

QUALITATIVE STUDY OF PARENTS CARING FOR CHILDREN WITH ASD

A Phenomenological Study of Parents Accessing and Receiving Professional Care for their Child
with Autism Spectrum Disorder (ASD) during the COVID-19 Outbreak in Washington State

Patrick M. Barry

Department of Community Care and Counseling, Liberty University

A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

Doctor of Education

School of Behavioral Sciences

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Abstract

COVID-19 changes and restrictions have necessitated a change in the way schools, mental health providers, medical providers, and other educational and therapy services provide for children with autism. This study explores, in-depth, the experience of parents of children with ASD as they have navigated the COVID-19 required changes to professional treatment and services for children with ASD and their families. Research suggests that raising a child with an autism spectrum disorder (ASD) can be an overwhelming experience for parents and families, and greater family burden is positively associated with the number of unmet professional help service needs. As services were moved to online or discontinued during COVID-19 in Washington state, participants experienced a reduced access to care and describe in this study how it impacted their families. Specifically, parents and children preferred professional supports that were in person and when treating the child, participants appreciated a whole family approach where they were included in the therapy process but were not compelled to provide the therapy. Parents added that the further isolation that lockdowns, move to online therapies, online schooling, and shutting down of parks, and other venues had an outsized negative impact on them and their family. The systemic family impact of the COVID-19 mitigation efforts by providers of professional supports were significant to parents and varied across delivery methods, age of the children, parental transgenerational challenges, and other significant factors.

Keywords: Autism spectrum disorder, ASD, professional support, COVID-19, parents

Dedication

I would like to dedicate this research to the families caring for children with autism. Their love, patience, support, and dedication to their children's development and ability to thrive in this world is an inspiration to all.

Acknowledgments

I want to acknowledge the five participants of this study who shared their story and their struggles so that others could benefit in the future. This was a selfless use of your time and another testament to the dedication you have to your children. To my dissertation chair, Dr. King, who was always encouraging, thorough, and quick to respond with excellent advice and guidance. To my committee member Dr. Doney, who recognized some potential obstacles in my proposal and helped me avoid them in my research.

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Table of Contents

Abstract	4
Dedication	5
Acknowledgments.....	6
Table of Contents	7
List of Tables.....	10
List of Figures	11
List of Abbreviations	12
Chapter One: Introduction	13
Overview.....	13
Background.....	14
Situation to Self.....	20
Problem Statement	22
Purpose Statement.....	24
Significance of the Study	24
Research Questions	26
Definitions.....	28
Summary	32
Chapter Two: Literature Review	34
Overview.....	34
Theoretical Framework.....	36
Related Literature.....	43
Summary	63

Chapter Three: Methods	65
Overview	65
Design	65
Research Questions	68
Setting	68
Participants	69
Procedures	70
The Researcher's Role	71
Data Collection	73
Conceptual Mapping Task	74
Memoing	82
Data Analysis	82
Trustworthiness	84
Credibility	85
Dependability and Confirmability	86
Transferability	86
Ethical Considerations	87
Summary	88
Chapter Four: Findings	89
Overview	89
Participants Portrait	90
Mandy	91
Ashley	104
Richard	112

Stacey	122
Caitlin.....	134
Results.....	145
Theme Development.....	149
Research Question Responses.....	167
Summary	177
Chapter Five: Conclusion	179
Overview.....	179
Summary of Findings.....	179
Discussion.....	181
Implications.....	188
Delimitations and Limitations.....	193
Recommendations for Future Research	195
Summary	195
References	197
Appendices.....	214

List of Tables

Table 4.1	Participant Demographics.....	91
Table 4.2	Statement Count to Theme Association.....	149

List of Figures

Figure 4.1	Mandy's Conceptual Map Representation.....	104
Figure 4.2	Ashley's Conceptual Map Representation.....	112
Figure 4.3	Richard's Conceptual Map Representation.....	122
Figure 4.4	Stacey's Conceptual Map Representation.....	134
Figure 4.5	Caitlin's Conceptual Map Representation.....	145
Figure 4.6	ATLAS.ti Concept Cloud.....	147
Figure 4.7	Numerical Code Representation.....	148

List of Abbreviations

Applied behavior Analysis (ABA)

Autism Spectrum Disorder (ASD)

Center for Disease Control (CDC)

Computer Assisted Qualitative Data Analysis Software (CAQDA)

Conceptual Mapping Task (CMT)

Diagnostic and Statistical Manual of Mental Health Disorders - V (DSM-V)

General Systems Theory (GST)

Individuals with Disabilities Education Act 2004 (IDEA)

Licensed Marriage and Family Therapist (LMFT)

Non-Governmental Organization (NGO)

Occupational Therapists (OT)

Patient Health Questionnaire (PHQ-8)

Physical Therapists (PT)

Severe Acute Respiratory Syndrome Coronavirus 2; SARS COVID 2 (COVID-19)

Chapter One: Introduction

Overview

My fear is that development will stop because there is no continuity with the special education services. As a parent, you are limited with what you can do with your child. Our understanding and knowledge of the developmental field is limited. Really, as parents, how much can we really understand and help these kids? - Nancy (Tokatly et al., 2021; p. 1051).

These words from a mother of a child diagnosed with ASD illuminate the fear that many parents have at witnessing stalled developmental progress for their child during the COVID-19 pandemic and the anxiety they feel surrounding the changes in the professional support they have come to rely on (Tokatly et al., 2021). The purpose of this study is to unveil the experiences of parents caring for a child with ASD during the many changes in the access and delivery of professional support services for their child during the COVID-19 pandemic. The study provides an in-depth view from the primary coordinators of care for an ASD child, their parents. With this knowledge, professional providers of care for ASD children can better understand how the changes in care have impacted the family system as a whole. Furthermore, parents can be increasingly prepared during potential future outbreaks and providers will have additional critical data to address their care procedures should the need arise again.

This chapter will explain the significance and procedures used in this research. In an attempt to understand the phenomenon more thoroughly, the study will begin by providing some background which will examine the history of the phenomenon as well as provide the proper social context for it. It is also important to understand who the researcher is because in qualitative research, the researcher is the primary tool of analysis (Creswell & Poth, 2018). It is

important to understand how the philosophies and experiences of the researcher might impact the study, so that will also be revealed in this chapter. Lastly the problem being researched, the purpose of the study, its potential impacts, and the research questions attempting to address the problem and purpose will be discussed (Creswell & Poth, 2018).

Background

Parents and caregivers of a child with ASD face tremendous challenges in securing the numerous professional services their children require for managing their symptoms. These challenges were compounded significantly during the COVID-19 outbreak, leaving many parents anxious about how to best provide for their children and families (Lindsey & Barry, 2018; Critchley et al., 2021; Dekker et al., 2022, Kalb et al., 2021). The varying symptoms and severity of symptoms that a child with ASD can have present from severe, requiring 24/7 services, to mild cases where the child needs only some support beyond typically developing children (Helkkula et al., 2020). This spectrum of differences is a challenge to parents, caregivers, and providers of services because with varying clusters of symptoms children often require individualized and complex treatment plans. The coordination of care for these treatment plans is typically left to the parent/primary caregiver (Helkkula et al., 2020).

The prevalence of autism has risen recently and currently the Centers for Disease Control estimates that this neurodevelopmental disorder affects nearly 1.7% of the U.S. population (American Psychiatric Association, 2013; CDC, 2022b). There is speculation surrounding the reasons for this increase in diagnosis, but regardless of the reasons, parents will spend much of their day caring for their child with autism at home and coordinating services outside the home (Lopez et al., 2019; White et al., 2021). The COVID-19 pandemic has changed the way services were delivered to children with ASD. There is little research that explores how these changes in

accessing and receiving care from professional providers has impacted the family system and no research from a parent's lived experience of it. This study will attempt to provide insight into that question through the voice of the parental subsystem within the family and their experience of how these changes have impacted the family. With this knowledge, professional care providers will have new insights in how to best deliver care that positively impacts the family system as a whole.

Historical Perspective

It is important understand how both the diagnosis of ASD and the professional supports surrounding this neurodevelopmental disorder have evolved before understanding the context of the COVID-19 pandemic mitigation efforts on parents' efforts to access and receive professional services for their children. The prevalence of ASD has risen in the general population from birth year 1931 to birth year 2012 by nearly 1000-fold and 25-fold between birth year 1970 and birth year 2012 (Nevison et al., 2018). Across the both race/ethnicity and sex demographics, males are four-times more likely to receive the diagnosis than females, and the prevalence in white populations is greater than other races. However, there is evidence that the discrepancy in race is mitigated by access to care in underserved populations and as access and awareness increases, research suggests the disparity will not be as great (Nevison & Zahorodny, 2019). Researchers have studied this alarming increase and it appears that a small amount of the increase can be associated with a change in the diagnostic criteria, but that most of the increase is a real increase with no agreed upon hypothesis for it (Nevison, 2014; Prior, 2003).

With this significant increase in children diagnosed with ASD, the demand for treatment from professional service providers has increased exponentially as well. Due to the well-established conclusion that the goal for treatment for those with ASD focuses on managing the

many symptoms rather than “curing” the neurodevelopmental disorder, parents seek multiple professional provider supports (Gray, 2006). Consequently, parents/caregivers rely on special education providers to assist with their child’s education services. They rely on occupational therapists, physical therapists, applied behavior analysis therapists, mental health therapists, and speech therapists to manage their children’s physical and mental symptoms. Lastly, they rely on medical doctors to manage comorbid medical problems that are common in ASD patients (Ameis, 2020; Manning et al., 2021). The providers who care for children with ASD and have experience with ASD symptoms and presentation are too few. In a study from Stanford University of Medicine prior to the pandemic, researchers found that the demand for service providers of ASD is 18 times higher than the available supply (Digitale, 2017). There are likely many reasons for this that are beyond the scope of this study. One issue that is cited for the dearth in provider care is related to inadequate compensation to service provider’s time required to treat (Hsu, 2018). Treating ASD is time consuming. Moreover, provider confusion and frustration with insurance reimbursement has caused many providers of ASD care to move to a private pay model, further limiting parents access to care providers (Hsu, 2018).

With this already difficult care provider landscape, the introduction of the coronavirus in 2020 with the myriad of mitigation and protective measures, had a significant disrupting impact on this vulnerable population and the parents that coordinate their care. In March of 2020, in an attempt to slow the transmission of SARS-CoV-2, the virus that causes COVID-19, states each implemented their own policies on closure of schools, distance learning, and modifications to education experiences for children (Verlenden et al., 2021). Following the first U.S. coronavirus death of a man in Kirkland, Washington on March 1st, 2020, the governor of Washington State, Jay Inslee, took many measures to reduce the spread of COVID-19 in the state. Those measures

had a direct and significant impact on the access and delivery of care for children with ASD. The impact of COVID-19 is, in some regard, still ongoing at the time of this writing in 2023; consequently, research is only beginning to understand its impacts on the general population and more specifically, vulnerable populations (Foley et al., 2021; Patrick et al., 2020; Russell et al., 2020). There are already some studies attempting to understand how best to support individuals with autism during the pandemic, but it is clear that more research should be done, specifically from a parent's perspective (Critchley et al., 2021; Dekker et al., 2022, Kalb et al., 2021).

Social Context

The importance of studying the impact on the family system due to changes in provider care during the pandemic is significant because of the largess of people effected. There are estimated to be over 5 million people who are diagnosed with ASD in the United States (American Psychiatric Association, 2013; CDC, 2022b). This vulnerable population depends on support from parents, extended family, and friends. The outcome of the care from professional care providers impacts all of these stakeholders well beyond the five million diagnosed with the disorder.

Parenting and coordinating care for a child with developmental disabilities is very difficult and time consuming. Moreover, caring for a child with ASD has many unique challenges that ranks it as one of the most stressful of disabilities to care for (Gray, 2006). Parents caring for children with ASD express that what makes autism so difficult for them is their child's antisocial behavior, challenges in communication, and lack of emotion or dysregulated emotional expression (Depape & Lindsay, 2015; Fletcher et al., 2012; Gray, 2006). There is a significant social difference between those diagnosed with ASD and other neurodevelopmental disorders because children with ASD appear as typically developing, yet

their symptoms present as “bad behavior.” In a social context, observers of the child’s behavior often conclude that the behavior can be controlled by better parenting (Depape & Lindsay, 2015; Koydemir-Ozden & Tosoun, 2012). Consequently, this dynamic tends to create difficult situations for the parents and their child. Compounding this, children with autism have difficulties developing friendships, playing with others, laughing, or interacting with extended family or the community. An unfortunate consequence is that many parents and families isolate themselves to avoid social situations (Depape & Lindsay, 2015; Fletcher et al., 2012; Gray, 2006). Additionally, parents of children with autism are acutely aware that it is likely that their child will have symptoms of ASD persist throughout their lifetime often requiring support from the parent the remainder of their life.

Those diagnosed with ASD, often thrive on sameness, engage in repetitive behaviors, have fixated interests, and display an over-adherence to rigid structure. One of the more effective treatment options is to provide routine and structure for children with only minor changes that are gently introduced by a care team well in advance in an effort to prevent severe dysregulation (American Psychiatric Association, 2013). Unfortunately, COVID-19 necessitated constant change in both the educational support and professional service support that parents of a child with ASD had come to rely on (Bhat et al., 2021; Huang et al., 2021). Current research into the effects of the pandemic have suggested that the changes in direct human contact, remote interaction, and disruption in daily routines have resulted in negative mental and physical outcomes for this population (Ameis et al., 2020, Bhat et al., 2021; Colizzi et al., 2020). Research conducted at the onset of the pandemic has demonstrated that children with ASD have an increase in symptoms and more extreme behaviors with a resulting increase in medication dosages (Masi et al., 2021; Pecor et al., 2021). The parents themselves also report extreme to

moderate stress due to a loss of or change in services or therapies for their children during the COVID-19 pandemic (White et al., 2021; Corbett et al., 2021). Parents reported that their children had elevated hyperactivity, conduct, and emotional problems (Foley et al., 2021; Patrick et al., 2020). Not surprisingly, parental distress was equally elevated which impacted parent-child conflicts and just plain household chaos. All the impacts on the family caring for a child with ASD are examined in this study through a systemic approach.

Theoretical Context

When caring for a child with ASD, family theorists stress that the child is part of a system, the family system, and to focus on not just one part of the system, the child, but to focus on the relationship and interaction between all the objects in the system (Von Bertalanffy, 1951; Hecker et al., 2015). This systems focus of care challenges the linear progression of causality prominent in many care models. The focus in systems thinking privileges a circular causality where “A does not cause B nor does B cause A; both cause each other” (Seligman & Reichenberg, 2014, p. 392).

This study considers three theorists who are pioneers in family systems theory, von Bertalanffy, Bronfenbrenner, and Bateson (Guise, 2015; Hecker et al., 2015; Seligman & Reichenberg, 2014). Von Bertalanffy (1968) introduced systems thinking to understanding families through his theoretical concept of General Systems Theory (GST). The second important theory that guides this study is Bronfenbrenner’s Social Ecological Theory focusing on the interaction between the microsystem (close family, siblings, peers), mesosystem (family, work, school interaction), and exosystem (community interactions) and how they influence families as well as how the family or individual influences the other systems (Bronfenbrenner, 1979; Seligman & Reichenberg, 2014). The third theory combines both general systems theory

and cybernetics through a focus on communications and feedback loops as they apply to families. The theorist/practitioner is Bateson (1972) who developed and researched these ideas as he was training a new generation of family therapists (Hecker et al., 2015). Their combined work on the study of how families interact is the lens through which this study will view the systemic impact of accessing and receiving ASD professional supports on the families they serve.

This systems approach to understanding a phenomenon such as this has many variables and systemic impacts. Therefore, rather than choosing a quantitative approach to address the many variables, this study examines the phenomenon through the lens of the lived experience of one of the primary stakeholders, the parent/primary caregiver.

Situation to Self

As the sole researcher in this qualitative study, I proposed the study, designed it, selected the sampling criteria, interviewed the participants, analyzed their data, then created themes, and addressed conclusions and implications. With such a singular perspective in research it is important for readers of the study to understand the potential biases and motivations I have (Creswell & Poth, 2018; Moustakas, 1994). To address this, I will first discuss the philosophical assumptions I bring to the research followed by the paradigm that will guide the study.

Philosophies and Paradigms

The philosophical assumption that led to this choice of research was an epistemological one. Specifically, I am interested in the subjective evidence obtained from the experience of the participants. During the research I will attempt to provide a view of accessing and receiving professional help services for a child with ASD from their parents' perspective during the pandemic (Creswell & Poth, 2018; Heppner et al., 2016). It is through the parents' perspective I

can add important information surrounding this phenomenon that adds just one more piece of data to a larger body of data in the search for truth.

However, the paradigm I come from is a post positivist view where there is a “real” reality, but that truth can never be fully known to us, even though the search for truth is among the worthiest of goals. Furthermore, as a researcher, I have biases that affect the research which I am either blind to, or decide they are important enough to leave in the study and ensure that I acknowledge them. As a post positivist, I believe that in the end, all research is flawed; but it is my hope that with enough research from many perspectives we can see real themes and important trends in the social sciences that can further our true understanding of the human person (Creswell & Poth, 2018; Heppner et al., 2016).

Researcher Motivation and Background

I am a licensed marriage and family therapist (LMFT) in private practice in Washington State and a doctoral candidate in the online community counseling program at Liberty University. As a part of my caseload, I provide professional mental health services for children, teens, and adults with ASD and their families. During my clinical work with these families, I came to understand the difficulties that they have in coordinating the expansive network of professional care providers who are important in managing their child’s symptoms. This was often the full-time “job” of one of the parents, if there were two parents. If not, then often the single parent, almost exclusively the mother, rallied family and friends to help out, requiring even more coordination.

