Howlett's (2015) five stream confluence model conceptual framework, both found within the qualitative tradition, will provide the data-rich material needed to explore this study accurately. A qualitative study can provide a more in-depth insight into the overview of the issue of childhood mental illness, the prevalence of childhood mental illness in the U.S, the impact of mental illness in children, on family/caregivers, and the services of availability for children with mental illness in the U.S. all relates to the caregiver's perception of the HR2646 Act. The qualitative design of this study and the conceptual framework of the Howlett's Five Stream Confluence model, both found within the qualitative tradition, will provide the depth of inquiry and material needed to explore the caregiver perceptions of the HR2646 Act accurately. The use of the conceptual frameworks chosen for this study will provide more relevant information related to the perceptions of the participants of this study.

Role of the Researcher

The role of the researcher in the proposed research is to analyze and collect data. I am committed to making every effort to treat the study and any information that is gathered objectively. I worked towards minimizing researcher bias by understanding that some bias will always be present. Despite this, in recognizing such existing bias, I increased my objectiveness when conducting interviews of the participants and analyzing the data. My interest in this topic stems from my profession and work in mental health and childhood mental illness.

When it comes to researcher bias that might occur, qualitative data makes it difficult for the person analyzing to separate himself or herself form the data. Creswell (2016) cautioned that data analysis and the gathering of data must be closely monitored. There are various ways to maintain objectivity and avoid bias in qualitative data analysis by using multiple people to code the data, having participants review the results, conduct triangulation by verifying with more data sources, check for alternative explanations, and review findings with peers (Creswell, 2017). Therefore, using the qualitative methods in this study on the caregiver perception of the HR2646 Act will help collect essential data needed to conduct this study.

For the duration of this study, I collected and analyzed the data to identify thematic content. I remained honest and open and always conducted myself in a professional manner and without expressing any personal agenda. I did not falsify, skew any data, or fabricate results to arrive at the products that I want to see, which did not take place. I kept accurate and complete notes, and my research activities were documented. I used an audio recorder during my telephonic interviews to capture the interviews verbatim. I transcribes all the records, to the best of my knowledge, and I carefully analyzed the recorded data. I provided study participants with a transcription of their interview to verify that I have accurately captured their responses.

Methodology

Participant Selection Logic

The setting for this study was in the Bronx, New York. Childhood mental illness is prevalent in the Bronx, NY. More than 18,000 children receive public mental health services in NYC weekly, and 26% of the children receiving public mental health services reside in the Bronx (Citizens Committee for Children,2020). The prevalence analysis conducted by the Citizens Committee for Children revealed that 108,204 children in the Bronx between the ages of 0-4 and 8,981 children ages 0-4 in the Bronx are estimated to have a behavioral problem (CCC,2020). There are 281,629 children in the Bronx between the ages of 5-17; 56,326 children ages 5-17 in the Bronx are estimated to have a mental health disorder, and 28,163 children ages 5-17 Bronx have serious emotional disturbance (CCC,2020). The prevalence analysis conducted by the CCC revealed that there is a significant amount of children who do not have access to mental health treatment in the Bronx, NY.

This study used purposive sampling. Purposeful sampling is widely used in qualitative research for the identification and selection of information-rich cases related to the phenomenon of interest (Palinkas et al.,2015). This sampling method involves identifying and selecting individuals or groups of individuals that are exceptionally knowledgeable about or experienced with a phenomenon of interest (Palinkas et al.,2015). In purposive sampling, the subjects are selected based on study purpose with the expectation that each participant will provide unique information of value to the study (Etikan et al.,2016). The purposive sampling technique, also called judgment sampling, is the deliberate choice of a participant due to the qualities the participant possesses (Etikan et al.,2016). It is a nonrandom technique that does not need underlying theories or a set number of participants. The researcher decides what needs to be known and sets out to find people who can and are willing to provide the information by virtue or knowledge or experience (Etikan et al.,2016). The goal of purposive sampling is to focus on people with characteristics who will assist with the relevant research. To achieve the best results, it is suggested that qualitative research be a minimum of 10 participants; this can be extremely fruitful and can yield relevant results (Shetty,2020). In this study, the sample for individual interviews will consist of 10 caregivers.

To identify potential participants for this study, I obtained written approval from the facility director, to conduct the study at a Health Home Community Based Agency. I will provided recruitment flyers and consent forms to the agency, at the time when the announcement was made via email and distributed in person at the facility. The announcement and the flyers were in English. I provided the recruitment flyer (see Appendix D) and a consent form (See Appendix C) which stated that the parents agreed and wanted to participate in this study. The recruitment flyer included the criteria for participation, those who (a) reside in the Bronx NY, (b) who are caregivers of a child receiving mental health services form the Abbott House agency, and enrolled for six months or more; (c) are interested in sharing their views on the HR2646 policy. This is the sampling frame for this study. I also planned to visit the facility on a weekly basis, in order to distribute the recruitment flyers and consents at the main office to encourage involvement in the study. To avoid putting the responsibility of distribution on the caseworkers, I had the agency mail the flyers and consents to the families via email as well. I paid for the cost of postage and provided the flyers. The clients would in turn contact me directly. This meant that the organization would not know which clients contact me. The clients also contacted me voluntarily as they would not feel any implied or direct pressure from their case manager. I continued the follow up process of distributing flyers at the facility, and making announcements until I obtained at least ten participants. Once those caregivers completed and returned their consent forms, which stated that they wanted to be a part of the study, I proceeded to contact each caregiver and explained the purpose of the study. I determined if participants met the criteria to participate in the study, and asked them if they would be comfortable participating in an interview via Zoom or / phone call. These interactions took place through email or by speaking on the phone. Once I identified the ten participants that meet this criterion, and the consent to participate in this research study was obtained, I contacted each parent via telephone and scheduled the interview sessions. The consent form serve as the parents agreeing to be a part of this study, and giving the facility the authority to provide the caregiver contact information. As stated earlier, the consent documents were provided to the facility, and the agency mailed them out to the families. I covered the cost of postage, and the goal was to avoid putting the responsibility of distribution on the caseworkers. I also provided the facility employees with my email and phone contact information, that they provided to the parents who showed interest in participating and actively sought to obtain more information about participation. My contact information was also be provided on the flyers and consent forms.

Samples in qualitative research tend to be small, to support the depth of case-oriented analysis fundamental to this mode of inquiry (Vasileiou et al.,2018). Data saturation can be attained if there are ten or more participants that take part in this study (Vasileiou et al.,2018). The justification for the number of interviewees asked to participate is support by the author, who considers that saturation occurs as the point in which additional data do not lead to any new emergent themes (Saunders et al.,2017). Birks and Mills (2015) relate saturation primarily to the termination of analysis, rather than collecting new data.

When it comes to the characteristics of the study participants, selection criteria occur in purposive sampling, which is prepared by the investigator. This criterion contains elements that are relevant to the propose of the topic of this research study. Purposive sampling was used to obtain participants and included participants who (a)reside in the Bronx, New York, (b)have had their child enrolled in the mental health agency being used in this study for at least six months, (C) is caring for a child diagnosed with a mental illness, and (d) are interested in sharing their experiences. The study participants will also need to be able to read/ comprehend English. Since the interviews were electronic, participants also needed to have access to the internet and access/knowledge of using Zoom. The primary reason for selecting the Bronx, New York, is because I have specific knowledge of the geographic area. The prevalence analysis conducted by the CCC reveals that there is a significant number of children who do not have access to mental health treatment in the Bronx, NY.

Triangulation was used to ensure that all the collection materials are used appropriately and efficiently. The term triangulation refers to the practice of using multiple sources of data or various approaches to analyzing the data and to enhance the credibility of the research study (Sage,2015). In this study, triangulation will occur when the data that is gathered from the interviews are interpreted in fulness. To ensure accurate triangulation, I read back participant responses to the participants to ensure that I have heard them correctly. I also recorded interviews so that I could have a second source of data and the notes I will take. I sent the transcribed responses to participants to make sure the transcription accurately reflected their responses. This provided me with three checks of the data to ensure that I did not misinterpret what the participants said.

Instrumentation

Semistructured Interviews

Instrumentation in this research study involved the use of semi-structured zoom interview sessions. The use of semi-structured interviews allowed me to explore the experiences and caregiver perceptions of the HR2646 Act. Semi-structured interviews are a beneficial tool for participants. Semi-structured interviews allowed the participants the freedom to express their views on their terms and also provided reliable, comparable qualitative data (Crabtree,2006). Another benefit of semi-structured interviews is that the interview questions can be prepared ahead of time.

In addition to semi structured interviews, there was both an audio recording and a manual recording of notes during the study. While conducting phone interviews, I served as the moderator to lead the discussion with my main objective being to enable the conversation to flow freely and ensure that the participants feel comfortable. I gathered data through the collection surveys and demographical data from respondents. I wrote and recorded the interview questions. In line with significant policy components of the HFMCHA, I developed questions to drive the direction of the phone interviews (see Appendix A). Before recruiting participants, the items were provided to subject matter experts in mental health and public policy, familiar with caregivers of children with mental illness to receive feedback.

The following table outlines the policy points, aligned with the interview questions posed to the caregivers during the interviews, to determine the impact this policy has on the caregiver experience. The follow- up questions depended on the answers that the caregivers provide to the initial questions. Notably, the HFMCHA policy focuses on mental health reform by providing incentives to build an adequate and skilled mental health workforce to expand access to mental health care by providing quick and effective diagnosis and treatment (NAMI,2016). This legislation was aimed towards helping to promote a patient-centered mental health care system. This policy incorporates measures and funding to help caregivers and families get the necessary care required. The proposed interview questions listed were answered by participants within the 60-90 minute timeframe in order for participants to tell me their story. The goal was for the participants to answer the research questions, while addressing the four issues of availability, billing, patient rights and policy responsiveness. My data analysis focused on the theoretical aspects. The participants involved in this study, did not need to be experts on the theory or the policy, instead they need to be experts in taking care of children with mental illness.

Table A

Policy points & questions

Policy section	Proposed Question	Continued question
•Sec. 503: Policy provides grants to enhance crisis response services, to develop psychiatric inpatient and residential bed tracking, and to support assertive community treatment programs.	What types of crisis or emergencies have your children experienced due to their diagnosis?	What is your view of the quality of response services offered to you in your community? How effective were the services provided during this period of crisis, and what is your view on the level, variety, and impact of community treatment programs available in your area?
• Sec. 717: Policy supports the mental health workforce by adding pediatric mental health professions to the National Health Service Corps loan repayment program.	From a caregiver perspective, what is your view on the number of mental health professionals currently focused on pediatric mental health? How do you feel that the assistance of the loan repayment program would impact the number and level of pediatric mental health professionals?	
• Sec. 202: About hospital discharge procedures, this policy requires Medicare reimbursed hospitals to prepare discharge plans and facilitate connection with outpatient treatment for patients they are discharging.	From a caregiver perspective, what is your view on hospital discharge procedures?	What is your view on the available support and the connection with outpatient treatment programs?
• Sec. 713: This policy increases the minority mental health workforce by authorizing fellowships to increase the number of culturally competent behavioral health professionals.	From a caregiver perspective, what is your view on the behavioral health professionals representing minorities in the Bronx, NY? What race do you consider yourself?	What impact do you feel that an increase in more culturally competent behavioral health professionals will have on the level of care provided in your community?
• Sec. 503: Policy encourages early intervention by setting aside 5% of state mental health block grant funds for evidence-based programs that address early serious mental illness.	What evidence-based programs address early serious mental illness? How impactful do you feel that the 5% allocation of grant funds will be in bringing about change and increasing the number of such programs?	
• Sec. 201: Policy eliminates the 190-day lifetime cap on inpatient psychiatric hospitalizations in Medicare.	What has been your experience with your child and inpatient psychiatric hospitalization that lasted more than 190 days?	How did the lifetime cap affect the level of care received?
• Sec. 101: In Congress, the assistant secretary for mental health and substance abuse treatment must be a licensed psychiatrist or clinical psychologist. This raises the profile of mental health and ensures that the lead policy official for something about mental illness.	What is your view that those in Congress and at the government level, who are involved in making decisions concerning mental health in this nation, are licensed psychiatrists or clinical psychologists?	How do you feel that the requirement for policy officials to know something about mental illness impacts the policies and laws that are passed in the field of mental health?

To adequately interpret the lived experiences of the participants, I used Montoyas's (2016) approach to the interview protocol in this study. Montoya's interview protocol refinement (IPR) framework is a four-phase process geared towards developing and fine-tuning interview protocols. IPR's four phases include ensuring the interview questions align with the study's research questions, organizing an interview protocol to create an inquiry-based conversation, having the protocol reviewed by others (Montoya, 2016). The flexibility of Montoya's semi structured interview protocol will allow the qualitative researcher to strengthen the reliability of their interview protocols as instruments by refining them through the IPR framework. The IPR framework is most suitable for purifying semi-structured interviews by enhancing interview protocols; researchers can increase the quality of data they obtain from research interviews (Montoya, 2016). Examples of how my protocol does this was achieved by ensuring that I apply the four-phase process of the interview protocol refinement. I ensured that the interview questions all aligned with the research question. I constructed an inquiry-based conversation and received feedback on interview protocol. Finally, the fourth phase involved piloting the interview protocol,

As previously mentioned, telephonic semi-structured interviews took place due to the current COVID-19 crisis and ensured safety and practice for social distancing. The primary intention of this study was to ensure that all participants felt comfortable and not inconvenienced. Conducting telephonic interviews was beneficial to the participants, in that they were able to participate in whichever location they feel most comfortable. The meetings lasted between 60-90 minutes. Also, I used an audio recorder to caption the interviews to be transcribed. The participants also had the opportunity to review their interview transcripts to verify accuracy.

One of the instruments used in conducting the interviews was a researcher's journal, that allowed me to keep track of participant answers. I assigned a participant designation number so that I could know which responses to send to each participant for them to review. This was how the participants could validate that what I had written down and collected is what they intended to relay. The journal was used to take notes and to record my thoughts in the margins. To ensure that there are reliability and validity, and until the data saturation occurs, I conducted the questioning in an iterative style by capturing in-depth descriptive data from study participants. I also performed member checking during the study to ensure that the participants share precisely what they intend to share.

The interviews were recorded using the software platform called Otter.ai, for ease in later transcription, with the permission of the participants through a signed consent form (See Appendix C). I conducted audio recordings of the meetings and transcribe the tapes. I then asked the participants to check the interviews to ensure credibility. The participants were provided with a copy of the transcript after all the interviewing and transcription had been completed. When the recordings were transcribed, I listened to the recorded audios and reviewed the transcripts, participant feedback, and related notes that I had taken in the margins of my codebook. I followed this up by conducting the open coding of the data manually, and I did a thorough review of the associated notes to identify the categories of information shared by respondents. Through the coding of this data, I located possible themes that emerged from the responses. I saved the interview transcripts in a Microsoft Word Document and backed up on a hard drive. The hard drive, consent forms, and transcripts will be stored in a locked location for five years. After five years, the data will be discarded.

Artifact data.

When studying culture, social setting, or phenomenon, collecting and analyzing artifacts produced and used by participants can foster understanding (Crabtree,2006). An example of an Artifact are written texts such as , documents, diaries, journals, memos, meeting minutes and letters. Artifacts are things that societies and cultures make for their use; they provide material evidence of the past by documenting and recording the past (Given, 2008).

Analyzing documents from N.Y. Office of Mental Health (OMH) and the city of the Bronx, NY, were be useful in this qualitative study and allowed for the utilization of existing documentation related to the phenomenological studies. Using such material will provide a greater understanding of the issue in context. An analysis of the respective artifacts (OMH and the city of the Bronx, New York) was blended with a review of the interview data to provide additional detail and depth about the phenomenon.

Procedures for Recruitment, Participation, and Data Collection

I directed this study towards caregivers with children currently enrolled or participating in a specific community-based rehabilitation facility in the city of the

Bronx, New York. Given that I recruited with parents of members of a protected group (i.e., children with mental illness receiving services from a treatment facility), the recruitment process was particular and transparent. I requested and received approval from the facility director to conduct the study at the facility. This was done via the Community Partner agreement, and I also attached the letter from the agency, which states that I was notified of my official clearance date pending the results of a background check (See Appendix A). Subsequently, I provided the agency with the recruitment info and a cover letter (see Appendix B), and a parent/guardian consent for contact, for potential participation (see Appendix C). The agency then mailed out the information to the parents. The parents then contacted me if they were interested. The goal was to make this process as easy and efficient as possible for the agency.

The sampling frame included participants living in the Bronx, NY, who are caregivers of a child receiving mental health services. A criterion for inclusion in this study was that the child of the parent or guardian has been an enrolled member of this mental health agency for six months or more. This period is an adequate timeframe for a caregiver to gain experience and familiarity with the child's symptoms of the diagnosis and treatment. I used convenience and purposive sampling method to recruit ten caregivers that were utilizing the community-based facility. To recruit from the sample frame, I provided the facility administrator with both a hard copy and an electronic copy of the recruitment flyer (See Appendix B). The administrator facilitated having the hard copy of the flyer displayed in the facility. The flyer explained the purpose of the research and the requirements of participation. The flyer also included contact information for me, so parents who were interested in participating could contact me via phone or email, based on their preference. Parents/ caregivers who would prefer to have me contact them could request such from the agency staff by completing the Memo of interest (See Appendix C), which served as written confirmation that they are amenable to contact for potential participation in the research.

Once interested parents/ caregivers contacted me or the facility identified interested parents and parent/guardian consent for contact for potential participation forms (See Appendix C) were received, I contacted each parent via telephone, to schedule the interview sessions, and answered any questions they might have prior to the interview. Before scheduling or conducting the interview, I consented the participants by having individuals complete the consent to participate in research form (see Appendix D). Once the forms had been signed and submitted by the participant, I conducted an in-depth phone interview with each caregiver. Qualitative samples must meet the balance of being large enough to represent most or all the salient perceptions, but at the same time, the sample should not be so large that the data becomes repetitive (Mark, 2016). As stated earlier, the workers and care managers from the facility collected documents that demonstrated the parent/ caregiver’s willingness to be contacted in order to receive more information to determine if they wanted to participate in the research. The parents were not consented until they agreed to participate.

I used in-depth interviews to dig deeper and go further in gaining specific insight into the perceptions of the caregivers. The interviews conducted during this study were the source of data collection. I used a semi structured interview method; I also audio recorded all the interviews, and single notes manually on paper as well. I completed 10 in-depth interviews, one for each participant. If there happened to be too few participants that were willing to take part in this study from this organization, I planned to obtain more participants from a second community-based mental health agency, also located in the Bronx, NY. It is important to note that the participants could opt-out at any point in the research process. Also, the frequency of data collection of events occurred every week and lasted for four weeks. I conducted follow up phone interviews one week after the initial meetings. I again reminded the participants that they have the option and ability to opt-out and withdraw their consent to publish the results and findings of the study.

The in-depth interviews were completed when I obtained all the responses to my questions from the participants. However, the participants could stop at any time they desired without consequence. Based on current literature, there are specific methods that I used to quantify or determine when I have exhausted the information, also known as saturation. Data saturation occurs when there Is enough information to replicate the study, and when it is no longer possible to obtain additional information (Fusch & Ness, 2015). When I reached saturation, stopped collecting data, I began to round off my analysis. I could not assume that I have entered data saturation just because I have exhausted the resources; congestion is not about numbers, but about the data (Fusch & Ness, 2015).

The intent was to interview at least ten people or until data saturation was reached. Data saturation is achieved when no additional data is being found whereby the researcher can develop the category (Saunders et al., 2017). As the researcher sees similar instances repeatedly, the researcher becomes empirically confident that a category is saturated (Saunders et al., 2017). I knew that I had reached data saturation when the ability to obtain new information had been attained. I also planned to reach data saturation by structuring the interview questions to ask multiple participants the same question. I went out of my way to stretch the diversity of data as far as possible to ensure that the saturation is based on the broadest possible range of data on the category. The interview questions were structured to facilitate the responses. Based on this, I determined when I had exhausted the information found when I came to the point of the study where there is no new data, theme, or coding. Following the completion of interviewing, the debriefing session concluded the study process. This included explaining what will occur with participants' information after I complete the research study. I reminded the participants about the purpose of the research study to ensure each participant had a clear understanding of the overall goal.

Data Analysis Plan

Qualitative data analysis involves processing rich data, such as from interviews and field notes, into striking patterns and themes (Maxwell, 2015). The first step of data analysis in this study was to record my data and prepare memos. I maintained an accurate record of data collected during this research study, documenting all phases of the research and evaluation process through detailed notes, transcripts, diagrams, and other materials. During the focus groups and phone interview process, I maintained records and audio recordings of each session. After each interview session, I systematically transcribed notes into a template to support the organization. I prepared memos during the data collection while also investing time in listening to the audio recordings from my interview sessions and noting the critical points discussed by the participants.

The second step of data analysis is labeling and archiving my data to aid in the study and identification of sources. I used a spreadsheet to store and maintain information such as the name of the interviewee and the researcher, the location of the interview, the date and time of the meeting, and the data collection methods such as interviews, observations, and focus groups. All names were kept separate from the data to protect confidentiality.

The next step in my data analysis process was to understand the subjects of the data collection. I organized the research participants' demographic data with a template or chart to record their age, gender, ethnic group, occupation, educational level, and other relevant details that help understand the sample representation. This information informed and helped those reading the study to understand the experiences of the caregivers and their diverse backgrounds, which supported the validity of my results and conclusions. Additionally, when I returned to review my notes, this recording method enabled me to remember the subject of the data.