Unfortunately, COVID-19 significantly increased the challenges with coordinating this care as these families had to manage unprecedented changes in care. In the State of Washington providers of mental health service experienced many disruptions in their ability and methods of

providing support to their clients as the Department of Health issued varying guidance during the pandemic. It varied among health care settings, but most providers' guidance from the Health Department involved closing the practice for a short while, then re-opening with new mask and cleaning requirements, then many moved to all online appointments, then moved back to masked and cleaning requirements. Individual health care provider tolerances and/or parental health concerns also impacted continuity of care. Moreover, these changes significantly impacted both the special education and applied behavioral analysis (ABA) therapy that families were dependent on.

As a result, I listened to the parents and children as they expressed a significant increase in anxiety, depression, and just general chaos in the home due to the pandemic and the difficulties they were having while their child was attempting to adjust to the many changes in care. As a family therapist with a family systems focus, I became interested in understanding more about the phenomenon I was witnessing. This research is an attempt to give those parents a venue to gather their thoughts and experiences surrounding this phenomenon and provide a detailed, rich, and expansive description of it.

Problem Statement

During the outbreak of COVID-19 in Washington State, every professional service that supports children with autism and their parents had to change their delivery of care in some way. From moving to online services only, social distancing, wearing masks, discontinuing, or reducing services. Parents were left with the task of coordinating, accessing, transporting, and scheduling care in the midst of unpredictable change. Children with ASD have difficulty with any change (Lindsey & Barry, 2018), but change of this magnitude is particularly difficult.

Parents caring for a child with autism were required to navigate all these changes, both in terms of their own work and family schedules and also for their child with ASD.

The problem is that there is a dearth in research attempting to understand the impact that the change in professional service care has had on the family system, specifically from the lived experience of the most knowledgeable people in the family system, the parents. This a problem that is far reaching and effects over five million families in the United States and over 119,000 in Washington State (American Psychiatric Association, 2013; CDC, 2022b). Fortunately, research is being conducted to understand related phenomenon. Researchers are attempting to understand the impacts of COVID-19 on children with ASD and there are emerging studies attempting to understand how to best support individual children with autism in the midst of the COVID-19 pandemic lockdowns and mitigation efforts. This research has focused on wellbeing and mental health for children with ASD during the pandemic (Manning et al., 2021; Masi et al., 2021; Pecor et al., 2021). Other research has been conducted on the benefits or problems with online services (Bhat, 2021; McKenzie et al., 2021; Vera San Juan et al., 2021; White et al., 2021). Some research has focused on the changes that professional providers experienced during the pandemic (Hopcan et al., 2021; Rice, 2022; Simpson & Adams, 2022).

However, none of these studies has examined parent and caregiver lived experiences in accessing and receiving care for their vulnerable children. It is important to view this phenomenon from the parent's perspective so that we can understand the impacts on the family system more accurately. This study was designed as a transcendental qualitative study that will provide a thick, rich, and deep look into this phenomenon that has so many variables impacting, influencing, and interacting with the family system.

Purpose Statement

The purpose of this transcendental phenomenological study is to describe the experience of parents caring for a child with ASD as they are accessing and receiving professional services for their child in the midst of a global COVID-19 pandemic in Washington. For this study, professional help services are defined as providers of occupational therapy, physical therapy, applied behavior therapy (ABA), social skills training, speech therapy, family counseling, marriage counseling, social worker services, special education, neurology, pediatrics, psychiatry, individual psychotherapy, residential programs, and special camps. The theory guiding this study is a family systems framework consisting of the general systems theory (GST) of von Bertalanffy (1951, 1968), the social ecology theory of Bronfenbrenner (1979), and the cybernetics theory from Bateson (1972). These theorists provide the framework for understanding the complex interactions and circular causality experienced in families as they interact with professional support systems. Understanding how the family attempts to adapt to changes as a whole system during the pandemic is an important part of understanding the outcomes for children with ASD and their parents.

Significance of the Study

In caring for a child with ASD there are many essential services required for the management of symptoms in conjunction with the warmth, love, and care of the child's parents or primary caregiver. Therefore, the coordination of the care that a parent accesses for their child touches many different professional care providers, special education teachers, ABA therapists, speech, occupational, and mental health therapists, and medical doctors (Gray, 2006; Ameis et al., 2020). Early research suggests that the clinical service shutdowns as well as the special education closures have led to significant loss of service for children with ASD and their families

(Bhat et al., 2021; Huang et al., 2021). The changes in direct human contact, remote interactions, and daily routines for this vulnerable population have resulted in negative mental and physical health consequences (Ameis et al., 2020, Bhat et al., 2021; Colizzi et al., 2020). Parents felt overwhelmed and lacked the tools they needed to provide for their children's developmental needs (Bhat et al., 2021; Tokatly et al., 2021).

This study can make a difference by highlighting parent's experience of professionals providing necessary services for their children during the pandemic. It will provide critical information for professional providers to help meet the needs of children with ASD in future pandemic situations and possibly even current care protocols

This study will also provide a glimpse into how Washington state, one of the more restrictive states, approached its mitigation efforts to protect its citizens from the negative effects of the virus (Ballotpedia, 2021; MyNorthwest, 2021). The study can provide information to policy makers so they can better understand the impact that policy has on the over 119,000 persons with autism in the state and the families that support them.

Currently researchers are attempting to understanding how best to support individuals with autism during pandemic lockdowns and mitigation efforts. However, none of these studies attempts an in-depth understanding of the experiences from parents and caregivers as they navigate the changing landscape in professional care. Moreover, there are no studies investigating how those challenges in accessing and receiving care for their vulnerable children affect the family system (Helkkula et al., 2020). This study is important because it privileges the primary caregiver's voice in describing the lived experience, the frustrations, challenges, and benefits, that parents have felt during the pandemic.

Parents caring for a child with ASD can benefit from this study through any positive government procedural changes or professional caregiver changes that are a result of this study. Any small positive effect in the family system can positively impact the system through a positive feedback loop (von Bertalanffy, 1969; Bateson, 1972). This study will give parents the opportunity to narrate their lived experiences of accessing and receiving professional support during the pandemic and in doing so, give an in-depth understanding of the phenomenon to other key stakeholders like professional care providers and government policy officials.

Research Questions

1. How do parents of children with ASD describe their experiences of accessing and receiving professional services for their child in the midst of COVID-19 mitigation efforts in Washington State?

This question and question number four are the primary questions that this research is attempting to answer. Questions two and three are sub-questions of this first primary research question. This first research question addresses the phenomenon surrounding the accessing and receiving care from professional care providers during the COVID-19 pandemic in an open-ended manner that allows the participant to provide rich and thick description (Creswell & Poth, 2018). This question focuses on the lived experience of the parent; their answers represented their subjective experience and provided insights into the challenges and successes they experienced over a two-year period with the system of professionals they came to rely on (Bhat et al., 2021; Tokatly et al., 2021; Helkkula et al., 2020).

2. How do parents describe their interactions with professional services for their child with ASD during the pandemic?

This is a sub-question to question one sharpening the focus to the interactions and the interpersonal relationships that were a part of their experience with the phenomenon. These two sub-questions further specify the central question into this specific area of inquiry (Creswell & Poth, 2018). Understanding the relational aspect of this phenomenon can shed light on either negative or positive exchanges between parent and professional care provider, which in turn impacts their subjective experience (Helkkula et al., 2020; Prime, 2020; Dahiya et al., 2022).

3. How do parents describe the difference between accessing and receiving professional services before the COVID-19 pandemic and during the pandemic?

This sub-question attempts to understand the temporal aspects of the phenomenological research (Heppner et al., 2017). In the selection process participants were selected only if their child had received their diagnosis prior to 2020 to ensure that the parents were exposed to the services both before and during the COVID-19 pandemic and its subsequent mitigation measures.

4. How do parents of children with ASD describe the impact on their family system while accessing and receiving care from professional ASD service providers during the COVID-19 pandemic?

This final research question is a primary research question that attempts to understand the systemic impact on the family system by the change in accessing and receiving professional care for their child with ASD during the COVID-19 pandemic. This is a descriptive question leaving the participant room to free associate in any direction in describing their experience (Creswell & Poth, 2018). This study has a family systems focus and this question addresses that focus and recognizes that families can be morphogenetic or rigid. Families that were able to adapt to the change were no doubt better off. However, systems that were rigid and continually moved

toward homeostasis, or families that were chaotic and with little structure, faced an enormous threat to the functioning of the system (Balswick & Balswick, 2014). The accessing and receiving of care from providers had an impact on this system and this question attempts to better understand a parent's experience of this impact.

Definitions

1. *ATLAS.ti* - A software program designed for qualitative research data collection and analysis (Creswell & Poth, 2018).
2. *Age of Majority* - The age in which an individual can make their own decisions concerning their care without parental consent or knowledge (Wilcoxon et al., 2013).
3. *Autism Spectrum Disorder (ASD)* - A neurodevelopmental disorder that affects 2 – 7% of children in the world (CDC, 2022). Key features are deficits in social-emotional reciprocity in language and nonverbal communications as well as restricted patterns of behavior, interests, or activities, repetitive motor movements or speech, sensory deficits, and inflexible insistence on sameness (American Psychiatric Association, 2013).
4. *Computer Assisted Qualitative Data Analysis Software (CAQDA)* - Software created to assist qualitative researchers analyze, collect, store, and organize text and image data (Creswell & Poth, 2018).
5. *Conceptual Mapping Task (CMT)* - a qualitative interviewing tool and protocol, which contains four distinct, internal member-checking mechanisms within a single-interview format (Impellizzeri et al., 2017).
6. *COVID-19* - COVID-19 is a respiratory disease caused by SARS-CoV-2, a coronavirus discovered in 2019. The virus spreads mainly from person to person through respiratory

droplets produced when an infected person coughs, sneezes, or talks (Centers for Disease Control and Prevention, 2022).

7. *Cybernetics* - The science of communication and control in humans and machines; the study of the self-regulating properties of systems (McGeorge et al., 2015).
8. *Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-V)* - A classification of mental disorders with associated criteria designed to facilitate more reliable diagnoses of these disorders (American Psychiatric Association, 2013).
9. *Family Systems Theory* - The unique attributes of the family members and the relationships between family members to include extended families or relatives of those making up the primary family combined with various systems theories (Hecker et al., 2015).
10. *Feedback loop* - A circular causal process in which a system's output is returned to its input (Hecker et al., 2015).
11. *General Systems Theory* - A theory that defines relationships of objects or individuals within biological, economic, or physical systems (Hecker et al., 2015).
12. *Homeostasis* - Occurs when a system maintains stability or the status quo. Refers to the tendency of families to develop recurring interactional patterns to maintain stability and balance (Hecker et al., 2015).
13. *Individuals with Disabilities Education Act 2004 (IDEA)* - A piece of legislation that ensures students with a disability are provided with a free appropriate public education that is tailored to their individual needs (Dewey et al., 2017).

14. *Licensed Marriage and Family Therapist (LMFT)* - A professional license regulated by State Department of Health allowing the individual to assess, diagnosis, and treat mental health disorders and relationship distress (McGeorge et al., 2015).
15. *Lockdown Measures* - Steps that government agencies and private enterprises have taken to aid in slowing the spread of COVID-19, typically restricting movement of the community to only essential tasks (Patrick et al., 2020).
16. *Mandated Reporter* - A person working in a profession that is required by state law to report the suspected abuse of a minor or elderly person to proper authorities (Wilcoxon, 2013)
17. *Mitigation Efforts* - Measures taken by government agencies or private enterprises to slow or stop the spread of COVID-19 (Patrick et al., 2020).
18. *Morphogenesis* - The tendency of a system to evolve and to change its structure refers to constructive, system-enhancing behaviors (Hecker et al., 2015).
19. *Otter.ai* - Speech and text transcription and translation application using artificial intelligence and machine learning (Creswell & Poth, 2018).
20. *Pandemic* - When a disease affects the global population normally caused by a new infectious agent, bacteria or virus that spreads quickly, like COVID-19 (Patrick et al., 2020).
21. *Paradox* - A statement that tends to disqualify itself, like a parent ordering a child to be more spontaneous would disqualify the command (McGeorge et al., 2015).
22. *Patient Health Questionnaire (PHQ-8)* - Eight question measurement tool to assess current depression in the general population (Kroenke et al., 2009)

23. *Post positivist* - A scientific approach to research through a social science theoretical lens that does not adhere to the notion of strict cause and effect but recognizes all cause and effect as probability that may or may not occur. Post positivists believe in multiple perspectives from participants rather than a single reality and espouse rigorous methods of qualitative data collection and analysis (Creswell & Poth, 2018).
24. *Professional Care Provider* - Special education teachers, applied behavior analysis (ABA) providers, Speech Therapists, Occupational Therapists (OT), mental health providers, Physical Therapists (PT), Medical Doctors (MD).
25. *Reductionist* - Either a theory or a process of reducing complex data or systems into parts and its most basic components (Hecker et al., 2015).
26. *Social Distancing* - A measure used to slow the spread of COVID-19 involving staying approximately 6ft from other people, not attending large gatherings outside or small gatherings inside. It also includes installing barriers between the public and workers, usually plexiglass (Centers for Disease Control and Prevention, 2022).
27. *Social Ecological Theory* - A biopsychosocial approach to wellbeing where one develops in the context of relationships while being influenced by and influencing the environment (Rosa & Tudge, 2013).
28. *Standard Deviation (SD)* - A statistical term used to explain deviations from the mean in either direction from the center of the distribution, typically there are only three deviations from the mean, and they are represented by this number (Warner, 2021)
29. *Storying* - A term used in conceptual mapping task during phase II describing the process the participant engages in to narrate their experience of the phenomenon being studied (Impellizzeri et al., 2017).

Summary

The problem this study addresses is the limited research attempting to understand the impact that the change in professional service care during the COVID-19 pandemic has had on the family system, specifically from the lived experience of the parents. Professional care supports are so important for the development of a child with ASD, so understanding how changes in care have impacted the over 119,000 people who are diagnosed with his disorder in Washington State is an important endeavor (American Psychiatric Association, 2013; CDC, 2022b). The purpose of this phenomenological study is to describe the experience of parents caring for a child with ASD as they are accessing and receiving professional services for their child in the midst of a global COVID-19 pandemic in Washington.

Additionally, this study privileges the view of the child with ASD as an important member of a family system and this child both influences and is influenced by his family. The study recognizes a tension in the medical and professional support services between addressing the individual client needs and concerns and honoring the family and cultural relationships in which that child develops (Balswick & Balswick, 2014; Von Bertalanffy, 1951, 1968). This systems approach understands the child with ASD as residing in a system that is an identified whole composed of many interrelated individual parts including professional support. Therefore, as the family is impacted by the quality, quantity, and expense of care the child with ASD receives, so is the child, and even the professional providers.

This chapter and the chapters that follow highlight the many potential benefits of this study, but ultimately the focus is on research that informs providing the best care possible for children with ASD and their families. Parents caring for a child with ASD can benefit from this study through any positive government procedural changes or professional caregiver changes

that are a result of this study. Moreover, even a small positive effect to the family system can positively impact the system through a positive feedback loop (von Bertalanffy, 1969; Bateson, 1972).

Chapter Two: Literature Review

Overview

Being a parent and caregiver to a child with autism spectrum disorder (ASD) has many of the same rewards of parenting typically developing children, but it comes with many additional challenges, key among them is navigating the many professional services designed to assist children with ASD. Autism is a neurodevelopmental disorder that effects nearly 1.7% of the U.S. population and is characterized by persistent impairment in reciprocal social communication and interaction, restricted and repetitive behaviors and interests, and presents from early in childhood (American Psychiatric Association, 2013; CDC, 2022b). The intensity of these symptoms varies greatly with those diagnosed and therefore the term spectrum is used. Raising a child with ASD can be an overwhelming experience for parents and families as they face many challenges with the behavioral, emotional, interpersonal, and intellectual atypical presentations from their child (Ooi et al., 2016; Gray, 2006). Parents spend much of their day caring for a child with ASD and on average bring their children to 12 or more appointments a week for professional supports often necessitating at least one parent provide full time care. Professional medical and educational providers are considered essential for management of the symptoms and their presentation within this neurodevelopmental disorder. Research demonstrates that greater family burden for those caring for a child with autism is positively associated with the number of unmet professional supports (Lopez et al., 2019; White et al., 2021).

The COVID-19 pandemic and subsequent restrictions and lockdowns have necessitated many changes in the care a child with ASD and their families receive. Children with ASD have difficulty with any change (Lindsey & Barry, 2018), but change on this magnitude is particularly

disorienting for children with ASD and their families. To address the systemic nature of the changes to professional supports for an ASD child, this chapter summarizes three foundational theoretical frameworks that guide the reciprocal nature of ASD family's internal systemic interactions and their interaction with the health and education providers in their community. General systems theory, social ecological theory, and cybernetics all emphasize circular causality within families and their interaction with their communities (Bateson, 1972; Bertalanffy, 1968, 1979; Bronfenbrenner, 1979). These important theorists look beyond linear causation into the circular and systemic causes. They explore beyond the intra and interpersonal systems and communities that impact and influence interpersonal relationships. This exploration is useful when attempting to understand the impact of the changes in care for a child with ASD and their families.

Research is only beginning to understand the impacts of the COVID-19 pandemic mitigation efforts on the general population and more specifically, vulnerable populations (Foley et al., 2021; Patrick et al., 2020; Russell et al, 2020). There are studies attempting to understand how best to support individuals with autism during the pandemic (Critchley et al., 2021; Dekker et al., 2022, Kalb et al., 2021). However, none of these studies has examined parent and caregiver lived experiences in accessing and receiving care for their vulnerable children. It is important to assess the impact on the family from the parent's perspective so that one can understand the impacts on the family system more accurately. This study will make a difference by highlighting parents' experience of professionals providing necessary services for their children during the pandemic. It will provide critical information for professional providers to help meet children with ASD needs in future pandemic situations and quarantines from a major stakeholder's perspective.

Theoretical Framework

To understand the impact of the pandemic on families with an ASD child, it is important understand the systemic way families interact through the lens of some of the most influential family system theorists. There are generally considered to be three foundational theories that guide both the systemic study of families and counseling them (Guise, 2015; Hecker et al., 2015; Seligman & Reichenberg, 2014). The first of these is Bertalanffy's (1968) General Systems Theory (GST) that introduced systems thinking to understanding families. The second is Bronfenbrenner's Social Ecological Theory focusing on the interaction between the microsystem (close family, siblings, peers), mesosystem (family, work, school interaction), and exosystem (community interactions) and how they influence families as well as how the family or individual influences the other systems (Bronfenbrenner, 1979; Seligman & Reichenberg, 2014). The final theorist/practitioner is Bateson (1972) and his theories on how families communicate, bringing both general systems theory and cybernetics focus on communications and feedback loops as they apply to families. Their combined work in the study of the way families interact is the lens through which this study will view the systemic impact of accessing and receiving ASD professional supports on the families they serve.

General Systems Theory (GST)

The first theorist, Ludwig von Bertalanffy's (1951, 1968, 1976) was a biologist who developed general systems theory (GST), a theory that focused its concern with understanding how things worked by looking not just at one part of the system but by focusing on the relationship and interaction between all the objects in the system (Von Bertalanffy, 1951; Hecker et al., 2015). He describes GST as a concept of a doctrine of wholeness, a deductive system of principles that flow from the definition of system (Von Bertalanffy, 1951). He thus provided us

a model for investigating and understanding living systems, not by breaking them down into parts, but by focusing on how apparently unrelated events or phenomena can be seen as interrelated parts of the larger system (Hecker et al., 2015; Bertalanffy, 1968).

General Systems Theory as applied to Families

As a biologist Von Bertalanffy (1951) applied his general systems theory to many disciplines theorizing that GST provided a conceptual framework for understanding how the biological, psychological, and sociological dimensions are interrelated (Von Bertalanffy, 1972; Tremonti et al., 2019). Von Bertalanffy (1951) distinguishes between simpler elements in science and living organisms, the latter of which he explains are organized as goal directed open systems and not as simple passive receivers of inputs from their environments. These complex systems in living organisms interact with and influence their environments (Tramonti et al., 2019).

Family systems theorists and indeed the inception of family therapy is built on the foundation of general systems theory, and it is considered one of the most important theories in family systems focused therapy (Guise, 2015; Hecker et al., 2015; Seligman & Reichenberg, 2014).

The systemic approach of Bertalanffy's theory challenged the linear progression of causality prominent in science that studied matter in a reductionist way. His theory explained a circular causality where "A does not cause B nor does B cause A; both cause each other" (Seligman & Reichenberg, 2014, p. 392). This approach provided a holistic way of looking at systems, particularly family systems. To wit, as an individual interacts with others in the family system, the whole family system changes slightly, and consequently as the family system changes it will naturally gravitate towards a homeostatic or "stable" state (Von Bertalanffy,

1951, 1968; Hecker et al., 2015). That is until it is moved out of that homeostatic state and forced to adjust to novel changes to the family system, either by individuals in the system or by influences from sources outside of the family e.g., extended family, schools, community, or professional providers. When this change happens, the system attempts to regain the homeostatic state and to do so uses both positive and negative functioning to achieve it (Von Bertalanffy, 1951; Hecker et al., 2015).

GST and the Professional and Parental Caregiving to Children with ASD

General systems theory is useful in attempting to understand the impact on the family system as it interacts with the changes in the way they access and receive professional provider support as a result from the COVID-19 pandemic. We know from many sources that providers of special education, occupational therapy, mental health therapies, applied behavioral analysis (ABA), and physical therapy have had to significantly change the way they provide support to children with ASD (Hoofman & Secord, 2021; Powers-Dirette, 2020; Rice, 2022; White et al, 2021). These changes impact the family on a weekly, daily, or in the case of some ABA treatments, even an hourly basis. The change for the family or even one individual in the family can affect the entire family system. Research suggests these changes in social and professional supports, increase the risk for mood and anxiety disorders, which are co-occurring for many ASD children (Bhat, 2021; Diamond et al., 2020). Moreover, the increase in mood and anxiety disorders in a family member can have an impact on other members of the family system in a circular way as theorized by GST and also by the next theory which examines how one's social environment plays an important role.

Bronfenbrenner's Social Ecological Theory

Another key theory in understanding how family systems behave is Bronfenbrenner's social ecological theory focusing on the interaction between the microsystem (close family, siblings, peers), mesosystem (family, work, school interaction), and exosystem (for this research would be professional ASD care supports). His theory provides a framework for understanding the social of the biopsychosocial approach to mental health and well-being and the theory is primarily a theory of how one develops within the context of relationships (Bronfenbrenner, 1979; Neal & Neal, 2013). Bronfenbrenner's (1979) theory of social ecological development viewed the individual as continually developing and as such influencing and being influenced by the environment (Rosa & Tudge, 2013). The family is central to this development and plays a key role in the microsystem where the beginning development occurs, through individual characteristics of other family members, and especially through interactions among family members as proximal processes (Rosa & Tudge, 2013). In short, Bronfenbrenner wanted to explain his theory of human development by ensuring a focus on the context in which one develops, primarily the family. Bronfenbrenner during his lifetime developed his theory as a comprehensive theory describing the contextual influences on children's development (Ungar et al., 2013). Moreover, ASD is a neurodevelopmental disorder and suggests that development and impacts on development are exceedingly important.

Central to this theory is that the interpersonal relationships and processes in the parent-child relationship are embedded in larger social structures in the community from the individual to the macrosystem of culture and ideologies (Bronfenbrenner, 1979; Ungar et al., 2013). In agreement with this model of development as it applies to mental health, Haehnel et al. (2021) found a significant association between the various aspects of individual health and a

comprehensive measure of family health. Specifically, depression had the strongest association in its interaction between individual and family health, indicating that one part of a family system can have a significant impact on the functioning of the whole system, consistent with Bronfenbrenner's (1979) social ecology model (Bronfenbrenner, 1979; Haehnel et al., 2021). This is but one example of how the exosystem extends its influence on the microsystem.

Bateson: Applying General Systems Theory and Cybernetics to Families

The final theorist important to this research is Gregory Bateson (1972) who was an anthropologist and considered one of the most influential figures in the family systems movement. He is credited with integrating both general systems theory and cybernetic theory to understanding how families behaved and interacted (Guise, 2015; Hecker et al., 2015). Bateson explored cybernetics theory of communication and control as the means through which systems maintained themselves through both positive and negative feedback loops. In this exploration he and his team of communication theorists and therapists focused on the paradoxical communication styles of animals and then family systems (Bateson, 1972). In understanding these feedback loops and their importance on the family system, one can begin to unpack the mechanisms that impact parents of children with ASD based on the quality of interactions with professional providers.

To illustrate this theory, one must understand a key paradox that Bateson (1972) studied, the paradox of the double bind. An example of this type of double bind in communications theory, is a child eating with an explosive and prickly parent who tells them that they need to talk more at the dinner table. The child is punished if they do not talk and punished when they do talk, creating a false free decision for a positive outcome. It has been observed from early studies on communication and cybernetics that family functioning and the delivery of messages

in the parent-child dyad can impact child mental functioning (Bateson, 1972; Sojit, 1969). This confusing style of communication is common in dysfunctional family communications and hampers the family system, but this also happens in the wider social ecological system (Sojit, 1969). For example, when providers of key and essential services for children with autism say to parents that early intervention services for autism are essential for better outcomes for their child with autism, and at the same time change services through cancellations, movement to online, or mask wear during social interactions, parents can feel that they are in a situation like the double bind.

Importance of These Systems Theorists for Parents Caring for a Child with ASD The theorists described above provide very useful language and concepts for understanding how families interact within their own family systems and how the family system interacts with other important systems in their broader environment. This system of systems, or interactions between systems, cannot simply be viewed in a linear or reductionistic way. Thus, multilevel systems theory was developed primarily to address inadequacies in simple cause and effect models used for explaining the complex social behavior that transpires in the family (Balswick & Balswick, 2014). When attempting to understand how parents caring for children with autism are impacted by changes in their important services, one must understand how systems are impacted and not just the individual.

There is a tension in the medical sciences between honoring the individual's needs and perspectives and honoring the family and cultural relationships that are part of the individual's world. In the state of Washington, the age of majority for mental health decision making is 13 as well as for many medical decisions regarding sexuality (Washington State Health Care Authority, 2018). However, many care providers in clinical professions are shifting the focus

from the individual to the systems that they reside in, specifically the family system and beyond (Balswick & Balswick, 2014). This systems approach, as described above, understands the child with ASD as residing in a system that is an identified whole composed of many interrelated individual parts. It goes without saying that the family is impacted by the quality, quantity, and expense of care the child with ASD receives. The family system is influenced by and influences the professional support that they receive (Bronfenbrenner, 1979).

A family viewed through the lens of general systems theory allows inputs and directs outputs through the boundaries it creates (Balswick & Balswick, 2014; Von Bertalanffy, 1951, 1968). If the family system is always attempting to create homeostasis, then it tends to have rigid boundaries that are designed to protect their homeostasis from external threats that may change it. For example, changes to the family system that may be more beneficial for the child with ASD can be rejected by the family system so that the system can maintain the status quo or homeostasis. Fortunately, families with clear boundaries will typically operate out of a morphogenesis response pattern where they are generating new responses to adapt to minor changes in their environment (Balswick & Balswick, 2014).

In complex systems like the family and its interaction with professional supports, one can observe the various ways in which behavior is regulated, balanced, or changed through a feedback process (Balswick & Balswick, 2014). This type of cybernetic control as described by Bateston (1972) in relation to feedback loops works automatically in the family system much like a thermostat does. When the temperature is set to 70 degrees the feedback that the thermostat receives from measuring the temperature of the room triggers a response to either turn the heat on or leave it off until homeostasis is restored. With many of the professional support systems shutting down during COVID-19, the feedback loops that family systems relied on to

balance the family were also shut down. When families had to seek alternative sources and generate new response patterns to achieve their homeostasis, the process was rarely a smooth one.

COVID-19 response created a significant and impactful change to the family system. Professional care providers of children with ASD and their parents significantly changed the way they provided care during the pandemic. Children who were being treated at ABA schools or at public schools in special education environments were now required to stay home, and parents out of necessity had to stay with their children instead of work (Bhat et al., 2021; Dahiya et al., 2022; White et al., 2021). Other care providers such as speech therapists, mental health therapists, and medical providers, moved to an online platform with disrupted care. Even for the most morphogenetic families, this change to their system was extremely difficult, for they had to continually redefine and change the rules, regulations, and procedures within their family system and the greater system that supported them. Families that were able to adapt to the change were no doubt better off. However, systems that were rigid and continually moved toward homeostasis, or families that were chaotic and with little structure, faced an enormous threat to the functioning of the system (Balswick & Balswick, 2014). Understanding how the family system attempted to adapt during the pandemic is an important part of understanding the outcomes for children with ASD and their parents.

Related Literature

The above theories concentrate on not only the family system and interactions within the system, but also how the family system interacts with other systems that are important in its environment. This study attempts to understand the impacts of COVID-19 protective measures on the interaction between two systems, the ASD child's family system and the professional

supports funded to support these children, through the experiences of the children's primary caregivers, their parents. The review of this literature exposes the dearth of qualitative research aimed at understanding the impact of COVID-19 mandated and voluntary protective measures taken by important ASD health and education providers on the ASD family system as expressed through the lived experiences of parents/caregivers. Through understanding the perspectives and experiences of parents as they have had to navigate all the changes, one can learn both the positive and negative impacts on the family system that this pandemic has caused in the access and receiving of professional care for ASD children.

Autism Spectrum Disorder (ASD)

ASD is a neurodevelopmental disorder that affects 2 – 7% of children in the world (CDC, 2022) and is one of the most rapidly growing developmental disorders (American Psychiatric Association, 2013). There are approximately four times as many males as females diagnosed with ASD and although there is no cure, professionals have been successful in improving many symptoms through therapies and behavioral interventions (Depape & Lindsay, 2015; Fletcher et al., 2012). The goal for treatment is to improve overall functioning, develop functional communication, social abilities, academic skills, communication, and lessen maladaptive behaviors and repetition habits (Woodgate et al., 2008).

Autism is a disorder that presents in varying ways with all the individuals it touches. Children with autism spectrum disorder (ASD) experience different levels of severity as defined by the DSM-V (2013) from “requiring very substantial support” to just “requiring support.” The defining characteristics of ASD are persistent deficits in social communication and interactions across multiple contexts. These can be deficits in social-emotional reciprocity in language, deficits in nonverbal communication such as eye contact, lack of facial expressions, or abnormal

body language. Those with ASD have deficits in relationships because they lack the social understanding and have difficulties adjusting their behavior to fit the context. Another key feature beyond social reciprocity is restricted and repetitive patterns of behavior, interests, or activities. Commonly, they present as repetitive motor movements or speech, an inflexible insistence on sameness with typical extreme distress at small changes, fixated interests, and/or hyper or hypo sensitivity to sensory input (American Psychiatric Association, 2013). Autism is not a hidden disorder but a very public one due to the child/adult's lack of social understanding. This lack of social understanding constitutes the most difficult aspect of the disorder for parents and the aspect that can lead to social isolation for the family (Caicedo, 2014; Depape & Lindsay, 2015; Fletcher et al., 2012).

A View into the Life of Caregivers of a Child with ASD

Parenting and caring for a child with autism has many unique challenges but parents express that what makes autism so difficult for them is their child's disruptive social behavior, challenges in communication, and lack of emotion or dysregulated emotional expression (Depape & Lindsay, 2015; Fletcher et al., 2012; Gray, 2006). The major difference between ASD and other neurodevelopmental disorders is that the children appear as typically developing children so that those viewing the parents and children may think the behavior can be controlled by better parenting (Depape & Lindsay, 2015; Koydemir-Ozden & Tosoun, 2012). This often creates difficult situations for their child and difficulties in developing friendships, playing, laughing, or interacting with extended family or the community (Depape & Lindsay, 2015; Fletcher et al., 2012; Gray, 2006). There is an additional burden for parents in knowing that their child will have symptoms of ASD persist throughout their lifetime, often requiring support from the parent the remainder of their life. Moreover, many of those with ASD have comorbidities

with diagnosis such as epilepsy, metabolic disorders, gastrointestinal, anxiety, and depression which increases the challenges in parenting (Ameis, 2020).

One can imagine the changes in the family structure that parents will likely undergo in order to meet these challenges. Many parents pay for multiple professional services or drive long distances to get their child the services they need to improve their symptoms. Some relocate near services that are better for their child or make career changes to cover the cost of services or leave their job altogether to caretake for their child because they cannot afford the expensive care for an autistic child (Caicedo, 2014; Depape & Lindsay, 2015; Fletcher et al., 2012). Parents make impactful life adaptations in several areas by structuring family activities around ASD. Additionally, they often make repairs and modifications to their homes for safety or increased accommodation reasons directly related to their child with ASD (Depape & Lindsay, 2015). As a result of the difficulty in managing extreme behaviors, parents will frequently socially distance their families from the community and extended family, leaving them feeling isolated. Many homeschool after trying to work within the school system and finding it too emotionally and financially difficult, adding yet another responsibility on these parents (Samsell et al., 2022, Song et al., 2018)

Parents and caregivers are often required to seek weekly and daily professional supports such as special schooling, daily applied behavior analysis (ABA) therapy, speech therapy, occupational therapy, physical therapy, psychotherapy, neurology, and other health professionals depending on the severity of the autism. (Caicedo, 2014; Gray, 2003; Samsell et al., 2022). In one study of parent's care burden, the researchers attempted to quantify the financial costs on a weekly basis demonstrating that parents out of pocket expenses averaged \$348.78 a week with a standard deviation (SD) of \$623.34 (Caicedo, 2014). In the same study parents reported their

weekly hours of direct care for their ASD child was 33 hours with a $SD = 30.4$ hours. These numbers demonstrate the intensity of caregiving burden and also how substantially it varies between parents. Many parents seek the support of Applied Behavior Analysis (ABA) that can serve as a school for their children where they are in an educational environment that includes behavioral skills for ASD children up to 40 hours per week. This resource provides an excellent venue for both education and behavior therapies. However, this resource is difficult to access and can be expensive depending on the parents' health insurance provider (Pollard et al., 2021). Moreover, it will often include many hours a week of parent instruction and participation (Woodgate et al., 2008). In considering the costs for parents caring for a child with ASD there are also secondary costs that are significant to parents. Parents express that beyond financial and employment issues there are costs in family functioning, a higher divorce rate among parents caring for an ASD child, decreased individual and relational health of family members, social costs, and costs to family activities and involvement (Depape & Lindsay, 2015; Fletcher et al., 2012; Gray, 2006).