Subsequently, the process of reviewing all my notes and interview transcripts thoroughly began. I simultaneously made comments in the margins identifying the key patterns, themes, and issues in the data collected. Coding enabled the organization of my data in terms of its subject matter.

Next, I reviewed my data to code the data according to the identified themes and issues. During my analysis, I used codes to organize my data into four themes/ categories such as, availability of care plans and resources, medical billing practices, patient rights and protection and responsible governance of policy and resources. This coding method gave me the ability to identify relevant data and enabled me to synthesize related points later during my analysis. As I fully identified and labeled these codes, I simultaneously built up a detailed understanding of the data.

In addition to the summarization and organization of the data, I compiled a condensed version of the information in a matrix. Using a pattern provided an opportunity to display the data in an organized and concise format. I developed the design of the experiences of raising a child with a disability and their views on the current policy Helping Families In Mental Health Crisis Act. Based on the themes found in the data and supplemented with the literature that addresses how families cope with raising a child with mental illness and its impact on the family dynamic (Plumb, 2016). This matrix also included how the disability impacts caregivers' specific views on the current policy.

Further, reflected the data derived from the study, which pertained to the experiences and emotions that the caregivers felt while raising a child with mental illness. The matrix focused on the experiences of the caregivers, including the support from other family members or community members or lack thereof. The pattern also summarized information about the caregivers' evaluation of the amount of support they felt the existing policy provides, mainly dealing with everyday living while raising a child with a mental diagnosis. Additionally, I also included information on caregivers' perspectives on:

- Level of support from government officials and lawmakers in Congress.
- Effectiveness of developed policies.
- Struggles and barriers experienced when trying to obtain mental health services for their children.

Furthermore, I used the matrix to summarize the information derived on how these frameworks might impact the caregivers' beliefs of: (a) the strength of the state and government resources geared towards assisting the child's diagnosis, (b) how existing policies at the government level may have played a role and impacted the health and development of the child, (c) how current systems change the treatment available for the child's mental health condition, (d) the effectiveness of the child's mental health treatment, (e) the level of care and access to help, and (f) how their child's diagnosis impacts their own social life.

The emerging data must be tested for their plausibility, sturdiness, and confirmability—that is, their validity (Miles & Huberman, 1994). When it comes to the qualitative data analysis in this study, I must support that all the conclusions derived from the data are empirically sourced and defensible. During this data analysis phase, I synthesized the data by comparing the results I have obtained with my expectations, my original goals, and my research questions laid out before the data analysis. During this data analysis, I addressed the results of the interviews and how the results are consistent with or contrary to current relevant research in this field. Once I summarized the primary research, I identified the results of my analysis, and concluded the caregiver perceptions of HR 2646.

Issues of Trustworthiness

There are various strategies to ensure the maintenance of credibility and internal validity during this research study. The main goal of this qualitative study was to pursue, establish, and formulate a trustworthy source of data to address the study's purpose. This research aims to emphasize credibility, transferability, dependability, and conformability. Internal validity ensures that the review is testing the intended research question focus. The establishment of credibility involves the early development of the familiarity and the culture of the participating organization. It also consists of the event of an early familiarity with the respondents who are involved in the study. I researched the facility before starting the data collection and by reading the documentation of the previous history of the location. This preparation allowed me to understand the history of the organization involved in this study. When establishing credibility, the method ensured that there is prolonged engagement between the researcher and the participants. During this study, I encouraged the participants to be honest and candid with their responses. I ensured that the data collection process in this research involves individuals that are genuinely willing to participate in the study. Study participation is entirely voluntary, with the respondents being able to opt-out of the research study at any point. The use of triangulation, a method used in qualitative research to check and establish validity in the study by analyzing a research question from multiple perspectives to arrive at consistency across data collection sources (e.g., observations, focus groups, and individual interviews), assisted in strengthening credibility. Another method of establishing credibility is by employing tactics to encourage participants' honesty and accurate responses. All participants had the option of refusing to be a part of this study and withdraw their consent and participation during or after the review. Another method to establish credibility was through the use of peer scrutiny during the research study. Having a fresh perspective of a colleague or an academic peer helped obtain a new outlook on the research study.

Given that the data involves caregivers of a protected class of research participants (i.e., the mentally ill), it is vital to take that certain precautions to ensure confidentiality. I employed the "dominant approach," the most common method used to protect respondent confidentiality (Kaiser, 2009). I collected, analyzed, and reported data without compromising the respondents (Kaiser, 2009). I exercised the use of the "convention of confidentiality," which is a means to protect research participants from harm (Kaiser, 2009). In this research study, I dealt with vulnerable populations such as minors and their caregivers, who could potentially face negative consequences if I revealed their identities. I addressed the dominant approach and confidentiality during the research planning and during the process of obtaining approval to conduct research known as "procedural ethics" (Baez, 2002). Furthermore, I addressed issues of confidentiality during the data collection, cleaning, and dissemination processes.

During the period of data collection, I reassured confidentiality via online consent forms and statements. I discussed confidentiality agreements at the beginning of the data collection process. Talking confidentiality at the outset is necessary for obtaining informed consent and building trust with the respondents (Crow et al., 2006). I ensured confidentially during the data cleaning process in which I omitted or removed certain identifiable information from the dataset. In addition to the "dominant approach," I ensured confidentiality through the "alternative approach." The alternative approach provides practical guidelines to reduce the uncertainty surrounding the use of detailed data that might lead to deductive disclosure (Kaiser, 2009). The alternative approach ensured that I inform the respondents about using the data, and it will also facilitate dialogue with the respondents on how I will use their data post data collection.

To ensure transferability, I attempted this by thoroughly describing the research context and the assumptions that are central to the research study. In this case, the transfer was not sensible because I will not generalize my results much beyond the parents/caregivers who utilize the program from which my sampling frame will be generated. I cannot assume that parents’ experiences will be the same with other programs because other programs might implement the policy differently.

When it comes to dependability, the goal of this study will be to show that if another researcher replicated the investigation, he or she would obtain similar results. To address the issues of dependability, I conducted the study and reported the results in detail, which enabled future researchers to replicate and compare study results. I detailed my research practices and an account of the design, implementation, and execution of the research. Moreover, to ensure the conformability of this study and its results, it was necessary to admit my beliefs and assumptions before commencing this work. I acknowledged the potential shortcomings of the research study to maintain the integrity of the research and allow for a critique of the results.

Ethical Procedures

Specific ethical procedures were considered to conduct this research study. The moral system involved obtaining an IRB application and submitting all the supporting materials to Walden University before starting the data collection. The IRB application ensured that the selection of the data will provide beneficial information that outweighs the potential risks or costs. It also ensured that the procedures follow federal regulations and university policies. Following successful IRB approval, I provided the study documents to the facility and parties involved in the recruitment phase of the research study. Once potential participants are interested, I explained the details of the research and asked them to participate by providing informed consent. I clearly described to participants the study's goals and potential benefits and risks involved in taking part in the survey. I informed the participants of their role in the research and the options they have regarding their participation. There was an understanding of what the research entailed and full disclosure throughout the study. Participation in the survey was always be voluntary; there were no pressures through coercion.

There is a tendency for caregivers to feel obligated to participate in this study because they have a child receiving services in the location that the review is taking place; this raises an ethical concern. To address this moral concern, I ensured the facility administration clearly explained, in written and verbal formats, to all parents that there is no undue obligation to participate in this study, and no contingencies exist for treatment services. It was necessary for participants to consider the implications of their involvement. I maintained the confidentiality of participants' relationships and ensured participants are aware that they may stop participating in the study at any time, including before conducting the research, during the investigation, and after I have collected the data. This is an essential policy in terms of ethical consideration. It provided the foundation of freedom that enabled the participants to be open and unrestricted during the research study. Following the research study, I shared the study results with participants and any additional information that I discovered. When reporting the research findings, I used anonymous terms such as "Subject 1" or "Participant 1," to maintain the confidentiality of the participants throughout the study. I had exclusive access to all of the data, and I did not distribute it to third parties.

Summary

The main points of this chapter addressed the purpose of the study, the description, and rationale for the research design, my role as the researcher, and any existing personal relationships with the participants. The methodology included information on the selection criteria, the participant selection process, and the rationale for establishing the number of study participants needed. I also discussed the instrumentation procedures, in particular, software programming. Further, a highlight of this current chapter was the establishment of credibility and trustworthiness during the study. The establishment of credibility led to the discussion of ethical procedures required for this study to research in a proper manner that upholds the beliefs of the university and respects the participants involved. In the following chapter, I will continue to provide an in-depth explanation of the setting of the research study and the demographics. I will also offer evidence of trustworthiness, including descriptions of specific and methods of data analysis.

Chapter 4: Results

Introduction

The purpose of this qualitative study was to explore the caregiver perceptions of The Helping Families In Mental Health Crisis Act of 2016 (HR2646). I interviewed ten caregivers of children experiencing mental illness to learn their perspectives on HR2646. Since the bill dramatically tightens the definition of evidence to determine the efficacy of programs, the goal of the research study was to learn caregiver perspectives on the impact that the HR2646 Act has on their lives and in providing resources to assist the caregivers their children.

The research question – What are the caregiver perceptions of the Helping Families In Mental Health Crisis Act (HR2646)? – was accompanied by lines of inquiry in the data collection in four different areas of this policy: (a) availability of care plans and resources, (b) medical billing practices, (c) patient rights and protection, and (d) responsible governance. In this chapter, I will present the study findings and detailed analysis of the interview narrative responses. Specifically, this chapter covers the following topics: (a) setting, (b) demographics, (c) data collection, (d) data analysis, (e) evidence of trustworthiness, and (f) results.

Setting

The setting for this study was the Bronx, New York. It was directed towards caregivers with children currently enrolled or participating in a specific community-based mental health agency in the city of the Bronx, New York. Caregivers of members of a protected group (children with mental illness) receiving mental health services from this agency were chosen for the study. Due to the Covid – 19 pandemic, all interviews were telephonic/ via zoom. The interviews were conducted individually, which gave each participant the freedom to open up and talk freely with minimal prompting. I began each discussion with each participant by thanking them for being part of the study. I explained that their participation was wholly voluntary and could be stopped at any time. I thoroughly explained the purpose of the research study to each participant, and as a result, the participants demonstrated a willingness to answer each question. There were no organizational or personal constraints that influenced the participant's participation.

Demographics

The data collection method involved semi structured interviews focused on gaining specific insight into the caregiver perceptions of the HR2426 Act. Ten participants were interviewed for this study, resulting in enough information, making data saturation possible. As seen in Table 1, the participants consisted of 9 females and one male. All participants were residents of the Bronx, NY. They are all caregivers of children with mental illness who have received services from a community-based mental health agency for at least one year or more. Participants were all asked nine identical interview questions. Upon completing the interviews, the data was collected and analyzed, which contributed to answering the research question.

Table 1

Participant Demographics

Demographic Information	Data
Males	1
Females	9
Age Range of Children in the home	6-17 years
The Bronx, NY as a permanent place of residence	10
A child enrolled in the facility for at least six months	10

Data Collection

After receiving IRB approval on April 14, 2021 (IRB approval # 04-14-21-0414338), the interviews with participants who had given informed consent occurred between July 26th, 2021- August 13th, 2021, and lasted 30-60 minutes each. The data collection method involved the use of semi structured interviews. Triangulation ensured validity, a technique used in qualitative research to check and establish truth in the study by analyzing a research question from multiple perspectives to arrive at consistency across data collection sources through individual interviews (Guion et al., 2011). The interview protocol consisted of open-ended questions guiding the semi-structured interviews, exploring the caregiver perceptions of the HR2646 Act. Each interview session began with an explanation of the purpose of the discussion and the details. I informed the participants that there were no right or wrong answers, making them more comfortable, honest with their responses.

To locate participants for this study, I obtained written approval from the facility director to conduct the study at the specific health home community-based agency. I provided recruitment flyers and consented forms to the agency when the announcement was made via mail and distributed at the facility. The announcement and recruitment flyers were provided in English (See appendix A and Appendix B). A consent form that stated that the participants agreed and wanted to participate in this study was also provided (see Appendix C). The recruitment flyer included the criteria for participation, those who: (a) reside in the Bronx, NY; (b) who are caregivers of a child receiving mental health services from his community based mental health agency, enrolled for six months or more; (c) are interested in sharing their views on the HR2646 policy. During the distribution of the recruitment flyers, the agency also mailed the flyers and consents to the families. I also provided the facility employees with my email, phone contact information that they could provide to the parents who show interest in participating. During obtaining participants for this study, the agency director informed me that an audit within the agency was currently going on, so I would have to wait till their audit was finished before I could begin interviewing any participants. On June 24th, 2021, I was informed by the agency director that I would be able to start my interviews on July 26th because their agency audit would have ended by that time. Hence this process took a little longer than I anticipated; even though I had received IRB approval in April, the interviews took place between July and August due to waiting for permission to start the interviews once the agency audit was over. During the waiting period, I focused on recruiting participants, distributing my flyers, and fine-tuning and preparing my interview questions. The flyer and consent forms also included my contact information. Once the participants expressed interest in partaking in the study, I contacted each caregiver via phone call and explained the purpose of the research, and asked if they would be comfortable participating in an interview via Zoom or/ phone call.

Ten caregivers expressed interest in participating in the research study. I emailed the informed consent to the ten caregivers. I explained to the prospective participants that they could reply to my email with 'I consent" to participate in the study. Once consent was received, I followed up with the prospective participants to schedule a date and time for the interview. I conducted an in-depth semi-structured phone interview with each participant.

In-depth interviews were used to dig deeper and go further in gaining specific insight into the perceptions of the caregivers. The interviews conducted during this study were the source of data collection. I began each discussion by clearly explaining the purpose of the research, confidentiality as well as informed consent with the participants. I emphasized to the participants that their participation is voluntary, and at any time, they may choose to withdraw consent or stop participating. Interview data were collected from 10 participants, with three to four interviews conducted per week. All participants answered every question, and none of the participants expressed any frustration during the process. A voice recorder was used to record data, and after the 8th interview, it was evident that I had reached data saturation. Still, I continued until I had interviewed all 10 participants.

The interviews lasted between 30 and 60 minutes and consisting of the following questions:

1. What are your perceptions of the Helping Families In Mental Health Crisis Act (HR2546)?
2. How long has your child been enrolled in this facility? How has your experience been?
3. What types of crisis or emergencies have your children experienced due to their diagnosis? What is your view of the quality of response services offered to you in your community? How effective were the services provided during the crisis, and what is your view on the level, variety, and impact of community treatment programs available in your area?
4. From a caregiver perspective, what is your view on the number of mental health professionals currently focused on pediatric mental health? How do you feel that the assistance of the loan repayment program would impact the number and level of pediatric mental health professionals?
5. From a caregiver's perspective, what is your view on hospital discharge procedures? What is your view on the available support and the connection with outpatient treatment programs?
6. From a caregiver perspective, what is your view on the behavioral health professionals representing minorities in the Bronx, NY? Do you consider yourself to be a minority? What impact do you feel that an increase in more

culturally competent behavioral health professionals will have on the level of care provided in your community?

7. What evidence-based programs address early serious mental illness? How impactful do you feel that the 5% allocation of grant funds will be in bringing about change and increasing the number of such programs?
8. What has been your experience with your child and inpatient psychiatric hospitalization that lasted more than 190 days?
9. What is your view that those in Congress and at the government level who make decisions concerning mental health in this nation are licensed psychiatrists or clinical psychologists? How do you feel that the requirement for policy officials to know something about mental illness impacts the policies and laws passed in the field of mental health?

All interviews were conducted in English to ensure that participants understood all questions and answered them thoroughly. The interviews occurred individually, with only myself and the participant present. An audio recorder was used to ensure the accuracy of all responses and also to validate the transcription process. To clarify participant responses, I asked follow-up questions. I took notes during the interviews with the use of a codebook for each interview. I provided the participants an opportunity for a follow-up interview or dialogue session by phone to clarify any information they shared during the initial interview. After each interview, I transcribed each response within 24-48 hours, word for word. As a form of validation, I also sent the transcriptions to the individual participants for their feedback. During the transcription process, I noticed some of the responses to the research questions were identical, resulting in the same common theme. Upon discovering this during my review, I was confident that including more than 10 participants in this study would not yield any new findings.

Data Analysis

As Surmaik (2018) recommended, participants were assigned a number to protect their identity at the start of each interview. While analyzing the study's final results, I did not have any predetermined ideas of the codes I would use during this process. Inductive analysis analyzed individual semi-structured interviews. In inductive analysis, the process of abstraction is used to reduce and group data, to enable researchers to answer the study questions using concepts, categories, or themes (Kyngas, 2020). Participant responses were analyzed individually and then compared to identify themes. All 10 participants were clear, articulate, and answered all the questions thoroughly. Enough data was created, resulting in usable information. Codes in this study will occur ranging from P1 to P10 for all ten participants. In addition, I will be using each participants chosen pronoun.

I identified, analyzed, organized, described, and reported themes found within this data, by implementing the use of thematic analysis. Thematic analysis emphasizes identifying, analyzing, and interpreting patterns of meaning within qualitative data (Nowell et al., 2017). In order to create meaningful groupings of the data, I proceeded to disassemble the data. Disassembling consists of taking the data apart and creating meaningful groupings (Castleberry et al., 2018). The raw data were converted into usable data through coding, identifying, and connecting themes, ideas, or concepts. When reassembling, I took the codes or categories and created themes. By formulating themes, I captured essential things about the data as related to the research question. Interpreting the data was a critical stage in my research process, where I made analytical conclusions from the data presented. Finally, conclusions are the response to the research question or the purpose of the study, which was to explore the caregiver perceptions of the HR2646 Act.

The first step of data analysis involved transcribing the audio recording of each interview in an accurate manner. To ensure accuracy, once I completed all interview transcriptions, interview notes were typed up within 24-48 hours of conducting the interviews. After performing the interviews, all audio recorded data were transcribed by the researcher in Microsoft Word documents, followed by a preliminary assessment of the data began by reviewing the transcripts a minimum of two times. Upon reading through the data and preparing for the subsequent analysis process, I highlighted specific words, phrases, and introductory paragraphs to answer each research question. During the data review process, I sought to identify patterns while searching for both similarities and contrasts in responses between participants. Open coding, which involves the break down of data into discrete excerpts (Saldana, 2009) was used while analyzing the data. Open coding identifies and categorizes responses found numerous times in the data (Smith, 2009).

The next step involved highlighting each data section that linked to the research question. I used different highlighted colors for various data sections to quickly revisit in the future when needed. I started to code in NVivo (version 12) software, and this step involved relying solely on the data to conduct inductive analysis. Open coding was used for the first round of coding. Several codes were created, and as patterns began to emerge, I proceeded to group all related coded data. Pattern coding was used in the second round of coding. After reviewing the first couple of interviews, I noticed patterns in the data, so I started to make notes on possible connections. For example, the first few participants mentioned a lack of financial resources to assist caregivers. More funding was needed. They believed that the increase of the financing would increase evidence-based programs that address early serious mental illness.

Using Ozkan's (2004) recommendation, usage of the thematic analysis software NVivo, allowed me to automate the coding of my qualitative data. The use of thematic coding enabled me to identity themes in the data, by analyzing the meaning of words in each sentence structure. Through the use of thematic coding, I analyzed the participipnt response, and was also able to identify the themes that were most frequent in the data interview results. My interview recordings were imported and transcribed by the NVivo software. Once imported, NVivo provided verbatim transcription from the recordings. Once transcribed, the responses to each question were grouped and the documents were imported directly into the NVivo software. Since I conducted interviews, in which participants were being asked the same questions, I used heading styles to automatically organize the responses. I gathered and grouped each response in once place for easier analysis. For example, all responses to Question 1 by each participant were grouped together for easier analysis. Through the use of thematic analysis, I worked towards making sense of the data, and the responses of the participants. I looked into the main points of participant responses, in addition to the various perspectives they had. I noted how each participants response differed and I checked to see if there were any points of commonality.

Through the use of the NVivo software I ran word frequency queries to see which words participants were using often. The word cloud that resulted provided me with an insight into the emerging themes. I proceeded to read through each interview and ‘code’ the emerging themes by selecting any comments that stood out and placing them into containers called ‘codes’. I was able to open a code and was able to view all the references I had gathered there. I proceeded to code my data by theme, and I started to develop a list of codes. I was also able to see various connections that existed between the themes, which provided analytical insight. As I began to develop the list of codes, I grouped the related themes together in hierarchy. I used the Hierarchical coding frame to help organize the codes on how they related to each other. I gathered my material into theme codes and organized these codes in a hierarchy in order to help stay organized and on track.

The themes that emerged in the data are described in detail in the results section of this chapter. A summary of the themes is presented here:

Main Themes

- Lack of Financial Resources
- Communication and Support
- Quality of Services.
- Cultural competency
- Lack of pediatric mental health professionals

Evidence of Trustworthiness

The concept of trustworthiness is refined by introducing the criteria of credibility, transferability, dependability, and confirmability (Nowell et al.,2017). I remained objective during the study’s data collection and analysis phases. In order to establish trustworthiness: (a) accurate and complete notes were kept, (b) an audio recorder was used to capture each interview word for word, (c) unbiased coding and analysis of the data occurred, (d) honesty and openness was always at the forefront, (e)personal agendas were not expressed, (f) any behavior that will skew the data did not occur.