Researchers are attempting to understand the burden of care on parents of children with ASD through examining parents' well-being measures because of an acute awareness of the reciprocal nature of the parent-child relationship in the family system (Beckett, 2018; Broady et al., 2017; Cantwell et al., 2015; Gray, 2006). With the increased amounts of chronic stress, parents often present with physical and mental health challenges of their own. For example, parents caring for an ASD child report more depressive symptomology, often citing the stigma of being parents of an ASD child as a source of chronic stress and other mental health problems (Broady et al., 2017; Cantwell et al., 2015; Song et al., 2018). Parents are found to have increased levels of stress in general, are often sleep deprived, and experience increased fatigue

which is likely to compromise their physical health as well (Vasilopoulou et al., 2015; Cantwell et al., 2015). From a systemic perspective, there are other questions about the etiology of parental well-being while caring for a child with ASD, primarily the status of well-being and mental health before the birth of their special needs child or whether postpartum complications impact parental well-being and mental health.

Although the burden of caregiving is difficult, parents are always mindful in highlighting that caring for their ASD child is not all about challenges, but it is also about the joy they feel toward their children. One parent stated it well: “Gradually you get better. You have to, though. I accepted the disability, and I accepted my child. I love him so much. He is no different to me than my daughter” (Koydemir-Ozden & Tosoun, 2012, p. 60). As illustrated, parents emphasize that despite the problems they are often able to cope with them by employing a number of coping strategies (Beckett, 2018; Gray, 2006).

Mothers caring for children with disabilities cope in different ways; one is problem solving and the other is emotional-focused coping like distancing. Parents involved in the problem-solving type of coping typically showed less psychological distress than those using the emotional-focused coping (Bag, 2022; Depape & Lindsay, 2015). When exploring coping strategies, an interesting phenomenon is discovered where the strategies change as the child ages from a heavy reliance on professional supports and service providers in the elementary and pre-elementary years to parents coping through their religious faith and time-tested emotion-focused strategies for themselves as their children reach adolescence and young adulthood (Gray, 2006). The positive approach to coping while caring for an ASD child is helpful in reducing the anxiety in the entire family system and improving the overall quality of life for all members.

The Impact of COVID-19 Protective Measures on Typically Developing Families

The COVID-19 pandemic began for the United States in early 2020 and the impact of the pandemic can be measured not only in the tragic loss of life but on how the pandemic affected the social, physical, and mental health of the population as states introduced measures taken to attempt to minimize loss of life during the pandemic. Although all persons were impacted by the pandemic through fears of infection, disruptions in work including unemployment, and lack of reliable information, most research indicates that these stressors were heightened for those caring for children (Foley, 2021; Russell, et al., 2020). In a recent national study, 27% of parents have reported deteriorating mental health since March of 2020 and 1 in 7 parents reported worsening mental health for their children (Patrick et al., 2020). To highlight the impacts of the pandemic on parental mental health, research conducted at the beginning of the pandemic indicates that 40% of parents met the PHQ-8 criteria for major depression and moderate or severe anxiety (Lee et al., 2021). Parents reported that their children had elevated hyperactivity, conduct, and emotional problems (Foley et al., 2021; Patrick et al., 2020). Not surprisingly, parental distress was equally elevated which impacted parent-child conflicts and just plain household chaos. The disruption in family routines was also marked by more men staying at home and helping in the care of children leading to difficulty in adjusting to shifts in roles and responsibilities for men and women (Russell et al., 2020).

There is considerable variance in the impact on families from country to country, and from state to state in the U.S., based on the mitigation efforts imposed. Initial international research into the various government responses to COVID-19 demonstrated contrasting social, economic, and cultural effects based on the stringency in response (Foley et al., 2021; Russell et al., 2020). Peer problems with other children has a significant impact on children's reported

wellbeing and was associated with country-wide severity of containment as well as family-level disruption (Foley et al., 2021; Prime 2020). Of all of these changes and impacts, it is the disruption in educational services that have impacted parents most significantly. The change in the way children received education is cited as among the most important changes for families of all the mitigation efforts encouraged or imposed by the government (Foley et al., 2021; Prime 2020).

In March of 2020, in an attempt to slow the transmission of SARS-CoV-2, the virus that causes COVID-19, states each implemented their own policies on closure of schools, distance learning, and modifications to education experiences for children (Verlenden et al., 2021). The state of Washington has the notoriety of experiencing the first U.S. laboratory-confirmed case of COVID-19 on January 18, 2020 (Centers for Disease Control and Prevention, 2022). Following the first U.S. death of a man in Kirkland Washington on March 1st, 2020, the Governor, Jay Inslee, took many measures to reduce the spread of COVID-19. Beginning on March 13th, 2020, Governor Inslee ordered all K-12 schools in the state to close for six weeks effective March 17th and banned social gatherings of more than 250. Shortly thereafter, he extended the closures through the remainder of the school year (Ballotpedia, 2021). On March 24th Governor Inslee signed a statewide proclamation for all residents to stay at home for the next two weeks, which he extended to the 4th of May for a total of seven weeks (Ballotpedia, 2021; MyNorthwest, 2021). The stay-at-home order was extended again until May 29th and after that the Governor announced a planned phased county by county reopening plan, which changed multiple times throughout the next year (MyNorthwest, 2021). On May 11th, 2020, face coverings were mandatory in all indoor public settings (MyNorthwest, 2021). As of May 2022, face coverings

are still required for healthcare workers including most ASD providers (Washington State Department of Labor and Industries, 2022).

As noted before, the disruption in education caused the greatest impact on families with children (Prime, 2020). In Washington State, following the closing of schools for the remainder of the school year in March of 2020, dual working parents were left to find care for their children, and although there was still some online learning, all students were informed that their grades would go no lower than where they were before the pandemic lockdown (MyNorthwest, 2021). The future of in-person instruction in the fall was a question of great concern for parents during the summer. On June 11th, Superintendent of Public Instruction, Chris Reykal released guidance for reopening of schools which included mask wear and alternate instruction plans (Ballotpedia, 2021; MyNorthwest, 2021). At the beginning of the school year most schools adopted a virtual learning environment leaving students and parents to learn and teach from home. In March of 2021 Governor Inslee discussed a proclamation requiring elementary schools to provide at least two partial days of instruction by April 15th, and by the 19th of April Washington schools had to offer at least 30% in-person instruction (Ballotpedia, 2021). Consequently, children were out of school for over a year that included a year and a half of education. These measures illustrate that Washington State was one of the most restrictive states for COVID-19 mitigation efforts during the pandemic. The burden of adjusting to these changes fell on families with young children. These changes necessitated that parents had to find creative ways of having someone at home with their children to help with their online education and to watch them while they were at home instead of at school.

The speed and frequency of changes have led to numerous psychosocial stressors for both children in the U.S. and their parents. Moreover, the worsening of mental health for parents as

many reported a loss of childcare and income, also impacted child mental health (Patrick et al., 2020). It appears that even the change to virtual learning did not help in outcomes for mental health. In a Department of Health and Human Services survey conducted in late 2020, Verlenden et al. (2021) found that on nearly all indicators of stress and wellbeing for parents and children, the findings were worse for those receiving virtual or combined instruction than for those receiving in-person instruction (Verlenden et al., 2021). The closures of schools, lockdown mitigation efforts, health facilities and clinic closures, and the closure of community programs impacted typical families significantly. However, for vulnerable families of ASD children, these mitigation efforts were very difficult and increased their risk for negative outcomes (White et al., 2021). Although research is ongoing, the focus on parental lived experiences of caring for children during the pandemic's social disruption is still lacking and almost nonexistent for parents caring for ASD children.

COVID-19 Effects on Parents of Children with ASD

As indicated above, the COVID-19 pandemic was challenging for all and even more so for families caring for school age children. However, the pandemic has been particularly difficult for families caring for vulnerable populations like children with ASD (Dekker et al., 2022; Masi et al., 2021; Pecor et al., 2021; Reicher, 2020; White et al., 2021). From an increase of symptoms, to more extreme behaviors, to family readjustments, COVID-19 has hit parents of children with ASD hard. Many families reported an increase in medication dosage for their children and most parents reported that the pandemic had impacted their well-being (Masi et al., 2021; Pecor et al., 2021). Children with ASD and other neurodevelopmental disorders suffered from increases in stress, distress, fear, anxiety, depression, emotional dysregulation, and decreased mood since the beginning of COVID-19 (Corbett et al., 2021; Pecor et al., 2021). An

unfortunate but predictable research finding is that in a reciprocal way, child distress led to decreased caregiver well-being, and caregiver anxiety levels correlate with the severity of ASD-related behavior problems and the child's ability to thrive (Pecor et al., 2021). Thus, the anxiety from the pandemic exacerbates the family system by hindering the parents' ability to provide support and resources to their vulnerable children leading to a lower quality of life for both parent and child (Corbett et al., 2021; Pecor et al., 2021).

Not surprisingly, the impact of COVID-19 mitigation efforts for families with an autistic child were felt differently depending on the age of the child, resources of the parents, and severity of the disorder. Parents and caregivers of children with ASD were particularly impacted by the pandemic, but in nearly all reports, the impact was most difficult for parents caring for younger children with ASD (Corbett et al., 2020; Kalb et al., 2021; Masi et al., 2021; Pecor et al., 2021). On a more positive note, some studies found that a minority of adolescents with ASD were happy to not be confronted daily with the social difficulties they faced in school while participating in school online. However, these studies acknowledge the yet unknown deterioration in social skills as a result. Parents also indicated that as children with ASD entered their teens, many found not being in the social environments allowed them the ability to regulate their emotions better, preferring the online experience to being in school (Dekker et al., 2022; Pecor et al., 2021). Although a minority of teens and young adults with ASD, particularly high functioning individuals, fared better than younger children, they unfortunately had marked increases in anxiety and depression when compared to the general population (Dekker et al., 2022; Reicher, 2020; White et al., 2021).

With many of the informal and formal services discontinued or changed to online, parents of children with ASD were left, largely to their own resources, to meet the demands of their

children during the mitigation efforts (Corbett et al., 2020; Dekker et al., 2022). The changes to the family system were significant which for an ASD child, who is vulnerable to change, represented a complex and difficult situation for them to navigate. Many with ASD rely on clear structures and routines to function well and minimize externalizing behavior. Having clear structure and managing only minor changes aids those with ASD in responding to change (Gray, 2006). The changes that came with COVID-19 mitigation efforts in Washington State were severe with closed schools and services for a two-month period in the spring of 2020, opened them again online with restrictions in the fall of 2020, then would close and open depending on COVID-19 infection levels or school exposure to COVID-19. The structure and routine that helps down regulate externalizing behaviors for children with ASD was heavily impacted by these measures (Dekker et al., 2022; White et al., 2021).

Disruption to regular services provided to ASD children and their families was an additional stressor for parents during an already stressful time. The increase in ASD symptoms that followed, some of which were extreme in children, along with the loss of progress on skill development presented a stressful challenge for parents. In multiple studies, parents caring for a child with ASD during the COVID-19 pandemic, reported extreme to moderate stress because of the loss or change in services and therapies (White et al., 2021; Corbett et al., 2021). In nearly all studies conducted between 2020-2022, parents caring for a child with autism during this time were significantly impacted in well-being and mental health (Dekker et al., 2022; Masi et al., 2021; Pecor et al., 2021; Reicher, 2020; White et al., 2021). Exploring parent/caregiver experiences of accessing and receiving support from the professional service providers they rely on to assist in treating their child, has yet to be investigated. However, there are some emerging

studies that explore, from a provider's perspective, the changes they made to accommodate the mandated mitigation efforts.

Pandemic Impacts Professional Services

During the pandemic parents caring for children with ASD experienced extensive disruptions to all types of ASD services at the beginning of the pandemic and ongoing mitigation efforts for in-person therapies during the subsequent years. This discussion cannot begin without acknowledging the complications with this vulnerable population. Chief among the complications is the high rates for children with ASD comorbidity with medical diagnosis that often will cause them to be immunocompromised (Jeste et al., 2020). To guard against the possibility that COVID-19 could have a devastating effect on their children, parents in this situation would often opt out of in-person services when offered, like ABA or occupational therapy where their children would typically work on social skills and behavior regulation (Jeste et al., 2020; Simpson & Adams, 2022).

For families not concerned with pre-existing conditions that could make the COVID-19 virus more deadly, they experienced a different kind of disruption. Parents report that the disruptions were primarily for services that they relied on the most, the high intensity daily or weekly therapies such as ABA therapies, special education, speech and language therapy, and physical therapy or occupational therapies (White et al., 2021). This is probably due to the in-person nature of these therapies and although many transitioned to online therapies later in the pandemic, these online services have had mostly negative feedback for their efficacy by parents (Bhat et al., 2021; Dahiya et al., 2022; White et al., 2021). During the initial stages of the pandemic in the United States, nearly all families reported a loss of at least one educational or professional support for their child with ASD, with 74% of parents reporting a loss of access to

one or more therapies and 36% reported a loss of a healthcare provider (Jeste et al., 2020).

Parents caring for a child with autism often have other children in the home so the high intensity therapies of both ABA which can be all day and the child's special education at school, create a childcare burden for the parent along with the lack of treatments. For parents relying on two incomes, or single parents employed outside or inside the home, this increase in daily care when they would normally be working is far from trivial.

Special education for children with ASD is a high intensity and essential service. The pandemic resulted in school closures and major changes to the way education was delivered around the world and in the United States (Rice, 2022; Simpson & Adams, 2022). In the U.S. there was considerable variability in school closures. The most notable move in education during the pandemic was to online learning. Then hybrid learning environments for special education classes were the first in-person classes offered as the schools in Washington state began their reopening process.

To understand how professional providers for children with ASD have been impacted, it is worth examining the special education field, upon which parents of children with ASD rely heavily. Before the pandemic, schools struggled to find and retain fully qualified special education teachers, which is a requirement of the Individual's with Disabilities Education Act 2004 (IDEA) (Dewey et al., 2017). This Act was intended to provide appropriate and individualized educational programming for all students with disabilities. Special education teachers are among the most caring and concerned teachers, but their rolls have been steadily declining since 2012 leaving approximately 23,000 positions in special education in the US unfilled in 2017 (Dewey et al., 2017). There is an insufficient supply of special education teachers entering and in the workforce due to the lack of educator preparation programs and high

attrition rates among qualified teachers (Goldring et al., 2014). Most alarming, with this decline in fully qualified special education teachers, there is a recent growth in students with disabilities (Peyton et al., 2021). To compound the difficulties the areas where there are the highest shortages in special education teachers also have a substantially greater percentage of students of color and lower socioeconomic status (Peyton et al., 2021).

The COVID-19 pandemic has exacerbated the special education teacher shortage as it rises to the status of crisis and both the media and researchers are sounding the alarm (Maxouris & Zdanowicz, 2022; Dos Santos, 2021). Throughout the nation, teacher preparation programs are reporting shrinking enrollments, and in some cases, universities are suspending their education programs due to lack of enrollment (Maxouris & Zdanowicz, 2022). Teachers are leaving the profession and there are fewer people who want to replace them in the education system. The response to COVID-19 in the schools has led to many teachers feeling the government forced them to return to school for face-to-face instruction despite teachers' health concerns (Dos Santos, 2021). Teachers also cited that stress and disappointment with their positions and salary plus the risk of working in a closed environment with children who were unvaccinated, was too much to handle (Dos Santos, 2021).

One way policy makers attempted to alleviate exposure concerns was to turn immediately to distance learning. However, in the special education classroom this is a very challenging task, and many teachers were not prepared for the transition to online (Dos Santos, 2021). Schools quickly provided training and technology support, but teachers were required to completely rethink lesson plans and ways of teaching during and already chaotic time in their lives (Dos Santos, 2021). Many special education students require one-on-one instruction which was nearly

impossible in this new environment. The special education profession has been hard hit by the pandemic, and it may take many years to bring programs back to pre-pandemic levels.

Another high intensity therapy for children with ASD is ABA. In nearly every state in the U.S. a master's degree is the standard minimum requirement to become a licensed applied behavior analyst (ABA or BCBA) as noted by the Applied Behavior Analysis organization (AppliedBehaviorAnalysisEdu.org, 2022). In most cases ABA professionals are assisted by Registered Behavioral Therapists (RBT) who pass a 40-hour course and certification process. At the onset of the COVID-19 pandemic ABA therapists wrestled with new ways of delivering clinical services that traditionally involved direct social contact with clients (Jimenez-Gomez et al., 2021). Like most professions ABA therapists faced the additional burden of determining how to provide services during lockdown conditions while grappling with concerns for their own health, job security because of the critical hands-on nature of their work, and the care for their own families (Jimenez-Gomez et al., 2021). In a study conducted in late 2020, researchers found that 31.6% of the ABA and RBT therapists in their study experienced job insecurity, 45.4% indicated that they experienced burnout, and 42% of the therapists indicated reduced productivity with their therapies (Jimenez-Gomez et al., 2021). It should be noted that burnout rate in this profession, specifically among RBTs was high even before the pandemic.

Those in the behavioral analysis workforce, depending on state lockdown and mitigation requirements, provided either in-person or remote ABA therapies. In the state of Washington most ABA therapies were moved to an online format during the beginning of the pandemic. As noted above, researchers found a notable difference in terms of productivity with their clients as reported by Applied Behavioral Analysts between the online therapies and the in-person therapies (Jimenez-Gomez et al., 2021). Specifically, those behavioral analysts providing online

therapy reported lower productivity, a diminished quality of information exchange between workers, and an increase in distractions (Jimenez-Gomez et al., 2021).

As many providers of ABA therapy transitioned to telehealth delivery of treatment, the primary pathway of delivery of behavioral techniques through teletherapy was for therapists to work with parents, teaching them the skills so they could work these skills directly with their children (Pollard et al., 2021; Yi & Dixon, 2021). Contrary to the above report, Pollard et al. (2021) report that moving ABA to telehealth was successfully transitioned from in-person with minimal gaps in service and the participants indicate high levels of satisfaction with this type of treatment. This however is contrary to the documented reporting of parents in other studies (McKenzie et al., 2021; Vera San Juan et al., 2021; White et al., 2021).

In healthcare settings, like occupational, physical, and mental therapies as well as medical offices, many studies of the changes required during COVID-19 and the move to virtual delivery of professional support, found that health care workers liked virtual delivery for its convenience (Vera San Juan et al., 2021; Pollard et al., 2021). While face to face tended to be the preferred option for healthcare workers, they identified the benefits of remote care during the pandemic conditions (Corona et al., 2021; Vera San Juan et al., 2021). Unfortunately, this delivery of care is difficult to manage for children with ASD and their parents and come at a cost (Ameis et al., 2020; Wagner et al., 2021). It is speculated that the environmental changes, disruption in routines, reduced access to critical social and professional support for families with an ASD child amplifies challenges in education, increases socioeconomic disadvantages, and certainly increases parental burden caring for children with ASD (Ameis et al., 2020; Wagner et al., 2021). Understanding the lived experience of professional provider support changes in response to the mitigation efforts during the pandemic is critical considering the potential

negative impacts on the family system and the variation in initial research findings concerning the efficacy of online delivery of services.

How Changes to Professional Support has Impacted Parents of children with ASD

This leads to investigating the literature attempting to understand the phenomenon of parents trying to access and receive professional provider support while caring for their ASD child during the pandemic. Currently there is no research looking directly at the impact of accessing and receiving care from the typical ASD professional providers from a parent perspective, but there is research looking at specific providers and at how families in general are experiencing the COVID-19 pandemic while caring for a child with ASD. In general, early research is finding that the clinical service shutdowns as well as the special education closures have led to significant loss of service for children with ASD and their families (Bhat et al., 2021; Huang et al., 2021). The changes in direct human contact, remote interactions, and daily routines for this vulnerable population have resulted in negative mental and physical health consequences (Ameis et al., 2020, Bhat et al., 2021; Colizzi et al., 2020). Researchers have found that the initial and most enduring concern from parents was the shutting down of special education systems because of the increased burden it placed on families as care providers and the financial strain of necessitating care while their child was at home instead of school (Tokatly et al., 2021). The parents felt overwhelmed, lacking the tools they needed to provide for their children's developmental needs (Bhat et al., 2021; Tokatly et al., 2021). There appears to be some discrepancy between studies in how parental caregivers and professional support providers view the efficacy of professional ASD support's COVID-19 changes (Wagner et al., 2021; Pollard et al., 2021).

There are two qualitative studies on the pandemic impacts on parents of children with ASD. One explores the nature of family dynamics through the experiences of parents and siblings of children with ASD (Critchley et al., 2021). The other study was conducted in Tel Aviv to understand the core experiences of parents caring for children with autism during the COVID-19 pandemic lockdown in that city (Tokatly et al., 2021). At the time of this writing, scholars are just beginning to research the impacts of COVID-19, so there are likely to be more qualitative studies addressing quality of life for parents of a child with ASD during COVID-19. In the Tokatly (2021) study, parents express the difficulties of the shutting down of special education systems, dealing with multiple logistical problems for their families, and they detail the regression in behavior and social skills for their children. In the Critchley et al. (2021) study the focus was on exploring how COVID-19 impacted family function with a focus on bringing in the perspective of the child with ASD's siblings. However, neither of these studies directly addresses the impacts of the changes in accessing and receiving professional provider support during the pandemic.

In quantitative studies that primarily explored quality of life for parents of children with autism, parents report primarily negative survey-based response to changes due to COVID-19 mitigation efforts. For example, those children ASD and their families who moved to online learning about one quarter reported positive impacts from the movement and nearly half reported a negative experience with online learning with their child receiving “no learning” or “bare minimum” (Dos Santos, 2021; Jeste et al., 2020; Simpson & Adams, 2022). Parents caring for children with ASD reported that the needs of their children had not been considered in the implementation of tele-education and that it needed many adaptations. However, studies conducted from a perspective of the educators seem to be more favorable to online learning and

indicate satisfaction from parents, children, and educators alike (Hopcan et al., 2021; Rice, 2022; Simpson & Adams, 2022). Although most of the research points to online education as less efficacious, due to the early nature of this research, the question of efficacy for online supports of special education requires further study.

As providers of behavioral therapy wrestled with the best way to deliver their mostly hands-on-therapy, they transitioned to telehealth delivery of treatment. This was generally their only option in many states, but again parents reported mostly negative effects (Pollard et al., 2021; Yi & Dixon, 2021). It should be noted that in at least one study, Pollard et al. (2021) the transition to telehealth services for ABA was reported by the researchers as successfully transitioned from in-person with minimal gaps in service. The study's participants indicated high levels of satisfaction with this type of treatment. However, in subsequent research on the impact of the pandemic on wellbeing and mental health of both the child and parents, most parents reported mostly negative responses to this transition (McKenzie et al., 2021; Vera San Juan et al., 2021; White et al., 2021). There is a discrepancy between parent reports of changes in ABA delivery to online services and the reports of professional service providers. Likely the research was conducted while ABA therapists were moving to online platforms there was general acceptance that this was a short-term stop-gap measure rather than a long-term shift in services, which parents were more accepting of.

What seems unarguable is that parents, researchers, and service providers have been attempting to provide the best possible services to children with ASD during the unprecedented changes caused by the COVID-19 outbreak. In support of these efforts, it is important to take a clear-eyed look at the successes and challenges faced by this vulnerable population. Specifically, this look is critical because parents caring for a child with ASD are significantly

impacted by changes in the structure of the supports they receive and on the systemic impacts on their family and their child with ASD. Researchers are attempting to understand this through parent survey (Bhat et al., 2021; White et al., 2021); but to truly understand how accessing and receiving professional care for children with ASD and their families, the voice of one of the most important stakeholders in care, the parents, must be heard. This study will give parents the opportunity to narrate their lived experiences of accessing and receiving professional support during the pandemic and in doing so, give an in-depth understanding of the phenomenon to other key stakeholders. This study will broaden our understanding of the challenges and successes that parents experienced while interacting with critical professional supports during the pandemic. It will provide insights for health professionals and special professional service providers treating and educating children with autism as well as insight to working with and assisting parents caring for their children with ASD.

Summary

COVID-19 changes and restrictions have necessitated a change in the way schools, special education professionals, ABA therapists, occupational, speech, and mental health providers, medical providers, and special services for children with ASD provide care. This study is designed to explore the experience of parents of children as they have navigated the COVID-19 required changes to professional treatment and services for children with ASD and their families. This study will also provide a glimpse into how Washington state, one of the more restrictive states, approached their mitigation efforts to protect its citizens from the negative effects of the virus. However, it is important to note that engagement with professional supports was always an important individual consideration for the families caring for their

children with ASD. Considerations were based on both the families' own pre-existing conditions and concern for the health of themselves and those around them.

This chapter detailed the three theoretical frameworks that are foundational to understanding the systemic nature of families and the circular nature of family and professional ASD care provider relationships. These family systems theoretical frameworks are important to understanding the systemic nature of the family, the importance of the systems that surround and interact with the family, and the feedback loops that support or allow homogeneity or morphogenesis as parents interact with professional care givers.

There are many studies attempting to understand how best to support individuals with autism during pandemic lockdowns and mitigation efforts. However, none of these studies attempts an in-depth understanding of the experiences from parents and caregivers as they navigate the ever changing landscape in professional care designed to help those with ASD. Moreover, there are no studies investigating how those challenges in accessing and receiving care for their vulnerable children affect the family system. This study is important because it privileges the primary caregiver's voice and helps give the lived experience, the frustrations, challenges, and in some cases benefits, that parents have felt during the pandemic.

This study can make a difference by highlighting parent's experience of professionals providing necessary services for their children during the pandemic. It will provide critical information for professional providers to help meet children with ASD needs in future pandemic situations and quarantines.

Chapter Three: Methods

Overview

Chapter Three, methods section details the design of the study exploring the lived experience of parents of children with ASD as they are attempting to access and receive critical professional care for their children during the COVID-19 mitigation efforts in Washington State. This chapter details the guiding research questions that were used, the setting, a brief description of the process of recruiting and selecting participants, and the procedures used in the study. Moreover, this section will discuss the researcher's role, bracketing, and the data collection and analysis methods.

The data collection was conducted using a trans-theoretical interviewing strategy, the conceptual mapping task (CMT), a four-phase procedure that honors the participant's experience and provides built-in validity through verification checkpoints. This interviewing strategy also provided a second data collection strategy by allowing participants to deepen their description of the phenomenon through visual representations. The third data collection method was memoing, where the researcher documented his experiences while collecting and analyzing the data. Data analysis was aided by two computer programs, Otter.ai transcription software, and ATLAS.ti qualitative analysis software that supported the researcher in determining themes while providing an excellent audit trail. Lastly, this section provides a description the efforts used to reduce bias and ensure the trustworthiness of the data collection and analysis by the researcher.

Design

It is well known that the design of one's research naturally flows from the research questions the study is attempting to answer (Creswell & Poth, 2018; Heppner et al., 2016). This study is attempting to understand the complexity of parents' lives during a unique and

unprecedented event by examining their individual perspectives in context (Heppner et al., 2016). Consequently, the study uses a qualitative methodology of research because it emphasizes the importance of context and stresses the process in which parents of children with ASD create and give meaning to their experience of accessing and receiving professional support during the pandemic. The study, using Moustakas's (1994) transcendental phenomenology is less concerned with the researcher's interpretations, focusing more on the description of the experiences of the participants (Moustakas, 1994; Creswell & Poth, 2018). The procedures used in this study consisted of identifying the phenomenon, bracketing of the researcher's experiences, and then collecting data from several participants who have experienced the phenomenon (Moustakas, 1994). Following the collection of the data, the researcher analyzed the data collected, through synthesizing the information presented by the participants into themes and then developed a textural description of the experiences as well as a structural description (Creswell & Poth, 2018; Moustakas, 1994). The fundamental difference between the two descriptions is that textural descriptions describe what the participants experienced, and the structural description describes how the participants experienced it in terms of the conditions, situations, and/or context (Creswell & Poth, 2018).

This phenomenological qualitative approach allows for a deep and rich exploration of the lived experiences as the parents describe them. It then extracted the emerging themes from their descriptions through imaginative variation and synthesis of meanings and essences (Moustakas, 1994; Creswell & Poth, 2018). To increase validity in using this approach, the researcher used the epoche process, which Husserl (1970) called freedom from suppositions. In this process, the researcher puts aside, "bracketed", their perceptions or individual bias of the phenomenon to give meaning to the participant's experiences as a way to understand the essence of the

phenomenon (Creswell & Poth, 2018; Welch et al., 2018; Moustakas, 1994). Using Moustakas's (1994) approach allows the researcher access to a systemic process in the data collection and analysis as well as providing guidelines for assembling the descriptions. This method of data analysis provides a clear, logical, and sequential process for understanding this phenomenon while increasing the reliability and dependability of the results obtained (Heppner et al., 2016).

With the addition of the conceptual mapping task (CMT) the study is further honoring the participants' perspective of their experience through an inventive and thought-provoking process of member checking (Martin, 1987; Martin et al., 1989; Novak, 1990; Leitch-Alford, 2006, Impellizzeri et al., 2017). Conceptual mapping task increases the methodological rigor in both the data collection and the phenomenological data analysis by helping participants thicken their own narrative while producing another source of data, their pictorial map (Impellizzeri et al., 2017). It is suggested that this additional source of visual data carries the same value as information obtained from written text and numerical calculations and is linked to strong theoretical and methodological foundations in qualitative research (Wilson et al., 2016).

In all qualitative research it is difficult to truly capture an objective snapshot of a participant's subjective reality (Koelsch, 2013). Yet there are ways to increase the validity of a study, and among the most important for phenomenological qualitative research, is member checking (Koelsch, 2013). Using CMT as a qualitative interviewing strategy privileges participant voices through member checking in its procedures. It allows the researcher four distinct internal member-checking mechanisms during the single interview in each of the four phases of the interview process (Impellizzeri et al., 2017). Moreover, using CMT allows the researcher and participant to bypass the traditional hierarchy between participant and researcher by placing the participant in the "chair of the expert". This was conducted through constant

member checking, facilitated in vivo through a co-construction of the participant's lived experience (Impellizzeri et al., 2017; Wilson et al., 2016).

Research Questions

1. How do parents of children with ASD describe their experiences of accessing and receiving professional services for their child in the midst of COVID-19 mitigation efforts in Washington State?
2. How do parents describe their interactions with professional services for their child with ASD during the pandemic?
3. How do parents describe the difference between accessing and receiving professional services before the COVID-19 pandemic and during the pandemic?
4. How do parents of children with ASD describe the impact on their family system while accessing and receiving care from professional ASD service providers during the COVID-19 pandemic?

Setting

The general setting for the research is Western side of Washington State where the participants were selected. There were multiple parents selected and every effort was made to ensure the interviews are conducted in a comfortable setting convenient to the participant. The researcher coordinated the use of a private group practice family therapy office or conducted the interviews in an enclosed room in public libraries, in order to maintain confidentiality and remain free from interruptions. The participant selected the venue for the interview and the researcher traveled to the participant venue, ensuring the study had mobile and flexible recording and interviewing strategy. Each setting where the interviews took place, whether at the clinic, or library selected by the participant, were privacy friendly to ensure confidentiality and clear

recordings. Due to the nature of interaction using the CMT protocol for interviewing, virtual interviews were not offered to participants as an option.

Participants

The study recruited five parents of children diagnosed with ASD. The sample size for a study of this type is recommended by qualitative research experts Creswell and Poth (2018) and is within the recommended size of three to 15. The specific number was based on whether or not data saturation was met (Creswell & Poth, 2018; Moustakas, 1994). For this research saturation was met when parents presented with similar themes and experiences. Participation was voluntary and the participants were encouraged through their professional ASD care providers to contact the researcher if they were interested in being a part of the study. The research emphasized heterogeneity of participants based on the severity of symptoms, socioeconomic status of the parents, marital status, ethnicity, education level, and geographical living area (rural, suburban, or urban). Parents or primary caregivers were not interviewed as couples but as individuals. The inclusion criteria specified a parent or primary caregiver of a child diagnosed with ASD before 2020 who has been accessing or receiving professional services during the pandemic.

The sampling strategy used was *maximum variation sampling*, an approach that consists of determining, in advance, the criteria that differentiate the participants, then selecting the participants that are different on the criteria (Creswell & Poth, 2018). This strategy was used to ensure the maximum heterogeneity of the participants to provide a deeper understanding of the phenomena from multiple family situations and symptom severity. The criteria used to differentiate participants was based on age of caregiver, sex, the severity of symptoms of their

child on the ASD spectrum, socioeconomic status, relationship status, ethnicity, education level, and geography (Appendix E).

Participants were recruited from ASD parent support groups, local ABA, speech, occupational therapy, physical therapy, and mental health agencies. Additionally, the Kitsap County autism coordinator and parent group for children with developmental disabilities assisted in postings of the research participant flyers. Participants were recruited at these clinics and resources centers through emails, recruitment letters, recruitment flyers, and professional referrals (Appendices A, B, & C). Targeted agencies were Integrated Therapy Services NW, Center for Child and Family Therapy, Holly Ridge Center, Apple Tree Therapy, Easter Seals, Kitsap Children's Therapy, Kitsap Mental Health, and ABC occupational health. Information on the research to aid in the recruitment of participants was shared with professionals supporting children with ASD, through researcher in-person visits and discussions with local providers. Once the participants contacted the researcher, the researcher and participant conducted an initial screening phone call, where participants provided basic demographic information, without personal identifying information, to ensure they met the selection criteria prior to acceptance as a participant as well as ensuring diversity in the sample (Appendices D & E).

Procedures

Prior to initiating the study, the researcher submitted an application to the Institutional Review Board (IRB) at Liberty University to ensure that the study met the criteria for an ethical study. After receiving approval (Appendix J), the researcher began recruitment as described above and coordinated interview times. With first contact of each participant the researcher began phase one, the gathering information and rapport building phase of the conceptual mapping task (CMT). The next phases of the CMT interview process focused on the interview

process itself. This method of interviewing is considered a semi-structured interview technique because it involves questions that are intended to “put guardrails” on the free association requested of the participant. The semi-structured interviews are important in allowing the researcher to provide consistency to the questions asked about the phenomenon to each participant while allowing room for follow-up clarification questions so participants can offer deeper, thicker, and more personalized responses (Heppner et al., 2016; Impellizzeri et al., 2017).

The interviews were audio recorded using a dual recording method, a smart phone audio recording app and on a laptop using Otter.ai, to ensure excellent capture of the participant responses. One of the audio recording methods used was recorded using an application titled Otter.ai, which is an audio recording and transcribing app. During the interviews and using the CMT protocol, the researcher brought sticky notepads to record ideas during phase 2 of the interview protocol and allowed the participant to organize them on a large sheet of paper. During the data collection and analysis of this study the researcher used memoing techniques to describe his own interactions with the participants, data collection, and data analysis. Moreover, the qualitative software analysis program, ATLAS.ti was used to enter the transcripts, memoing, and participant drawings in a concerted effort to provide an audit trail of the research. This software also supported the researcher in developing themes and organizing data (Creswell & Poth, 2018).