Credibility

Credibility requires establishing that findings are dependable, relevant, and congruent, reflecting a researcher's intended reality obtained from the perspectives of those who provided data (Daniel, 2019). All qualitative researchers must incorporate strategies to enhance the credibility of a study during research design and implementation (Noble & Smith 2015). During the interviews, participants were asked to provide detailed and in-depth accounts of their experiences to ensure essential or relevant information in the study was not omitted during the data analysis process- the use of audio recording, member checking and a codebook strengthen the credibility of the findings. To achieve credibility, I used member checking once the auto recordings and the interviews were transcribed. Upon completing each transcript, each participant reviewed the transcript of their discussion to ensure that each response was accurate. To accomplish this, after transcription I emailed each participant my notes and asked for their feedback. All 10 participants replied acknowledging receipt of the email, and 8 out of the 10 participants stated that they had reviewed my notes but had no additional feedback at the current moment. The remaining two participants did not make any comments on offering feedback.

Transferability

Transferability in qualitative research suggests that findings from one study can be applied to other settings or groups of people (Houghton et al.,2013). To ensure that the data was accurate, I searched for consistency in the participant's responses. I used the thick descriptions of participants real life locations and participants experiences to achieve transferability. Through thick text descriptions, I was able to provide detail into the participant recruiting processes through purposeful sampling. I also provided information on how the data was collected, analyzed and coded. I used member checking to ensure that the participants responses accurately reflected the information they provided. While conducting the study, I created an audit trail consisting of notes documenting every step: Interview notes, a journal where I would write my thoughts and feelings during the research, and research information on coding.

Dependability

Researchers can ensure the research is logical, traceable, reliable, and documented (Nowell et al., 2017). Dependability refers to data stability over time and under different conditions (Elo et al., 2014). The dependability of the findings of this study was ensured through an audit trail created with the use of my researcher journal. Through the audit trail, I tracked the collected data and the decisions made during the research process. In addition, I took field notes during each interview and provided a written summary of each interview.

Confirmability

Confirmability is the confidence that the researcher's study findings are based on the participant's narratives and words rather than potential researcher biases (Davis,2021). Confirmability occurs once credibility, transferability, and dependability have been established(Thomas e al., 2011). To develop the confirmability of this study, I explored the use of an audit trail. Which provided detailed descriptions of all the steps that I have taken to conduct this study; the audio recordings of the interviews also assisted me in establishing confirmability.

Results

To explore caregiver perceptions of the H.R2646 Act, the research questions developed for the participants were centered around several policy sections found with the HR2646 Act. Table 2 reflects the various areas of the policy as it relates to the research questions. Upon completing the in-depth review and analysis of the collected data, five main themes emerged from the research study. The main themes were: (a) lack of financial resources/funding, (b) Communication & Support, (c) Quality of services (with a specific focus on the quality of mental, behavioral, and hospital services.) (d) Cultural competency and (e) Lack of pediatric mental health professionals. As reflected in Tables 2, 3, 4, 5, 6, and 7, these various themes that emerged during the analysis align with the research questions developed for this study.

Table 2

Alignment Between HR2646 Policy Section and Research Questions

Policy Section	Research Question	Follow up question
•Sec. 503: Policy provides grants to enhance crisis response services, develop psychiatric inpatient and residential bed tracking, and support assertive community treatment programs.	What types of crisis or emergencies have your children experienced due to their diagnosis?	What is your view of the quality of response services offered to you in your community? How effective were the services provided during this crisis period, and what is your opinion on the level, variety, and impact of community treatment programs available in your area?
• Sec. 717: Policy supports the mental health workforce by adding pediatric mental health professions to the National Health Service Corps loan repayment program.	From a caregiver perspective, what is your view on the number of mental health professionals currently focused on pediatric mental health? How do you feel that the assistance of the loan repayment program would impact the number and level of pediatric mental health professionals?	
• Sec. 202: About hospital discharge procedures, this policy requires Medicare reimbursed hospitals to prepare discharge plans and facilitate connection with outpatient treatment for patients they are discharging.	From a caregiver's perspective, what is your view on hospital discharge procedures?	What is your view on the available support and the connection with outpatient treatment programs?
• Sec. 713: This policy increases the minority mental health workforce by authorizing fellowships to increase the number of culturally	What is your view on the behavioral health professionals representing minorities in the Bronx, NY, from a caregiver perspective? What race do you consider yourself?	What impact do you feel that an increase in more culturally competent behavioral health professionals will have on the level of care provided in your community?

competent behavioral health professionals.		
• Sec. 503: Policy encourages early intervention by setting aside 5% of state mental health block grant funds for evidence-based programs that address early serious mental illness.	What are your views on the number of evidence-based programs that address early serious mental illness? How impactful do you feel that the 5% allocation of grant funds will be in bringing about change and increasing the number of such programs?	
• Sec. 201: Policy eliminates the 190-day lifetime cap on inpatient psychiatric hospitalizations in Medicare.	What has been your experience with your child and inpatient psychiatric hospitalization that lasted more than 190 days?	How did the lifetime cap affect the level of care received?
• Sec. 101: In Congress, the assistant secretary for mental health and substance abuse treatment must be a licensed psychiatrist or clinical psychologists. This raises the profile of mental health and ensures that the lead policy official for mental health policy knows something about mental illness. The requirement to be evidence-based guides spending.	What is your view that those in Congress and at the government level, who are involved in making decisions concerning mental health in this nation, are licensed psychiatrists or clinical psychologists?	How do you feel that the requirement for policy officials to know something about mental illness impacts the policies and laws passed in the field of mental health?

Main Theme 1: The Lack of Financial Resources/Funding

The caregivers of a child who has mental illness discussed the impact that a lack of funding has on the availability of behavioral mental health programs and how it limits the resources of assistance available to them. Participants were asked how impactful they felt the 5% allocation of grant funds would be in bringing about change and increasing the number of evidence-based programs that address early serious mental illness. Of the participants interviewed, 7 of the 10 participants responded that there is not enough grant funding for such programs and believed that a 5% allocation would positively impact. P1 stated that “there needs to be an increase in financial funding, I believe such a positive impact on mental health professionals and organizations in this field.” P1 continued saying “I believe that grant funding will create more resources for children and families.”

Similarly, P4 expressed that increased funding that will create more evidence-based programs is needed. She went further to state, “there is a huge need; children are walking around this community with undiagnosed mental illness due to a lack of funding and existence of such programs.” Conversely, 3 out of the 10 participants did not see grant funding as an issue, and believed that there is currently enough funding but a lack of the proper allocation of funds to the right places. P5 stated that:

> it is not about the increase of grant funding, but more about improving the quality of mental health professionals that are culturally in tune with the needs of caregivers and families in my community, who have the passion to help caregivers.

P9 expressed that there is sufficient funding and added that she has not experienced any lack in the availability of programs for her child. P9 stated that she does not feel that there needs to be an increase or 5% allocation of grant funding. Similarly, P6 responded stating that there is sufficient funding, but added that a 5% allocation of grant funding will have a positive impact on increasing the number of programs available for caregivers and families. The diversity of thought is reflected in the responses of these three participants.

Participants were asked their view on the number of mental health professionals currently focused on pediatric mental health and if they felt that the assistance of the loan repayment program would impact the number and level of pediatric mental health professionals. Five of the participants responded, stating that they did not believe that there are enough mental health professionals focusing on pediatric mental health. The assistance of the loan repayment program would have a positive impact in increasing the number of adequately trained mental health professions. P8 responded, stating that they believed "there is a shortage and a lack." P8 expressed a positive view about the assistance of the loan repayment program, saying that she thinks it will increase the number of pediatric mental health professionals needed. Similarly, P2 provided an in-depth explanation of why she believes that there are not enough mental health professionals focusing on pediatric mental health. P2 responded that she attributed the challenges she faced when her child was hospitalized due to the lack of available mental health professionals focusing on pediatric mental health. She added, "more mental health professionals are needed to meet the rising demand for services in pediatric mental health."

The remaining five participants indicated that they were satisfied with the number of available mental health professionals focusing on pediatric mental health but still added that the assistance of the loan repayment program will add more value in the field of pediatric mental health. P6 expressed that from her experience, she has never experienced a lack of pediatric mental health professionals available to assist with her child. P6 further explained that despite this, she still had positive views on the loan repayment program and added that it would draw more mental health professionals to this field. P5 expressed that even though she believes enough professionals are focusing on mental health, there has been a slowdown in receiving services due to the impact of the Covid pandemic and because most of her services for her child are now remote.

Table 3

Data Alignment between research Questions, Theme 1, and Participant Responses

Main Theme 1: Lack of financial resources/funding

Code	Survey Instrument Question	General Participant Response
Lack of programs addressing early serious mental illness.	What are your views on the number of evidence-based programs that address early serious mental illness?	“There are not enough evidence-based programs that address early serious mental illness. More programs are needed to assist families in detecting and treating early childhood serious mental illness.”
Proper allocation and Increased oversight of the distribution of grant funding.	How impactful do you feel that the 5% allocation of grant funds will be in bringing about change and increasing the number of such programs.	“More funding is needed; government officials and lawmakers need to ensure that the funding gets to the right people and organizations that it is intended to help.” “The 5% allocation of grant funds will bring about change and increase the number of programs.”

		"In addition to more funding, increased oversight is needed of the distribution of such grant funding, so that it can reach the communicates in need and alleviate the financial burden I am going through caring for a child with mental illness."

Main Theme 2: Communication & Support

Data from the interviews revealed that most participants indicated that they felt supported while raising a child with mental illness. Participants also indicated that communication during their child's hospitalization or when dealing with behavioral health professionals within the facility has been good. During the interview, participants were asked about the level of support and communication they have received during their child's enrollment at the mental health facility. Nine out of 10 participants indicated that they had felt fully supported since their child received service from the mental health facility. In addition, participants stated that there had been no barriers to communication. They added that they are always well informed on the mental health services their child is receiving from this facility. Conversely, P8 stated that she did not feel fully supported since her child has been receiving services from the facility. P8 added that she has been frustrated with the facility and does not see any consistency in service provision for her child.

P10 responded that her child had been enrolled and has been receiving services from this facility for more than five years. P10 indicated that her experience at the facility has been excellent so far. She added that the facility has always been very responsive to her needs, supportive, and willing to help her child. P6 responded, stating, “my child has been enrolled in this facility for five years; our experience with this facility has been a positive one; I have no complaints.”

P3 reflected on dealing with the challenges associated with her child's mental illness. P3 stated that her child had been enrolled in the facility since he was ten years old and is now about to turn 18. P3 noted that the child's behavior and mental health challenges took a toll on her as the caregiver because her child was disrespectful and had behavioral/ mental health issues. P3 stated that despite this, the staff located at the facility has been accommodating and supportive of her and her child for many years. This has had a positive impact on her life in alleviating the burden she was experiencing. The interview revealed that for P10, P6, and P3, the level of communication and support they received, shaped their overall views on the effectiveness of mental health services being received at the facility.