The Researcher's Role

In phenomenological research researchers must “bracket” themselves from the study by specifically stating their position in relation to the research they are conducting (Creswell & Poth, 2018; Heppner et al., 2016; Moustakas, 1994). This ensures the readers of the study are fully aware of any potential bias during the data collection and analysis. It follows that the

impact of COVID-19 pandemic mitigation efforts impacted the researcher as well as the participants. As a therapist living through the COVID-19 pandemic, the researcher, as a professional provider for mental health, was at the front-line of engaging with families suffering and surviving through the pandemic.

The researcher in this study is a licensed marriage and family therapist (LMFT) in private practice in Washington State and a doctoral candidate in the online community counseling program at Liberty University. As an LMFT the researcher provides professional mental health services for both children and teens with ASD and their families. During clinical work with these families and children, the researcher experienced a deep appreciation for volume of services and specialized professional care that parents of a child with ASD have to coordinate and rely on during the week. Unfortunately, COVID-19 significantly increased the challenges with coordinating this care for the parents of children for whom the researcher was providing services. Providers of mental health services in the State of Washington experienced many disruptions in their ability and methods of providing support to their clients as the Department of Health issued varying guidance during the pandemic. These involved closing the practice for a short while, then re-opening with new mask and cleaning requirements, then many moved to all online appointments, then moved back to masked and cleaning requirements.

The parents and children that the researcher provided therapy for expressed a significant increase in anxiety, depression, and chaos in the home due to the pandemic and the difficulties they were having while their child was attempting to adjust to the many changes in care. This research is an attempt to give those parents a venue to gather their thoughts and experiences surrounding this phenomenon and give a detailed, rich, and expansive description of their experience. In a transcendental phenomenological qualitative study, the researcher will make

every effort to bracket (set aside), his experiences and take a fresh, unbiased approach to this phenomenon, and that begins with “bracketing” so that those reading this study will understand the position of the researcher (Creswell & Poth, 2018; Moustakas, 1994). The researchers using this approach set aside their prejudgments and preconceived ideas about things by invalidating all commitments with, or reference to, previous knowledge and experience (Moustakas, 1994). This is not accomplished merely by will power, but by using techniques and protocols like the CMT interviewing method which allows the researcher to focus on facilitating the voice of the participant without influencing it. Specifically, the focus on participant narrative and the four different member-checking events which created an organic protection from researcher agenda seeking as it is the participant and not the researcher who is in the lead (Heppner et al., 2016; Impellizzeri et al., 2017).

Data Collection

This study will use multiple methods of data collection to understand the phenomenon as parents described their experiences. The first and most extensive data was gathered through in-depth semi structured interviews using the CMT interviewing technique which produced both text data and pictorial/conceptual maps designed by the participants. This technique naturally flows from the research process described by Moustakas (1994) in the phenomenological reduction step where the participant looks at the experience, describes it, looks again, and describes it again (Moustakas, 1994). There is a concentrated effort to “explicate the essential nature of the phenomenon” (Moustakas, 1994; p. 91) using the CMT interviewing technique.

The text was captured using recording devices during the entire process of the interview. The pictorial representation allowed the participants to create a visual representation of their experiences and then take a step back and reflect on and analyze the picture themselves during

the interview (Impellizzeri et al., 2016). This study also incorporated the data collection method of memoing, to record the researcher's thoughts and experiences during the interviews, data analysis, and participant confirmation discussions. The memos were important element of data collection and when added to ATLAS.ti, the qualitative software, aided in auditing transparency and in developing themes. By utilizing multiple methods of data collection such as interviews, drawings, memoing and participant confirmation, the research validity and trustworthiness were significantly increased (Creswell & Poth, 2018; Heppner et al., 2016; Moustakas, 1994).

Conceptual Mapping Task (CMT) Interviewing Technique

The conceptual mapping task (CMT) has its origins in the conceptual mapping (CM) research Novak (1990) used while studying elementary students in Ithaca, NY to examine their conceptual understanding of science and math in the early 1970's. Building on this idea, Martin (1987, 1989) introduced the conceptual mapping task (CMT), and Leitch-Alford (2006) adapted this concept further into a four-phase structure which is the form used by this study (Martin, 1987; Martin et al., 1989; Leitch-Alford, 2006, Impellizzeri et al., 2017). This interviewing technique is a projective, free association interviewing method that guides the participant through creating a visual depiction of the phenomenon while also recording their vocalized thoughts and ideas surrounding the experience (King, 2019). In this study eight participants were interviewed for 90 – 120 minutes each using the following CMT four-phase methodology and procedures:

Phase One: Rapport Building and Information Gathering

Nearly every counselor emphasizes the importance of the therapeutic alliance between client and therapist because it is one of the most important common factors in effective practice, significantly influences outcomes, and underlies all change occurring in therapy (Sprenkle et al.,

2009). In a similar way for CMT, rapport building is essential because it lays the foundation for a strong alliance between the researcher and the participant beginning with the first phase and sustained throughout the remaining three (Impellizzeri et al., 2017). Participants need to know that their personal information and their emotional safety will be sacred to the researcher and that the researcher is there to listen to their stories, not re-write them.

The rapport with the participants begins with the type of messaging and tone used in the recruiting materials, such as the letter requesting involvement (Appendix B) but the most important beginning to rapport building is the first contact on the phone while reviewing the screening criteria (Appendix D). This important first step allowed the researcher to gather demographic information to determine acceptability as a participant and heterogeneity of the sample (Appendix E). Moreover, it served to demonstrate to the participant their importance in the study. For this study, the recruitment letter was given to professional service providers to hand out to potential participants. The researcher's contact information was listed on the letter with a request that the participant contact the researcher by phone or text. The researcher then accepted or returned the call/text/email using script detailed in Appendix D. During this information gathering and, in an effort to establish the rapport necessary, the researcher used the same micro skills that are used in therapy to establish a therapeutic alliance. Specifically, the researcher ensured he was using what Bolton (1979) termed "listening skills," consisting of reflective responses, paraphrasing, reflecting feelings, reflecting meanings, and summary as well as attunement to metacommunications, and many more skills developed in therapy sessions with clients (Bolton, 1979).

The building of rapport continued with the researcher sending an email confirmation of the interview time and location (Appendix F). Establishing rapport was also important at the

beginning of the interview where the researcher emphasized participant safety, reviewed the informed consent forms, and discussed confidentiality while allowing time for participants to ask questions about and sign the form (Appendix G). Following gathering the signatures the researcher encouraged questions and provided answers about the process of the interview, the purpose and procedures of the study, and described the process involved in a conceptual mapping task interview before beginning the next phase in CMT (Berry, 2020; Impellizzeri et al., 2017).

Phase 2: Participant Storying

In the next three phases, beginning with this phase, participants created a vocal and pictorial description of their lived experiences as parents attempting to access and receive care for their child with ASD during the pandemic, and thus addressed the four research questions developed for this study for the purpose of understanding the phenomenon. In this phase the participant was asked two open-ended questions and then allowed to free associate their answers to this question for the next 20 - 30 minutes while the researcher recorded the main ideas from the participant story telling on sticky notes; see Appendix H for the full script (Impellizzeri et al., 2017, Leitch-Alford, 2006). The researcher wrote the key phrases and ideas that the participant shared while using active listening skills validating and encouraging the participant to continue to tell their story. When the participant had completed their telling of the experience, the researcher asked them to review the sticky notes depicting their concepts to ensure they accurately represented what the participant said and felt (Impellizzeri et al., 2017). As they reviewed the notes, the participants were invited to correct or add to any of the concepts that were listed on the notes as well as provide greater detail where they deemed necessary.

The open-ended questions designed to allow the participant to describe their experience of the phenomenon were:

“Can you please describe your experience of accessing and receiving professional care for your child with ASD from either, special educators, ABA therapists, occupational therapists, speech therapists, mental health experts, and medical support during the COVID-19 pandemic?”
(See Appendix H).

Once the participant had completed answering this question, the researcher asked a follow-up question to deepen the discussion of the phenomenon and ensure all of the research questions were addressed:

“Can you please describe how the change in care during the pandemic impacted your own well-being, your child’s, and your family’s?” (See Appendix H).

Participants were happy to tell their stories and provided rich descriptions to the questions asked, each taking between 20 and 30 minutes. Upon completion of their description of the experience the researcher followed the protocol listed above and asked each participant to review the written concepts, correct them, add to them, or approve them as needed (Impellizzeri et al., 2017). The free association and the participant correction during this phase provided a venue for a rich description of the phenomenon. Moreover, to deepen and expand on this description as well as create a visual depiction of their experience, the participants were asked to conduct two more tasks.

Phase 3: Creating the Conceptual Map

According to Moustakas (1994) during the data collection process in phenomenological research, the participant and researcher should be able to describe the experience in textural language beyond what one sees as an external object but also in “the rhythm and relationship

between the phenomenon and the self” (Moustakas, 1994; p. 90). The qualities of the experience became the focus and in this third phase, the participant was invited to deepen their description of their experience through creating a conceptual map that included grouping their sticky note concepts, labeling the groups, and then adding symbols to indicate their relationship to one another (Impellizzeri et al., 2017; Leitch-Alford, 2006).

To accomplish this, the participants were instructed to arrange their notes on a large white butcher block paper in a manner that grouped major concepts together in the way the participant “sees” their experience. The instructions given to the participant before beginning this task were:

What I would like you to do is take some time and arrange each of these Post-it notes® on the easel pad in a manner that represents your experience of parenting your child with ASD while accessing and receiving care from professional ASD providers during the global COVID-19 pandemic. You can group them in a manner that shows how you think the notes relate to each other. There is no right or wrong way to do this. Continue to move the notes around, grouping them and organizing them according to your experience so that a clear picture of your story emerges.” (See Appendix H) (Impellizzeri et al., 2017; Heath, 2022).

The next step in the process of creating a conceptual map that the participants exercised was to take a marker and draw geometric figures or conceptual figures around each of the clusters of sticky notes that they arranged into groups on the paper (Impellizzeri et al., 2017). Conceptual figures facilitate the participant to explore their inner-experience and the tactile element used in drawing these conceptual figures combined with the symbolism of the object in relation to the cluster it represents (Fleet et al., 2021). These figures should represent the cluster

in a way that has meaning for the participant. The prompt given to the participants to complete this task was:

"Wonderful! Thanks for doing that. I am now going to give you some colored markers. I would like you to draw a shape around each of the clusters of concepts; it can be a circle, triangle, square, star, a heart, a tree, etc. These shapes should represent the meaning of your cluster of concepts in a way that is important to you. Please feel free to make any comments you like about the process or the concepts as you are working." (See Appendix H) (Impellizzeri et al., 2017; Heath, 2022).

Following the completion of this task, the participant was asked to label each of the clusters with a word or phrase that represented the cluster for them and then draw lines, arrows, or symbols that indicated directional flow between the concepts. The instructions given to the participants for these two tasks were:

"Please take some time and label each of those concept clusters. Feel free to make any comments that you would like as you are working. Remember, you are always welcome to change or rearrange the concepts, symbols, or shapes at any time. (Pause while the participant completes this and use reflective listening skills and process observations.) Now, I would like you to draw lines or arrows indicating how these concepts interact with each other or how they are related to one another. If there is directional flow in the concepts, please feel free to use arrows or other symbols to depict that flow." (See Appendix H) (Impellizzeri et al., 2017; Heath, 2022).

The researcher made clear that at any time the participant wanted to change or modify their map they were welcome to do so until they were comfortable that the map corresponded to their lived experience (Impellizzeri et al., 2017; Leitch-Alford, 2006; Moustakas, 1994). During

the process of creating their maps the participants were encouraged to vocalize their thoughts. The researcher validated thoughts, reflected key ideas, or clarified concepts as the participant spoke as a way to facilitate the participant in assigning language to the experience which represented the core of their meaning making (Impellizzeri et al., 2017; Leitch-Alford, 2006; Moustakas, 1994).

Phase Four: Reflecting on the Conceptual Map

This final phase of the CMT protocol allowed the participant to synthesize meanings and essences through integrating the textural and structural descriptions of the phenomena while reflecting on the conceptual map they had just developed (Impellizzeri et al., 2017; Moustakas, 1994). To thicken the meaning and aid the participant in this task, the researcher freely asked exploratory questions based on the created map and the participants storying of their lived experience (Impellizzeri et al, 2017). The questions and instructions the researcher asked all the participants during this phase as they reflected on the conceptual map were:

“Now that you have created this conceptual map about your lived experience of accessing and receiving professional care for your child with ASD during the COVID-19 pandemic, take a few minutes to reflect on it. (Pause until participant indicates they are done reflecting.)

What strikes you as you look at your conceptual map?

How have things changed for you during the pandemic because of your experience in accessing and receiving care from professionals?

What advice would you give to yourself back in February of 2020 to make things better in accessing and receiving care for your child with ASD now that you have lived through it?

“Where are you now in your story?”

“Is there anything else that you feel compelled to say from this whole experience?”

The responses to these questions added a rich textural and structural description of the meaning the participants associated with their experience and often allowed them to develop themes and concepts that they had not considered previously (Impellizzeri et al., 2017; Leitch-Alford, 2006; Berry, 2020, King, 2013). During this phase the participants were given a final opportunity to revise their map and reflect on the gestalt of their experience as well as evaluate the effectiveness of the map at describing the meaning of their experience (Impellizzeri, et al., 2017). It is often difficult to describe in words the meaning one attaches to an experience. However, the addition of visual representations linking the participants “cognitive understanding with emotional engagement through arts-based approaches” (Impellizzeri et al., 2017; p. 40) allowed the participants to describe the phenomenon with richness and depth.

Each interview was scheduled for up to two hours based on participant response. The creation of the CMT conceptual map was designed for 90-minute interviews and the extra time was allocated in the event of heightened emotional responses. This remaining time was added to allow time for the emotions to dissipate if necessary. The CMT protocol was practiced beforehand by the researchers and refined through pilot testing to ensure familiarity with the questions and recording equipment (Creswell & Poth, 2018).

At the conclusion of the interview, the researcher secured the Post-it notes® on the concept map using tape so they would not move around in transit. The researcher also took a picture of the map to ensure redundancy in data collection and storage. The pictures were used in the study to visually represent for the reader, the participants concepts. The interview was ended by the researcher and a follow-up email was sent thanking them for their time (H and I) (Berry, 2020; Impellizzeri et al., 2017; Heath, 2022). The participants were asked if they felt

emotionally comfortable with concluding and asked if they had any concerns that they would like to follow up with a professional counselor based on their experience in the interview. For those requesting a referral one was prepared by the researcher.

Memoing

An additional source of data collection, memoing, was used during the interview process by the researcher. Memoing is a process where the researcher journals their experience during interviews and data analysis (Creswell & Poth, 2018). During the interviews the researcher writes down ideas as the process unfolds from the first screening phone call to the end of the interview and then adds this data to the analysis process. The memos document the process that is seen by the researcher and allows the researcher to sketch out the flow of the process and the details that are not addressed by the participant (Creswell & Poth, 2018).

Data Analysis

The general process used in the analysis of data in this research was first to prepare and organize the text into transcripts and the image data into its conceptual form for analysis. Then the researcher went through the process of reducing the data into themes using qualitative software and a thorough reading/re-reading of transcripts. Finally, the data was represented in figures, tables, and themes for discussion (Creswell & Poth, 2018; Heppner et al., 2016). Again, the methodical process described by Moustakas (1994) was used by the researcher. In this process of analysis which Moustakas (1994) describes as Imaginative Variation, the researcher explored the systematic varying of the potential structural meanings that underlie textural meanings. Then after recognizing foundational themes that accounted for the emergence of the phenomenon, the researcher considered the universal structures that precipitated the participants' feelings and thoughts. During the analysis the researcher identified key imagery, either visual or

exemplary text that vividly illustrated the participant description of the phenomenon (Moustakas, 1994). The final step in the analysis, synthesis of meanings and essences, involved the intuitive integration of the fundamental textural and structural descriptions into a unified statement of the essence of the experience as a whole (Moustakas, 1994).

In keeping with this general process of data analysis in phenomenological qualitative research outlined above, the researcher recorded the data using two devices; one was a voice recorder, the other was a computer transcription and recording application called Otter.ai. The researcher then compared the transcription with the software translation and corrected where necessary to ensure a verbatim transcription of each interview. Privacy for the participants was ensured using pseudonyms. The data was protected using encrypted thumb drives where all the data was stored after being worked on by the researcher on password protected computers.

These transcripts were read several times in an attempt to generate themes. Each of the concept maps were analyzed along with the transcripts so the researcher could gain awareness of both the textural and conceptual meanings the participant was communicating. Significant phrases or sentences that directly explore a participant's experience with accessing and receiving care for their child with ASD were identified. Meanings were formulated and clustered into common themes by the researcher and aided by the qualitative software. The themes were then integrated into an in-depth description of the phenomenon. Although the focus of CMT is in data collection, CMT also has embedded with its protocol three levels of analysis to aid the researcher (Impellizzeri et al., 2017). The first level of analysis occurred when the participant reflected on their conceptual map and arranged concepts into clusters of ideas. These represented potential themes that the participant identified from their own experiences. The second level of analysis that CMT provided during data collection, was conducted by the

researcher through his own interpretation of the data as it was being told and conceptually depicted for him. The final level of analysis was conducted through the use of probes and follow up questions, and clarifications of participant data in vivo (Impellizzeri et al, 2017; Leitch-Alford, 2006).