Table 4

Data Alignment between research Questions, Theme 2, and Participants’ Responses

Main Theme 2: Communication & Support

Theme	Survey Instrument Question	General Participant Response

Emotional support during hospitalization.	What was the quality of service when your child was hospitalized?	“My child always has an abundance of support during hospitalizations, staff checked on him frequently and were very attentive.” “ I did not feel supported emotionally during my child’s hospital stay, I felt emotionally disconnected from the staff at the hospital and it was an unpleasant experience.” “My child was admitted to the hospital right before Christmas last year. I felt extremely supported during this time, the hospital staff was kind, and kept in constant communication with me, providing updates on my child’s status.”
Responsiveness	What has been your experience in this facility?	“I have had a good experience at this facility; I am satisfied with the level of responsiveness to my needs, and the service being provided.” “There have been instances where the facility should have done a better job communicating and responding to my questions, but for the most part, 90% of the time, the facility is on target of meeting my child's needs and my needs as the caregiver. I feel supported.” “My experience has been excellent so far. The facility has been very

		responsive to my child's needs, and has been very supportive to me, and always willing to help my child." "There have been times where I have not received a response to my questions or request as it pertains to dealing with my child's needs and diagnosis, it can feel frustrating at times."

Main Theme 3: Quality of Services

The data shows that quality of services, with a specific focus on the quality of mental, behavioral, and hospital services was another central theme that emerged. The study suggests that the participant's view of the quality of services they received impacted their view on the effectiveness of the behavioral health programs and services. 8 out of the 10 participants indicated that their child had experienced hospitalization for an extended period. P3 and P7 stated that their child had not experienced any significant crisis or hospitalization.

Participants were asked about their view of the quality of response offered in their community, how practical the benefits were provided during this period of crisis, and their perspective on the level, variety, and impact of community treatment programs available in their community. P9 responded, stating that their child's hospitalization service was good. "My child was hospitalized last year during the height of the pandemic, so the hospital did not allow any visitors." "Despite this, the hospital made sure that phone calls were always scheduled so that I could speak to my child several times daily."

P9 stated that the quality of service provided by the hospital was excellent, and the hospital staff was very responsive to her needs, providing updates on how her son was doing." P9 indicated that she has positive views of the quality of service offered in her community.

P10's child also had a similar hospitalization experience as Participant 9. She indicated that her child was hospitalized last year during the start of the Covid19 pandemic. She suggested that the quality of service during her child's hospitalization was above standard. The services provided during this time were effective and brought a sense of relief to her as the caregiver. She also stated that the quality was also reflected during the child's discharge format in the hospital. P10 believes that the hospital discharge procedures were adequate and enough. P8 reflected on the quality of service offered in the community stating, "I have positive views towards the quality of service being offered in my community, I feel it is up to standard." She added that her child went to a day treatment school, and the psychiatrists and therapists are located in the school.

Table 5

Data Alignment between research Questions, Theme 3, and Participants' Responses

Main Theme 3: Quality of Services

Theme	Survey Instrument Question	General Participant Response
Hospitalizations associated with the diagnosis	What types of crisis or emergencies has your child experienced due to their diagnosis?	"My child has been hospitalized several times for mental health issues;

		my child was doing many things to hurt himself." "My child experienced a major anxiety attack which triggered an asthma attack and created a breathing problem." "No, my child has not experienced a crisis or hospitalization."
Level of support	What was your view of the quality of response services offered to you in your community?	"The quality of response service is always excellent; my child always has an abundance of support during hospitalizations." "I was disappointed with the quality of response service offered in my community; my child's psychiatrists were not attentive to my child's diagnosis and were not able to identify my child's needs." "I believe that the quality of services offered in my community is above standard, and I am pleased with the services."
Accessibility and attentiveness of the staff.	How effective were the services provided during this period of crisis?	"Through every hospitalization, the staff at this facility were easily accessible and always available to answer any questions I might have had." " I am satisfied with the quality of service provided to my child and me during this period of crisis."

		"I believe that the services were ineffective, due to my child not being complaint and rejecting the services, and not being cooperative. I believe that the services are effective, but the issue was that my child refused to comply and was unwilling to do what he was told." "I do not feel that the quality of service during my child's hospitalization/ crisis was good. I do not feel that my child's hospitalization was beneficial because the hospital staff did not attend to my child or answer any of the questions that I had to my satisfaction."

Main theme 4: Cultural competency

Sec 713 of the HR2646 Act policy increases the minority mental health workforce by authorizing fellowships to increase the number of culturally competent behavioral health professionals. Participants were asked about their views on the behavioral health professionals representing minorities in the Bronx, NY. Participants were asked about the impact of more culturally competent behavioral health professionals on the level of care provided in their community. Seven out of the ten participants responded, stating that enough behavioral health professionals represented minorities in the Bronx, NY. P5, 7, and 8 responded that there are not enough behavioral health professionals representing minorities in the Bronx. P5 attributed this to a lack of funding. P7 added that there were enough behavioral health professionals representing minority caregivers and children that attend the mental health facility. Still, there were not enough behavioral health professionals representing minorities in the general community. 9 out of 10 caregivers identified themselves as minorities, and all 10 participants confirmed that they are residents of the Bronx, NY.

When asked about the impact that an increase in more culturally competent behavioral health professionals will have on the level of care provided in the community, P1 responded that they have never felt that there were not enough culturally competent behavioral health professionals in their community and that all the behavioral health professionals she has dealt with in her community have been culturally competent. P2 further spoke about the importance of diversity, especially cultural diversity amongst behavioral health professionals in Bronx, NY. She explained that a culturally competent behavioral health professional would understand what she needs as a caregiver, especially what she is going through. P2 responded, that the diversity of behavioral health professionals must increase, and once this happens, it will increase in culturally competent behavioral health professionals.

Main theme 5: Lack of pediatric mental health professionals

Participants were asked about their views on the number of health professionals currently focused on pediatric mental health and how they felt about the assistance of the loan repayment program impacting the number and level of pediatric mental health professionals. P1, P2, P7 and P8 all indicated that there are currently not enough health professionals now focused on pediatric mental health. P8 mentioned a shortage or lack of health professionals presently focused on pediatric mental health. P2 further explained that more pediatric mental health professionals are needed to meet the rising demand for services in pediatric mental health. P2 expressed that due to her experience when her child was hospitalized, she attributed the challenges faced to the lack of available mental health professionals focusing on pediatric mental health.

P9, P10, P4, P5, P4, and P3 responded that enough mental health professionals are focusing on pediatric mental health. P9 answered that she had not experienced any available pediatric mental health professionals to assist her child; there was always an abundance of mental health professionals working on her case and helping her child. There was also a distinction in P10’s response. Even though she believes that there aren't enough mental health professionals focusing on pediatric mental health, she believes there needs to be an increase in pediatric mental health programs and resources. P5 added another angle, stating that even though she feels that enough mental health professionals are focusing on pediatric mental health, there has been a slowdown in receiving services due to the impact of Covid. P4 stated that even though they believe that sufficient mental health professionals are focusing on patriotic mental health, there are not enough mental health professionals qualified to provide mental health services.

Summary

The purpose of this qualitative study was to explore the caregiver perceptions of the HR2646 Act. I conducted interviews with ten caregivers whose children received mental health services from a facility in the Bronx, NY. This chapter included discussions of the data collection process and the sharing of the results of the data analysis. Every participant answered the interview questions based on their experiences as caregivers—major and minor themes such as lack of financial resources, support, and quality of services emerged. Minor themes touched on cultural competency and access to pediatric mental health professionals. The responses from the participants to the research questions displayed the perceptions caregivers have of the various policies embedded in this Act.

Chapter 5 discusses the findings, interpretation of the findings, limitations of the study, recommendations, implications, and conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This qualitative study aimed to explore the caregiver perceptions of the implementation of The Helping Families in Mental Health Crisis Act. To obtain caregiver perspectives of the HR2646 Act, ten caregivers of children experiencing mental illness were interviewed. This study filled a gap in the current, relevant literature by identifying caregivers' perceptions of the current policies and laws embedded in the HR2646 Act, measured how effective the current policies are, and placed the areas of lack within these policies regarding the caregivers' identified needs. This study was also critical because we can examine the impact that the HR2646 Act has on the lives of the caregivers in providing the various resources to assist the caregivers and their children.

The primary research question that guided this study was: What are the caregiver perceptions of current policies such as the H.R. 2646 helping Families in Mental Health Crisis Act of 2016? For this study, I used the qualitative method to explore the caregiver perceptions of the H.R 2646, and I used the Five Stream Framework of the Policy process by Howlett et al. (2015) and the Kingdon’s multiple streams model (1984), as part of the development of the theory as a framework. I conducted ten individual telephonic interviews with caregivers of a child receiving mental health services interested in sharing their experience and insight on this existing policy. I asked the participants questions to determine their lived experiences as primary caregivers of children receiving mental health services. This study revealed the effectiveness of the current policy H.R. 2646 and informed additional guidelines that will meet the demand in areas of lack. The following categories consisting of major themes emerged, showing a clean line from the Act. The main themes were: (a) lack of financial resources/funding, (b) communication & support, and (c) quality of service, (d) cultural competency and (e) lack of pediatric mental health professionals.

The findings of this study provide enhanced awareness for policymakers and support for programs and policies impacting caregivers of children with mental illness. The results of this research may also help inform more effective public policy by identifying opportunities for improvement based on caregiver lived experiences. The results of the study are provided in chapter 4. In chapter 5, the following topics will be covered: (a) interpretation of findings, (b)limitations of the study, (c) recommendations, (d) implications, and (e) conclusion.

Interpretation of the Findings

The interpretation of the study data provided answers to the research question that guided this study: What are the caregiver perceptions of the HR2426 Act? The findings confirm and extend knowledge in this discipline, correlate with what has been found in the peer-reviewed literature described in Chapter 2. The exploration of each theme carefully established the association to literature reviewed in Chapter 2, the Five Stream Framework of the Policy process and Kingdon's Multiple Streams Model as part of the development of the theory as identified in Chapter 1.

The Kingdon streams approach extended to other stages of policymaking, such as formulation, decision making, implementation, and evaluation (Howlett et al., .2015). Uniting Howlett and Kingdon allowed for a thorough assessment of the research question posed in this study and combined the strengths of each, thereby better describing, understanding, and explaining policymaking.

To reconcile the conceptual pillars of the multiple-stage and cycle models, a five-stream framework that retains Kingdon's conceptual architecture and analytical vocabulary offer a more comprehensive and capable framework for capturing the full range of policymaking dynamics (Howlett et al. 2015). According to Howlett, in the Five Streams Model, each confluence point (policy solution, process, problem, politics and program) brings about new actors, new tactics, new resources and ultimately joins the flow of policymaking events. Kingdon suggests that the first confluence point occurs in agenda setting, when the problem, politics, and streams coalesce in a temporary policy window. Howlett notes that new policy streams that become the central pathway upon which other streams converge are created. Critical junctures have made the future impetus for the policy process, essentially becoming the 'choice stream.' After this crucial agenda-setting process, actors such as policy analysts and stakeholders organized in advocacy coalition contribute to deliberations and propose policy alternatives (Howlett et al., 2016). The five streams framework explains how and why new actors, ideas, and interests merge into an existing policy flow and explain the various patterns of policymaking that result from a presence or absence of relevant inputs at different critical junctures. Using a combination of stages, streams, and coalitions provides a more integrated and holistic understanding of policy.