To assist the researcher in managing the large amount of data and to cluster the data into themes, ATLAS.ti, a qualitative processing software program, was used. The interview transcripts were uploaded to the program as was the memoing, allowing the researcher to rapidly retrieve, search, document, organize, and browse all data segments (Creswell & Poth, 2018). The qualitative software was instrumental in identifying potential themes from the rich descriptions in the interview transcripts and through the concept maps. However, the researcher never lost sight, that in data analysis for phenomenological qualitative research, the researcher is the primary analysis tool and the analysis in this study reflects that (Heppner et al., 2016).

In describing and classifying the codes generated by ATLAS.ti, the researcher decided on the most appropriate themes in an attempt to synthesize text and conceptual data collected from the interviews into experiences central to the phenomenon. The researcher also created memos along the process of analysis and inputting these memos in ATLAS.ti to deepen the data and enrich the themes generated.

Trustworthiness

Standards of trustworthiness in terms of credibility, dependability, transferability, and confirmability are essential in qualitative research (Creswell & Poth, 2018; Heppner et al., 2016). The importance of good evaluation is central to the design of this qualitative research and can be understood through the many mechanisms used to ensure trustworthiness in the following paragraphs. To aid in trustworthiness, the CMT interview protocol increases validity in research

by including four separate member-checking points throughout the creation of the participant's conceptual map.

In phase I, the participant reviewed for accuracy the written concepts that the researcher prepared as they were listening to the storying. They had the opportunity to correct, add, expand on, or delete concepts at that time. The second member-check was conducted in phase 2, after the participants created their concept map, they were invited to make modifications until they were satisfied it accurately reflected their experience (Impellizzeri et al., 2017). The third member-check is unique and helpful in the analysis for the researcher because the participants assigned their own labels and themes to their concept clusters, then they use symbols to demonstrate relationships between them. The last member-check built into the CMT protocol was completed when the participants reflected upon their concept map and were given the opportunity to modify the map and provide summative insight to ensure the concept map represented their lived experience (Impellizzeri et al., 2017).

Credibility

To assist in the credibility of the study, the participants reviewed the analysis after it was complete and provided feedback to the researcher to ensure accuracy of the information surrounding the phenomenon from the participant viewpoint. The Conceptual Mapping Task (CMT) interview protocol is a trans-theoretical interviewing strategy that is naturally participant-centered, sensitive to context, and narrative focused (Impellizzeri et al., 2017).

Additionally, three types of memos were used throughout the study; segment memos, document memos, and project memos (Creswell & Poth, 2018). Memoing was conducted during data collection, during each analytic session, and organized in ATLAS. This method is important

because it helps track the development of ideas through the entire process and lends credibility to the analysis process and outcomes (Creswell & Poth, 2018).

Dependability and Confirmability

Dependability and confirmability were aided through the use of computer assisted qualitative data analysis software (CAQDA), ATLAS.ti in this research. The use of this software allowed for an audit trail for others who are interested in studying this phenomenon to understand the cognitive process and clarify understandings in the study (Creswell & Poth, 2018). The use of ATLAS.ti allowed for both an excellent documentation of the procedures used during the analysis, and it also allowed for replication of the study should that be a goal of future research.

Transferability

Using participant feedback during the interviewing process aided in transferability ensuring that future studies researching the same phenomenon will likely have similar outcomes. This type of transferability is supported by bracketing the researcher from the problem and the unbiased approach of the researcher. The researcher concentrated on setting aside prejudgments and predispositions to allow the experience of the participant and the things, people, and events they described, to enter anew into the researcher's consciousness as if seeing them for the first time (Moustakas, 1994). Moreover, using the CMT interviewing technique allows built-in interpretive power sharing between researcher and participant. The researcher has limited power over the story and only acts as a process guide allowing the participant limitless creative space to conceptually depict their experience (Impellizzeri et al., 2017). This protocol creates an organic protection from researcher agenda seeking as it is the participant and not the researcher who is in the lead of their storying (Impellizzeri et al., 2017).

Ethical Considerations

Participant protection from harm and disclosure of comprehensive findings during this research was of paramount importance throughout the study (Creswell & Poth, 2018). Directly following the interviews, the names of the participants were changed to pseudonyms to protect their identity. The use of embedded member checking during the CMT protocol ensured that participant information and experiences were not shared with other participants through disclosure of the comprehensive findings (Creswell & Poth, 2018).

Directly following IRB approval, a critical ethical step, data was transferred to an encrypted 256GB external storage device that was also password protected. Whenever the research was worked on, it was done on a password protected computer and all data was stored only on the encrypted external device that was stored in a locked bank bag, in a locked file cabinet, in a locked room ensuring multiple levels of security. The concept maps were similarly stored in the locked file cabinet. Participants signed a consent form that details this security and privacy protection so that they were aware and confident of the safety of their information (Appendix G).

The researcher ensured the participants understood their right to decline or withdraw from participation at any time in the research process (American Association for Marriage and Family Therapy, 2022, section 5.1 - 5.5). Furthermore, as a licensed therapist, the researcher made every effort to avoid multiple relationships with the participants that could impair professional judgement or increase any risk of exploitation (Wilcoxon, 2013).

In the event the participant, during interview process, reveals information that leads the researcher to reasonably suspect abuse or neglect of a minor or disabled adult, this event will be reported by the researcher to officials following applicable Washington State laws for mandated

reporters. This requirement for disclosure was specifically described to each participant through the informed consent form that was read to them, and they acknowledged and signed. It must also be considered that while describing their experience, participants may become emotionally overwhelmed. To aid with down regulating emotions, the interview was extended to two hours to allow adequate time for processing before concluding the interview. If the participant requested additional support to further understand confusing emotions surrounding their experience, they were referred to licensed providers near them by the researcher.

Summary

This chapter describes the methods of research that were used to conduct this transcendental phenomenological research. The purpose of this study is to describe the experiences of parents caring for a child with ASD while accessing and receiving professional provider supports during the pandemic. In describing the methods, this chapter explained the research design, questions, setting, participants, procedures, data collection, data analysis, and validity measures. The researcher focused on methods involved to produce a professional, unbiased, trustworthy study into the lived experience of parents of children with ASD as they navigated accessing and receiving care for their child from professional providers in the midst of COVID-19 mitigation efforts. Every effort was taken to provide a voice for parents of this vulnerable population in an ethical way from the design of the research through the selection of the participants and their representation of the diversity of parents caring for children with ASD.

Chapter Four: Findings

Overview

The purpose of this transcendental phenomenological study is to describe the experience of parents caring for a child with ASD as they are accessing and receiving professional services for their child in the midst of a global COVID-19 pandemic in Washington. This chapter will provide a portrait of the participants, their demographics, and their description of experiences in accessing and receiving care for their child with ASD during the pandemic. Moreover, this chapter will provide the results of the research in terms of the themes that emerged and conclude with answers to the research questions that initiated this study.

This research findings were the result of five in depth, semi-structured interviews of participants of varying demographics with children presenting differently on the spectrum and of different ages and circumstances. Additionally, participants completed a Conceptual Mapping Task that was used so the participants could deepen their description of their experience and provide a pictorial representation as they organized their concepts and linked them to one another (Impellizzeri et al., 2017). Both the transcripts of the interviews and the conceptual maps were used in conjunction with researcher memoing during the process. Every effort was taken by the researcher to allow the participant voice to come forward in describing their experience and many participant quotes are used to aid the reader in seeing the participant experience through the stories they have told.

Six themes, one with three subthemes, emerged during the analysis of the data in relation to the research questions. The themes were 1) online delivery of professional supports led to increased isolation, increased parental demand, and decrease in efficacy 2) an increase in parental and systemic family stress 3) a loss of momentum/developmental progress 4) difficulty

in accessing professional support 5) relief of returning to in person school 6) increased involvement of fathers. The themes will be explained and supported in the results section of this chapter, which will conclude with a description of how the research questions were answered by the participants.

Participants Portrait

The five participants were parents of children with ASD living in Western Washington State who experienced a change in professional supports from before the pandemic to during the pandemic and also as the restriction in the state eased. The time period researched was from prior experiences to March of 2020 to December of 2022 when the interviews took place. Of the participants all but one was married; they aged from around 35 years old to around 60 years old. Their income ranged from upper middle class to below the poverty level in the county they resided in. None of the participants resided in an urban setting, rather rural or suburban. Their children ranged in ages from 4 to 13 years old during the time of the interview. Their children with ASD also experienced differing levels of required support for their ASD, from Level 1 (requiring support) to Level 3 (requiring very substantial support) in accordance with the DSM-5 (American Psychological Association, 2013). The participants were of various races. The participants had never experienced the procedures used to create their conceptual map, although one participant had expressed that she had used something similar in another job.

Digital pictures of the participant conceptual mapping task are included in Appendix K and figures representing these pictures are located at the end of each participant portrait to allow the reader a reference by representation to the conceptual maps created by the participants located in the appendix. Pseudonyms were given to each participant, and participant's child, to protect their identity. Some direct quotes were altered only to protect confidentiality.

	Participant Demographics				
	Mandy	Ashley	Richard	Stacey	Caitlin
Parent Age	45-50	35-40	55-60	35-40	35-40
Relationship Status	Married	Single	Married	Married	Married
Race	Multiracial	Caucasian	Caucasian/ Native American	Caucasian	Caucasian/ Native American
Household Income	75K	15K	72K	140K	70K
Household Geography	Rural	Suburban	Suburban	Rural	Suburban
Number of children in the house	1	1	2	3	2
Child with ASD age/sex	10 yr old Female	4 yr old Male	4 yr old Male	13 yr old Male	4 yr old Male
Severity of ASD per DSM-5	Level 1	Level 3	Level 2	Level 2	Level 2
Professional Services Needed	Mental Health/ ABA/ Speech Therapy/OT/ Psychiatry	OT/Speech/ ABA/Special Needs Pre-School/PT	In home nurse/ABA/ Special Ed Preschool/ Speech/ OT	IEP w/ Para/OT/ ABA/ Speech	ABA/Special Ed preschool/ Speech/OT Nurse Specialist

Table 4.1

Mandy

Mandy (pseudonym) is a 45–50-year-old multiracial woman and mom of two children, one over 20-years-old and living out of the home, and the other child is Olivia (pseudonym), 10-years-old who was diagnosed with ASD level 1 (requiring support) when she was six. Mandy currently works for a county in social services and support, where she is set up to work from home. Before the pandemic, she had a job in a field that she felt she struggled in, and she

eventually lost that job during the COVID-19 pandemic. She is married and living in a rural setting in Western Washington State with her husband and daughter, and their annual income is roughly \$75,000.00. Mandy stated that she struggles with her own mental health challenges, specifically ADHD. She described how she has learned to cope with this challenge throughout her lifetime.

Mandy participated in the interview, which lasted 104 minutes and was conducted in a regional library meeting and study room. Mandy was engaging and articulate and had little trouble understanding the concepts and tasks required for the conceptual mapping exercise. Throughout the interview, Mandy discussed her frustrations, struggles, stress, and happy surprises as she described her experience of accessing and receiving professional services for Olivia during the COVID-19 pandemic.

There were times that were emotional for her as she told her story, and the times she recounted centered on the initial difficulties with her husband and her daughter as her dad took over primary responsibility for Olivia's online schooling. That family dynamic seemed to elicit negative emotions, but Mandy was quick to point out that there was a significant benefit to this process as well. At the conclusion of the interview, we discussed resources for mental health to address the stress that was identified in the interview.

Textural Description

Before the pandemic, Mandy and her husband both worked out of the home in different jobs. Although Mandy was part-time, her husband's employment was at a local grocery store, where he was in contact with the public on a daily basis. Olivia, who was then seven years old, was in a local public elementary school and had an individualized education plan (IEP) to

accommodate for her ASD constellation of symptoms and ADHD. Based on their schedules, the family no longer required after-school care for Olivia. Olivia received occupational and speech therapy from the school in 30-minute time periods multiple times during the week. Mandy stated that Olivia was in a gifted “Venture” program and in the general education population. She described this program as a “highly capable program that has supports in place for kids like her (Olivia) because they have special needs too.”

As a part of her IEP, Mandy appreciated that Olivia had access to a resource room that she would go to as a “sanctuary” when she needed extra help to do homework or when she just needed a break. There was also another room she could use to decompress that Mandy called a cave. She stated, “It’s so sad they closed because the room was.... they had a little cave, for if a kid got overwhelmed, they could go in there with their little stuffy or a book and decompress”. Mandy thought her daughter was progressing well in both speech and OT, where the focus was on working to improve social-emotional development and managing extreme emotions. Mandy explained that the occupational therapist had a swing in her room that Olivia would use to help her calm down. Mandy remembered that with the swing, she could spin, and it worked really well for her “resetting.”

Olivia was also receiving mental health services from a psychiatrist she saw online for medication management and a psychotherapist whom she saw in person every week for an hour, both in the same outpatient clinic. These two services were paid for by insurance and were not delivered through the school system. In Olivia’s mental health therapy sessions prior to the pandemic, the therapist primarily used play therapy to address her symptoms. Mandy believed that Olivia responded well to this therapy model.

Before the COVID-19 pandemic, Mandy had just begun setting Olivia up for ABA services from a local outpatient provider through her insurance. Olivia was seven years old at the time, and her mother believed with the 20 hours a week that they provided of direct behavioral contact, that Olivia would have the best care she could provide for her. Unfortunately, they could not access ABA therapies until after COVID-19 began to spread.

March of 2020 to Fall of 2020. In March 2020, the governor of Washington State issued a stay-at-home order for residents who were not considered essential workers that lasted until the end of May 2020. He also shut down all schools for the remainder of the year to in-person learning, and they needed to adjust to an online environment. The schools opened in the fall of 2020 for online education only; then in late spring of 2021, schools allowed some students to attend one or two days a week in person. Olivia was one of these students. It was not until the fall of 2021 that the schools in Washington State resumed in-person education, albeit with many new restrictions.

For Mandy and her family, this meant that they had to adjust to this new environment. Mandy's husband continued to work at the grocery store in the evening and would homeschool Olivia during the day. Mandy continued working but moved many of her tasks online from home. The lockdown in Washington was initially described as two weeks only, so Mandy's husband used two weeks of vacation initially, and then, when the order was extended, they both adjusted their schedules to accommodate Olivia's new at-home schedule. Mandy explained that they started to change their schedules to adjust to this "new reality." Mandy's husband worked at the grocery store from 5 pm to 11 pm and became the primary education help for Olivia as she began her online schooling. Their schedule was from 9 am to 4 pm for online asynchronous education.

This period from March 2020 to October 2020 was the most stressful time for Mandy because, as she describes, there was such a monumental change in support for Olivia, and the family's initial adjustment to it did not work well. Mandy described the change this way:

Even though we were all in the same house, we were all on different schedules. So, it's like, Oh, your turn to take care of her. I'm in my room working and then switch, and I would take over [in the evening]. Her school didn't end at 4 p.m. because there was music and PE that he didn't get to. So, then it switched, and we would switch, so really, it was her school did go till 8 p.m.

What Mandy felt was so stressful for her were the times she would be in her room doing her remote work during the day, and she could hear her husband and Mandy struggling with school:

It just changed the family dynamic. He never had to deal with her. I knew her secret language. I am the only one that knew it, and all of the sudden, he is in charge of her, her care and feeding, getting dressed, and doing school. He didn't get it. He did not understand that his methods were not correct, and he couldn't read her cues or understand her language ... during the day, while I was working, I could hear it, and it was really bad ... He never had to be that, his role before was fun dad. Right.?

Before this, Mandy felt comfortable because Olivia was at school doing these things with people who were trained and knew how to work through those situations. She explained that Olivia had places to go and outlets to help her.

In addition to the changes in special education, Mandy discussed some of the changes to Olivia's other professional supports like speech therapy, occupational therapy, and mental health

counseling from March 2020 through the fall of 2020. The most important to Mandy was the mental health support Olivia was receiving through play therapy before the pandemic. Once the stay-at-home order was issued in March, Olivia's counselor transitioned to online support. Mandy describes what the change was like for Olivia: "Before the pandemic, she was in a playroom with the counselor and could play and talk however she wanted; when it transitioned to online, she was in our kitchen with very few toys and other people around. Mandy did not believe the online play therapy was effective at all for Olivia.

Fortunately, Olivia's outpatient mental health therapy allowed her back in June of 2020 for in-person sessions. Mandy described this as a big relief because Olivia was commenting about wanting to "stab people." Olivia was also perseverating on things that happened in first grade. Mandy said that Olivia would "think back to people that were mean to her and that had betrayed her ... and getting really upset about those things." It was also a relief for Mandy because it meant she could see her own therapist at the same time as her daughter was being seen, and that helped her manage her emotions about how her husband was handling Olivia with her online schooling.

Mandy recalled that Olivia continued her psychiatric services online and that it was fine because she already had a relationship with her provider, and he was doing check-ins to manage medications. Mandy thought that the reason Olivia really liked meeting with the psychiatrist every other month was that the online meetings were a lot like her mother's online meetings. She felt more mature because of them.