Finding 1: Lack of financial resource/ funding

Participants stated that there is not enough grant funding for evidence-based programs that address early serious mental illness. P 1 said that "there needs to be an increase in financial funding; I believe that an increase in grant funding will create more resources for children and families." Similarly, P4 expressed increased funding that will create more evidence-based programs is needed. She went further to state, "there is a huge need; children are walking around this community with undiagnosed mental illness due to a lack of funding and existence of such programs." These direct participant responses show that the participants believe there should be increased funding. During the study, I asked for respondent impressions that the funds were appropriately allocated. P2 responded, "even though there is an allocation of grant funding, government officials, and lawmakers need to ensure that the funding gets to the right people and organizations it is trying to help." P2 added that "there needs to be increased oversight of the distribution of such grant funding so that it can reach communities in need and help children."

The respondents' feelings that additional funding would improve services to their children and families are supported by research conducted by Cummings et al. (2016). Researchers found that increasing funding for outpatient therapy decreased the need for inpatient hospitalizations and decreased caregiver-reported stress. This correlates with the results obtained as participants were interviewed. P4 stated that "the increased funding can reach the communities in need, and alleviate the financial burden and stress I am going through caring for a child with mental illness." By increasing funding and integrating support services to children and their families, Cummings et al. (2016) found that youth-serving hospitals and community-based mental health facilities aided low-income populations. The authors found that privately owned for-profit and nonprofit mental health treatment facilities were more likely to serve this population than publicly owned facilities (Cummings et al.,2016). The authors added that despite reports of increased investment in privately held for-profit corporations expanding their role in the organization and delivery of mental health services, the delivery of services has declined. Rural counties where most residents were minorities or counties with a higher percentage of uninsured residents were less likely to have a community-based mental health treatment facility that served youth (Cummings et al.,2016). This literature reported that state mental health agencies experienced more than $4.4 billion in budget reductions between the year 2008 and 2013, resulting in an estimated 9% reduction in the number of state psychiatric hospital beds, the closure of state psychiatric hospitals, and a reduction of community- based mental health programs (Cummings et al., 2016). According to the author Pruchno (2015), one of the values of the HR2646 legislation would be to ensure oversight so that funds are used to treat and prioritize those with the most severe mental health diseases; provide funding for assisted outpatient treatment; increase the number of psychiatric beds for crisis treatment and emphasize evidence-based treatments. The results of this research study agree with this current and relevant literature because it shows the impact that increased and proper funding can have on creating and improving needed resources in this field. The literature review suggests that appropriate oversight is required to allocate the resources correctly. The author Pruncho indicated various bill provisions, including increased funding for assisted outpatient treatment centers in underserved urban communities that access needed mental health care. The study findings fit and point to a correlation and pattern regarding the barriers expressed in this literature review that lack of funding creates. 7 out of the 10 participants interviewed for this study stated insufficient grant funding and added that a 5% grant allocation would positively impact. The participants in this study expressed that increased funding would bring about solutions and create more evidence-based programs and resources for children and families.

Finding 2: Communication & Support

The results related to this section heading showed that participants felt supported while raising a child that struggles with mental illness. Participants gave examples of this felt support by reflecting on how they felt while their child was hospitalized. Participants expressed that they thought they could communicate effectively with mental health professionals and felt very supported during their child's hospitalization. In addition, results showed that participants felt that they had felt fully supported since their child had been enrolled at this mental health facility and did not identify any barriers in communication. In addition, the results showed participants who said they felt supported and that communication was good; they also expressed the positive impact that this increased support and communication has on alleviating the burden being experienced. The results from the interviews indicated that participants felt supported while raising a child with mental illness. Participants accredited this to the ease of communication and support they had experienced when dealing with behavioral health professionals. 9 out of 10 participants expressed that the level of support they received during their child's enrollment at the mental health facility was high, and there was no communication barrier. Despite this, the results showed that participants expressed that they do not feel fully supported since their child began to receive services from the facility. Some participants expressed frustration with the facility and did not see any consistency in service provision for their children. The study results showed that the level of communication and support those participants received shaped their overall views on the effectiveness of mental health services. The results of this research fit and agree with the relevant literature listed in this section by showing the impact that support and communication, or a lack thereof, can have on children and families dealing with such challenges. The study showed that for caregivers, the effectiveness of mental health services resulted from proper communication and the elimination of all communication barriers.

Nine out of the ten respondents indicated positive communication experiences with facility staff. The author Merlino (2017) found that effective communication leads to improved outcomes and caregiver support. The author Merlino (2017) described communication as the cornerstone of healthcare. Effective communication is critical to meeting patient needs and providing safe, high quality, and patient-centered care; it is necessary to manage healthcare delivery (Merlino, 2017). Merlino discovered that poor communication among care team members and with patients, family members, and facilities could confuse follow-up care and medications. Communication between caregivers and patients has the most significant impact on reducing readmissions (Merlino, 2017).

The importance of effective communication between program staff and caregivers has also been demonstrated in research conducted by the author Press Ganey (2017). Ganey discovered that communication affects the safety, quality, and care experience, including caregiver engagement. This is consistent with research that links these critical performance areas to patient-centeredness and care and aligns with the findings from the new cross-domain analysis, indicating that these elements are highly interrelated with one another (Press Ganey, 2017).

Finding 3: Quality of Services

Participants expressed that they were pleased with the child's quality of services while enrolled in a mental health program or hospitalized due to mental health issues. P10 stated, "the quality of service I received while my child was hospitalized last year during Covid was good." "During the outbreak of Covid, I was not allowed to visit my child, but the hospital made sure there was constant contact and communication between me and my child." Participants stated that mental health professionals and staff members responded to their questions during their child's hospitalization and were very interactive and responsive to inquiries while enrolled in the mental health facility. P9 stated, "mental health staff members maintained constant communication with me and were very responsive to my needs." P9 added, "the staff were very responsive to my needs, especially during the height of the Covid pandemic, and ensured that they kept me informed with how my son was progressing." Participants identified the quality of services as an above-average standard. This study also included sentiments on participants' views on the services provided after the child was released from the hospital.

P8 stated, "I believe the hospital discharge procedures are adequate; after my child was discharged, I still felt supported, and staff members kept in touch with me to ensure that the discharge procedure went smoothly." Participants stated that the discharge procedures were adequate, and their opinions on the quality of services offered in the community were positive.

The importance of quality in service provision has also been demonstrated in research conducted by Kilbourne et al.(2018). "Quality of care includes structure, or organization of care, the influence of structure on clinical processes of care as delivered by providers, and ultimately, patient-level health care outcomes." Kilbourne et al. (2018). Kilbourne et al. (2018) state that many of the quality improvement methods used in mental health care have influenced the growing field of implementation in overall science. The recommendations found in Kilbourne et al.'s (2018) study show how improving the quality of mental health service providers can apply to health care in general.

The importance of quality in service provision has also been demonstrated in research conducted by Druss, Rosenheck, and Stolar (1999). The authors reported that the satisfaction with several aspects of service delivery at the patient level was associated with fewer readmissions and fewer days readmitted. The results of this research fit and agree with the relevant literature listed in this section by showing the effect quality of service provision has on the overall wellbeing of caregiver and their families. The study results aligned with the literature review demonstrated that there is indeed a relationship between patient satisfaction and quality of service.

The additional two major themes discovered were cultural competency and the lack of pediatric mental health professionals. When it comes to cultural competency, the results of this study showed that three out of ten participants reported that not enough behavioral health professionals represented minorities in the Bronx and not enough behavioral health professionals represented minorities in the general community. Participants spoke about the importance of diversity, especially cultural diversity, amongst behavioral health professionals. P2 stated, "diversity is important and especially cultural diversity amongst behavioral health professionals in my community of the Bronx." P2 went on to explain, "there has to be an increase in diversity and an increase in culturally competent behavioral health professionals in this community." P2 indicated that "the diversity of behavioral health professionals must increase, and once this happens, it will bring about an increase in culturally competent behavioral health professionals." Participants spoke about the importance of diversity, especially cultural diversity, amongst behavioral health professionals. P4 responded stating that "an increase in more culturally competent behavioral health professionals will be helpful because they will have an understanding of the financial and cultural barriers that exist in my community, especially when it comes to accessing mental health services." P4 added, "increased culturally competent behavioral health professionals would truly aid in understanding the effect and impact that things such as poverty have on limiting access to mental health resources for minorities that are living in the Bronx." Participants expressed that culturally competent behavioral health professionals would understand the needs of what caregivers are going through.

The importance of cultural competency is demonstrated in research conducted by Henderson et al. (2018). The authors state that their findings indicated that the consequences of cultural competence are satisfaction with care, the perception of quality health care, better adherence to treatments, effective interaction, and improved outcomes. The second minor theme, lack of pediatric mental health professionals, is demonstrated in research conducted by authors Mayberry & Haflinger. In the study conducted by Mayberry & Heflinger (2018), the authors explore the supports and services available to caregivers, the usage of the supports, and the various challenges the caregiver encourages. Mwei(2015) conducted a study using qualitative design, where six participants were selected and interviewed regarding their experiences raising a child with a mental illness. Mwaei(2015) indicated that support is available to caregivers, but there were often barriers to reaching such support services. The authors identified the barriers caregivers experienced in obtaining assistance, in addition to their perceptions of support systems they need to receive relief. In the research findings, participants highlighted a lack of pediatric mental health professionals available to assist with their child's needs. Four out of ten participants reported a lack of pediatric mental health professionals. P8 stated, "I do not believe there are enough mental health professionals focusing on pediatric mental health; there is a shortage and a lack." Similarly, P7 stated, "there are not enough mental health professionals focusing on pediatric mental health; there needs to be an increase in this field." This study showed that participants believed that there needs to be an increase in pediatric mental health professionals, programs, and resources.

Limitations of The Study

This qualitative study aimed to explore the Helping Families' caregiver perceptions in Mental Health Crisis Act. One limitation identified in this study was the sample size of 10; the unique experiences of the 10 participants may not represent all the caregivers raising a child with mental illness. Another limitation was that the study's geographic location was concentrated in the Bronx, NY. The study results may not generalize to other localities and to caregivers who have children in other facilities. All the parents included in my study had children in one program. Results from the present study may not generalize to non-urban, homogenous localities, as the present study was conducted in an urban city with a majority-minority population. In addition, COVID might have had a potential impact on the results, being that the responses might have been colored but changes in procedures, such as visiting due to the pandemic.

Recommendations

These results presented in this study have laid the groundwork for future research that can help improve public policy by identifying parent caregiver opinions and issues with current policy and their perceptions of existing policy impacts. The findings of this study enhance awareness for policymakers and support for programs and policies that impact caregivers with children living with mental illness. The recommendation is that future research should aim to evaluate and create more effective public policy by identifying opportunities for improvement based on the caregiver's lived experiences.

Policymakers should play a significant role in improving the lives of caregivers and children living with mental illness by following the specific recommendations listed below:

1. Increase financial resources and funding toward improving programs and services in childhood mental illness.
2. Improve communication and support in existing mental health agencies, facilities, and hospitals.
3. Improve the quality of support services available to families of mentally ill children.
4. Increase the availability of culturally competent training available for professionals currently in the field or entering the field of mental health.
5. Offer resources such as tuition incentives for students considering entering the field of pediatric mental health. Offer employment opportunities laced with better benefits which will encourage professionals to enter the field of pediatric mental health.

The main themes in this study, as well as the two minor themes of cultural competency and lack of pediatric mental health professionals, support these recommendations, which might be helpful to policymakers looking to improve the lives of caregivers raising a mentally ill child, and resources and services available to these families.

Implications

The study's implications for positive social change may include informing policymakers of the importance of increasing funding, resources, and programs for caregivers raising a child with mental illness and their families. The study's findings could also help increase the amount of financial funding available in programs geared towards assisting these caregivers and improving the quality of health services currently in place in childhood mental health. The current study uncovered opportunities where caregivers identified barriers preventing them from obtaining the support they need in helping their child. By sharing their personal experiences, appropriate recommendations may include offering mental health professionals training courses that can help improve their cultural competency when dealing with caregivers. An additional recommendation can consist of financial incentives to attract more pediatric mental health professionals and enhance the funding geared towards improving services in childhood mental illness. Parents and guardians are the primary caretakers in the family, and they play a critical role in the lives of children and adolescents. The results of this study may contribute to social change by raising awareness of the various challenges faced by caregivers and improving support services to caregivers. The potential implications for positive social change can occur in this study by enabling future systems to be developed and implemented to assist caregivers in the Bronx, NY, and in other areas of the United States. Results from this study may also reveal the effectiveness of the current policy H.R

2646 and potentially create additional guidelines that will meet demand in areas of lack within the field of mental health.

Conclusion

This qualitative study aimed to identify caregiver perceptions of The Helping Families In Mental Health Crisis Act. Using a qualitative method, I explored the perceptions of 10 caregivers raising a child diagnosed with mental illness. The purpose was to identify caregivers' perceptions of the HR2426 Act and identify the barriers these caregivers are experiencing when accessing their child's resources and mental health services. I collected the data by conducting in-depth semi-structured interviews with each participant. Nvivo qualitative computer analysis software assisted in organizing and analyzing the transcribed data for emergent themes. This study is valuable for policymakers seeking to improve and implement existing and new policies geared towards improving the lives of caregivers and their families. The study findings included five themes, three significant themes, and two minor themes. The centralized themes were (a) lack of financial resources/funding, (b) communication & support, and (c) quality of services—the findings of the study aligned with the literature and the conceptual framework.

The study results indicated a need to support caregivers raising a child with mental illness. Each participant shared their unique stories of the difficulties and challenges they have gone through while dealing with their child's mental health. The findings of this study included centralized themes that might be informative when developing policies and laws that impact childhood pediatric mental health programs and resources. The fundamental essence of this proposal is to bring awareness to the issue of childhood mental illness and its effects on caregivers and family members. While creating this awareness, studying all the current policies and laws geared towards assisting caregivers and families through this often arduous journey is essential.

It is essential to understand the value of policies such as the Helping Families In Mental Health Crisis Act and their role in shaping how we respond to the need for mental health. It is essential to reflect on the current policies and work and identify areas where improvements can be made. Over the past few years, mental health has become more prevalent. By studying the various policies at the government and political level, we can measure where we currently are and how far we must still go. I desire that there will be a continued exploration of childhood mental illness, particularly at the policymaking level.

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Appendix A: Letter to facility

My name is Odinakachi Chigewe, and I am currently a PHD student at Walden University. Childhood mental illness remains an important public health challenge in the United States. Caregivers often experience an increased level of stress when raising children who suffer from various mental illnesses. This research study will be focused on the HR2646 policy, because it covers various areas that enhance childhood mental health treatment and provision. The purpose of this proposed qualitative study is to identify caregiver perceptions of The Helping Families in Mental Health Crisis Act (HR2646), specifically their perceptions of policy impacts.

This research will examine four different areas of the H.R 2646 policy: (a) availability of care plans and resources, (b) medical billing practices, (c) patient rights and protection, and (d) responsible governance of policy and resources. Caregivers have described the process of obtaining a mental illness diagnosis for their ill child as stressful and unsatisfactory. Parents have indicated the difficulty associated with coping with children that are mentally ill, and the unpredictable behaviors that follow. Parents report many headaches and frustrations during the diagnosis process and express their stress and depression of their child’s degree of impairment. Awareness of the various challenges faced by caregivers in such situations enables improved support offered to such parents. Stability is an essential factor in how a child responds to mental health services.

This research study has the potential to positively impact social change by providing insight into areas of potential improvement for public policy regarding children’s mental health services. The results of this research may help to improve public policy by identifying parent/ caregiver opinions and issues with the current policy. In order to conduct this research study, I am requesting permission to recruit and interview 10 caregivers whose children are currently receiving mental health services from your facility. During this study, participants will be encouraged to be honest and candid with their responses. The data collection process during this study will involve caregivers who are genuinely willing to participate in this study. The study participation will be entirely voluntarily. I will ensure the confidentiality of the participants who agree to take part in this study and use the convention of confidentiality in order to protect the research participants from any harm.

During the recruitment process consent forms will be distributed to those caregivers that express interest in being part of this study. I will discuss confidentiality agreements at the beginning of the data collection, and cleaning process. Once potential participants have expressed their interest and desire to be a part of this study, I will explain the details of the research study and ask them to participate by providing informed consent. I will clearly describe to the participants the study's goals, potential benefits and risks. Participants will be informed of their role in the research and the options they have regarding their participation. There will be an understanding of what the research entails and full disclosure throughout the study. Each interview will be between 60-90 minutes, and I will be facilitating the interview. Participants will be asked if they will agree to being taped during the interview and recorded.

Please accept this letter, as a written request to recruit participants for this study, from your facility. Please feel free to kindly review the flyer attached to this letter, for further information on this research study and procedure. If you have any additional questions please feel free to contact me at the following number and email : (347)-271-2755. Email: odinakachi.chigewe@waldenu.edu

Appendix B: Recruitment Letter

Participants Needed for Research Study on The Caregiver Perceptions Of The Helping Families In Mental Health Crisis Act (H.R. 2646)

There is a new study entitled “The Caregiver Perceptions Of The Helping Families In Mental Health Crisis Act (H.R. 2646)” that could identify caregivers perceptions of policy impacts on the availability of care plans, mental health resources, medical billing practices, patient rights, protection, responsible governance policy, and resources. This study could help inform policymakers on policy success and opportunities for improving services and care for children with mental illness. For this study, you are invited to describe your perceptions of the existing policies within the H.R. 2646 act.

This survey is part of the doctoral study for Odinakachi Chigewe, a Ph.D. student at Walden University.

About the study:

- One 30-60-minute zoom/ phone interview
- To protect your privacy, no names will be collected

Volunteers must meet these requirements:

- 18 years old or older
- Currently, have a child enrolled in this mental health facility for 6 months.
- Open to sharing their experiences

To confidentially volunteer please contact Odinakachi Chigewe at 347-271-2755 or at odinakachi.chigewe@waldenu.edu.

Appendix E: Interview Questions

STEP 1: Welcome and Overview of Purpose of Interview and Protocol (2-3 minutes)

“Hello, I want to start by first of all thanking you for agreeing and being here to participate in this one-on-one interview.

My name is Odinakachi Chigewe, and I am a doctoral student at Walden University. I am interested in learning about your perceptions of the Helping Families In Mental Health Crisis Act (H.R.2646).”

“The interview today should take between 60-90 minutes. I will be facilitating the interview; and would you mind if I taped the interview? If you do agree to be recorded, your verbal agreement will be part of the recording, as well as your acknowledgment that at any time during the study, you can stop or withdraw participation.”

Recording the interview will help me remain focused on our conversation, and it will also ensure that I have obtained an accurate record of what we discuss. Once the transcripts are created from the recording, two additional steps will take place.”

“First, I will invite you to submit additional information that can help to provide additional insight into the questions asked. You or I may want to schedule a follow-up conversation over the phone or via email to clarify or elaborate on any of the responses shared at the interview. This can also take place in a second, follow-up meeting.”

"Second, I will erase the audio recording. The typed transcripts will be kept on a password-protected hard drive for five years. Individuals can decide at any time to discontinue or cease their participation. If you have any questions, please feel free to ask.

Shall we begin?

STEP 2: Introduction (2-3 minutes)

Can you tell me, is your child currently a member or enrolled in this facility? Are you a resident of Bronx, NY? How long has your child been registered in this facility? What are your perceptions of the Helping Families In Mental Health Crisis Act (HR2646)?

STEP 3: 9 Questions Posed to Interviewee (4-5 minutes per question)

1. What is your view of the response services offered for mental health emergencies to you and your child in your community?
2. What is your view on the adequacy of hospital discharge procedures, and is there enough support and connections with outpatient treatment programs?
3. What impact will the 5% allocation of grant funds have on the increase of evidence based programs that address early serious mental illness?
4. What is your experience on billing related issues regarding mental health services rendered to your child? What is your view on inaccessibility of Medicaid and payment denial due to reasons that occurred the same day and in the same facility?
5. What is your view on inpatient psychiatric hospitalizations that lasts more than 190 days and the lifetime cap that affects the level of care received?

6. What is your view on caregiver hospitalization due to stress and anxiety associated with caring for a child with a diagnosis? What is your view on the financial issues when it comes to billing for an extended length of stay in the facility, and also dealing with payment for a non – Medicaid caregiver?
7. How effective do you feel that this policy will be in protecting children and patients against abuse and neglect while receiving mental health services?
8. What views/ values do you hold, when it comes to patient confidentiality, and the barriers experienced while obtaining information on a loved one or trying to schedule mental health services?
9. What are your thoughts of the requirement that political officials in Congress at the government level that make decisions concerning mental health in this nation, are required to be licensed psychiatrists or clinical psychologists? **STEP 4: Closing Questions (3-5 minutes)**

"Is there anything you would like to share about the HR2646 Act that I did not ask? Do you have any questions for me?"

STEP 5: Thank participants, recap next steps, and member checking will take place (2-3minutes)

"Thank you for participating in this study, and for sharing your experiences with me. Once your recorded interview is transcribed, I will contact you to read over the interview transcript. This will ensure that all that has been written down is what you intended to share. If you feel that the information is inaccurate or needs further clarification, we can discuss it further over the phone or in a follow-up interview. Thank you again for your participation."