Mandy stated that speech therapy and occupational therapy both shut down services for over a month at the onset of the pandemic. In May 2020, they restored services in an online format. Mandy thought that speech therapy online was fine for Olivia. "We worked on the skill

of getting directions without becoming frustrated, and they did a drawing; she likes to draw, so that was pretty effective over zoom.” Her speech therapy was reduced to 30 minutes a week online from May 2020 to the fall of 2021. Occupational therapy was also delivered to Olivia through the school, and the timeframe for the move to online was roughly the same as speech therapy. Mandy didn’t think occupational therapy was very successful online. She said, “they gave us pamphlets, and I can’t get her to do it. I couldn’t get her to do the things that they provided”. Mandy also talked about how Olivia missed the swing in the OT room and that she was sad that she could not use it.

The other professional service that Mandy really wanted for Olivia was ABA therapy. She could not get Olivia an ABA therapist until September 2020, even though she started applying to different places in January 2020. Mandy recalled that she,

was really looking forward to ABA because ... I saw from the TV show Parenthood what ABA looks like, and I thought I was going to get that, and it was going to be intense, and we were going to get training, and we didn’t get that ... we didn’t get the Hollywood ABA

In this Hollywood version that Mandy related, she talked about an ABA therapist coming into the home and working with the child for 20 hours a week and even going to Olivia’s school to work with her.

Fall of 2020 Through Fall of 2021. During this period in the state of Washington, children were not attending in-person schooling, and the schools began online instruction in earnest. In the late spring of 2021, Olivia was allowed to go in-person to school for one to two days a week because she had special needs. Professional support for children with ASD adopted

a hybrid of in-person with masks and/or online therapies depending on the clinic or if they were school-based. Mandy was happy that Olivia could begin her ABA therapy even if it were at the clinic and not provided in the home. Unfortunately, Mandy reported that this quickly broke down because the clinic that provided ABA had difficulties with staffing and eventually closed toward the end of 2021. Mandy discussed the experience this way: “It was not great because I couldn’t go inside and see or be a part of it. She (Olivia) did not enjoy going.” To make matters worse, Olivia disliked it so much that she would “run-away” by getting on the school bus after her mother had arranged with her and the school to pick her up for ABA. Then Mandy would have to work with the school and chase the bus down to recover Olivia from the bus somewhere in transit to their home.

Mandy also stated that the clinic couldn’t “find ABA therapists and assistants,” and she believed that was COVID related. Plus, with the staffing shortages, Olivia only received ten or so hours a week of the 20 hours she was authorized. Regarding the staffing shortages and the impact, Mandy stated, “it wasn’t just one therapist; she had to see a lot. It just depended on who happened to be working that day. Her time in ABA was building rapport with a new therapist because of the staff turnover”. Mandy stated that Olivia attended ABA therapy for about one year before they closed, and she did not try to find another provider because of the negative experience. In the end, Mandy had this to say about the impact of COVID-19 on her ABA experience “There’s a little bit of grief because that ABA would have been really helpful when she was younger when we could have got her before she matured... That’s critical development... Yeah, those are critical development years that impacted her.”

As for the remainder of the professional services, OT, speech, and mental health counseling, Mandy stated that speech was online and mostly effective for Olivia. Mental Health

services were in-person and a big relief to both Mandy and Olivia. OT was online, and she believes mostly ineffective.

A major change for Mandy and her family happened in the fall of 2020. At that time, Mandy said the conflict between her husband and her daughter in his effort to get her to do her schoolwork came to a head. Mandy's husband told her one day at the end of September, "he just couldn't do it anymore," and to this, Mandy said, "we have no choice." Mandy was visibly disturbed and emotional at recalling this impactful moment for her family and described her helplessness. She described the heaviness of the stressful job she was working and the stress of hearing the conflict between her daughter and husband every day as they tried to get through school together. At nearly the same time that fall, Mandy suddenly lost her job. Although that should have been a significant increase in stress, Mandy did not relate it as a sad event but as a relief that she could now help her daughter the way she wanted to and free up her husband to return to his role and relationship with Olivia as before.

Olivia stated that for the remainder of the 2020-2021 school year, she was Olivia's primary educator as they both worked on her online school together. Mandy was frustrated that they couldn't seem to limit the school day to just six hours and often were "in school" at home for nearly 12 hours a day. She said that "when she was with us, it was from 8 am to 8 pm, she is so slow... that meant from the time we got up to time for bed, it was school, school, school, and things still weren't getting done." Mandy remembered the stress of "having to be a special ed teacher, regular teacher, and I had to learn math actually." She said, "I didn't go to school for that." Mandy recalls lots of crying on her part, particularly when trying to teach Olivia long division.

The final service Mandy reported Olivia receiving was mental health counseling from the school counselor. This counseling was in addition to the insurance-based counseling she received at an outpatient clinic. Mandy expressed her sadness that “it was not effective because it was over Zoom, and she didn’t enjoy it.” She recalls thinking,

how are you going to build rapport with someone you have never met in person?

She (Olivia) was bored.... it just seemed like to her like interrupting something when she could be playing. You know she didn’t want to be in front of a computer for another person.

Mandy felt like this just added to the various other things she had to do, and it was not all that beneficial.

During this time, Mandy recalls the difference between online school counseling and the in-person outpatient mental health clinic in this way:

I was thankful for that [in person] because we could actually go and see people, you know, because it was just us three in the house by ourselves. We didn’t interact with our neighbors; we followed the protocols, and we didn’t have any family here or anything. We really did stay.... we really isolated because my husband worked at the grocery, and I didn’t want to be a super spreader. The in-person therapy took away from some of the isolation.

Fall of 2021 Through December 2022. In the fall of 2021, the schools in Olivia’s county returned to in-person education with restrictions. Those restrictions centered around mandatory mask-wearing and COVID-19 testing or quarantine when exposed. During this time, Olivia attended school in-person and received her speech therapy and occupational therapy at the

school. In the fall, Mandy discontinued the ABA for Olivia because she felt it never really benefitted her because of all the staffing issues, and Mandy felt that it did not make sense to pull her out of her special education classes to go to ABA. Olivia did not like going to ABA but did enjoy her school, so Olivia thought it best to let her stay in school rather than pull her out.

The other change in the family dynamic was that Olivia's father became a para-educator in the fall of 2021 and was pursuing a teaching degree. Mandy showed visible relief and joy at expressing how the relationship between her husband and her daughter had changed because of the work they did together. To her, it was a struggle that bore fruit. Additionally, Mandy was able to get a new job after Olivia went back to school in person, and Mandy said in this job "I help a lot of people and so I found a job that I like and has a lot of meaning".

Mandy did express regret at not cutting the school day off at 4 pm and saying, "we are done for the day" while she was schooling Olivia. She also wishes she had the ability to "just let things go" with Olivia, and as Mandy says, "except a lower quality of work for her and let her be a kid, I wish I'd done that." However, she also reflected, "you know, it's only after the fact that you realize, oh, we were all going through a transition. Yeah, because when you're in it, you don't go, oh, look at us growing and changing".

Structural Description

The response to the COVID-19 pandemic in the state of Washington impacted many industries and people. The impact on special education services, applied behavior analysis, and occupational therapy was the most impactful for Mandy and her family. It stands to reason that these services would be the most impacted because they require almost constant physical contact with the client, and in the case of ABA and special education, the time they are with the client is

also greater than other services. However, ABA and special education services are the professional services that Mandy and her family rely on the most.

When Mandy talks about the closing of in-person special education for over a year she relates it this way: “They had alternative seating, the teachers are trained in [working with] highly capable kids that tend to have behaviors that are seen by the general population as misbehavior, whereas these teachers were taught to let things slide or provide more support.” Mandy did not feel she had the same level of training to provide the same education to her child in an online learning environment. Additionally, Mandy was very excited about Olivia attending ABA, but the experience of attending, even though it was in-person, it did not match her expectations. She related that the facility used “to do ABA in home but changed because of COVID..... I think that they would have liked to if they had enough staff, okay, and during COVID, they couldn’t provide that”. Mandy looked back on time working with the ABA clinic: “there’s a little bit of grief because that ABA would have been really helpful when she was younger when we could have got her before she matured.”

Conceptual Mapping Task

Mandy’s conceptual map (Figure 4.1) was grouped on the top of the page into three columns representing the main services that impacted her and her family: special education, mental health, and ABA. In two clusters at the bottom of the poster were Mandy’s experience of stress and turmoil and the “resolution” phase of her experience after COVID restrictions were lifted. Mandy created the top left cluster column, special education, and filled it with the speech therapy, occupational therapy, and special education changes during COVID. In this cluster she highlighted her sadness at the “special education program closing,” the “loss of so many supports,” and how much the loss of the swing and resource room meant to Olivia.

The top middle mental health cluster represented Mandy's experience with accessing and receiving mental health care for Olivia and herself. She emphasized how mental health play therapy online was not effective for Olivia, and the move back to in-person early in June 2020 was a huge benefit for both. In the top right cluster, Mandy clustered her ideas and her disappointment at not receiving the ABA services that she was so excited for her daughter. In this cluster, she highlighted the difficulties that ultimately led to them pulling Olivia from this service shortly before the clinic closed.

In the bottom left cluster of concepts, Mandy placed all the stressors during that time. The cluster illustrates how she and her husband reordered their work schedules to home-school Olivia, to the stress of the conflict between dad and daughter, to the stress of wearing many hats for her daughter, none of which she felt qualified for. The last cluster was at the bottom right of the poster and represented a "resolution" of her COVID-19 experience in accessing and receiving professional support for her daughter with ASD. In this, she highlights the positives that came from this experience and her general satisfaction with where they are now.

The researcher prompted Mandy to depict how all these concepts related to one another visually, and this proved difficult for her. Looking at her poster, she thought they all interacted throughout a timeline of events, even though they were not particularly ordered that way. She stated the interaction this way: "the lines are where I stuck the stickies together," and that meant that in each category, she ordered the concepts from top to bottom in a time sequence inside of each cluster.

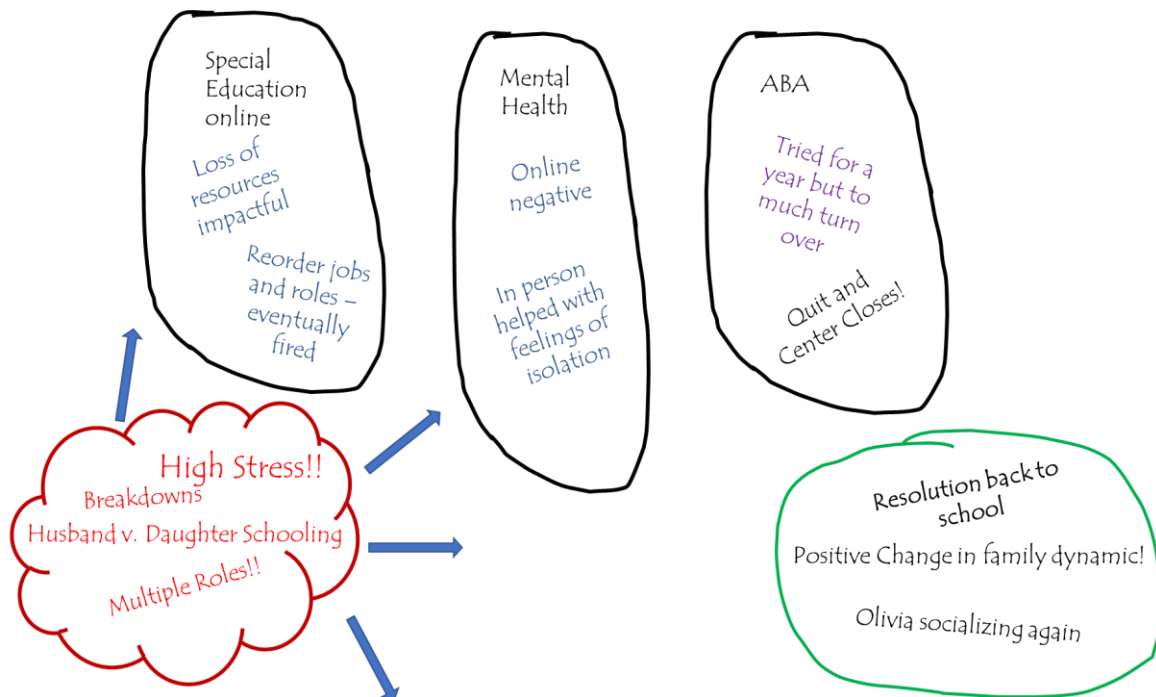


Figure 4.1 (Mandy's Conceptual Map Representation)

Ashley

Ashley (pseudonym) is a single mom between 35 and 40 years of age, living in a suburban area in Western Washington. She describes herself as Caucasian, and she earns around \$15,000.00 a year. Ashley's son Landin (pseudonym) was diagnosed by Seattle Children's Hospital in 2019 with Autism Spectrum Disorder, level 3 (requiring very substantial support), when he was just one year old. Ashley found it discouraging that even before the pandemic, Seattle Children's Hospital assessed and diagnosed using telehealth. Ashley was then referred to a local center that provided ABA, speech therapy, occupational therapy, and physical therapy for children diagnosed with developmental disabilities. Ashley started these services before the COVID-19 response. Her son continued services with this center, which offered services from birth to three. At three years old, Landin transitioned to a developmental preschool program that

supports children with neurodevelopmental disorders like ASD. Landin is currently attending this preschool.

Ashley met at a local library in her area to conduct the interview. The interview lasted 45 minutes and, compared to others, was relatively short. The interview took place on January 6th, 2023, and was arranged while her son was in preschool. It took several attempts of scheduling and then canceling interview times due to conflicts and care support for Landin to complete the interview. Ashley presented as reserved and a little anxious at the interview and answered questions briefly at first and then began to expand them as the interview progressed. She did not demonstrate any heightened emotional response as she recalled the events of her time during COVID. Ashley stated later in the interview that she is very self-conscious about speaking and writing in front of others. However, the information and concept-building that Ashley provided were very helpful and illuminating.

Textural Description

Before the pandemic, Ashley began arranging occupational therapy, physical therapy, speech therapy, and applied behavioral analysis with the local early intervention center. This center is contracted with the state to provide birth to three services to children with developmental delays. The primary method of providing these services was in-home with parents and children. Their center has limited resources because they were set up to travel to homes instead of treating at their facility. Unfortunately, Landin did not have the services in place before the COVID-19 pandemic, so his only interaction with professional treatment was the assessment and diagnosis he received from Children's Hospital. Ashley was aware that in-home services were the primary method of delivery and felt like they would have been much more beneficial.

March 2020 Through Fall 2021. Ashley stated that after Landin received his diagnosis, she was “referred to the center for speech therapy, feeding therapy, occupational therapy, and ABA therapy.” She was disappointed that they were only provided via telehealth. As Ashley put it, it was all “through the computer, and he’s two at this time, so for him to want to pay attention to the computer screen.... really didn’t work that great.” During this time, there were no in-home or in-person delivered services. Ashley said they were all online.

Ashley spent three months coordinating services for Landin with the center, and by the time she was to begin, the center closed in March of 2020 as they worked toward moving their services online. Beginning in April 2020, Landin received speech therapy twice a week, OT once a week, and ABA therapy three times a week through a video conferencing platform. She remembers the stress of trying to get Landin to “stare at the computer for an hour and a half or so.... it’s not that easy. So a lot of times it was me and them, you know, when it’s supposed to be about him. It’s pretty stressful.” She also recalled having to keep to themselves and wanting more interaction with her son. She shared that they “just kind of kept to ourselves during that time, you know. We really didn’t know what was happening with that virus, so we all kept separate, which is actually very isolating for a two-year-old. Social skills picture could have been much improved if he had it, visitors and stuff like that”.

Ashley describes being worried about Landin’s development, especially in the area of speech. She describes “feeling like she is failing him” by not being able to get him the resources he needed during this time. She feels like he lost a year and a half of key development time with speech: “as far as the speech, actually therapy part, I don’t think he gained anything from it.” Ashley mentioned that toward the end of 2021 the occupational therapist was able to do in home visits. Unfortunately, that only happened twice before Landin turned three years old, which is

the age that the services are no longer available at the center because they are provided by the preschool special needs program in Washington State.

Ashley talked about her stress at not being able to access the services she wanted for Landin this way: “It’s very stressful, and it still is, well I just worry ... because well, I know he is getting farther and farther behind ... it weighs on my mind a lot, I mean it’s just very mentally, stressful and challenging.” She recalls trying to do it on her own saying “you know, I get online and look for ABA things I can do at home, stuff like that, but it’s just not quite the same without that instruction, you know.” Through her stress Ashley was still understanding of the environment and said, “I mean it was nice that they still tried to put the effort in, you know, they still ... the services were still offered, it’s just not the same, especially with kids that are young, it's just not.”

Fall of 2021 to December 2022. In the fall of 2021, when students were allowed to return to in-person schooling, Landin was turning three years old and transitioning from his online therapies at the center to his new special education preschool. Ashley recalls the transition to preschool and the time it took like this: “there was time in between for sure ... it’s just getting everything lined up, you know, with specialization and all that stuff.” She did emphasize how much the center that Landin had been with had helped her during this transition to preschool, and that help was instrumental in relieving her stress at moving to the preschool.

In late 2021 or the beginning of 2022, Ashley said that Landin was in preschool and starting some of his services through the preschool. In addition to special education preschool education, Landin was receiving speech therapy in-person for 30 minutes three times a week, and he was attending preschool four times a week. Unfortunately, the preschool did not offer

occupational therapy services or ABA services, so Ashley had to try to get them somewhere else. This was and still is a constant source of frustration for Ashley.

Ashley was relieved when Landin entered his special education preschool: “I think that his being in school right now, it’s definitely impacted better. Yeah, versus him being home with me all the time, okay. Social interaction it’s always good for kids; they have to have it.” She later in the interview describes the preschool this way: “the school would be a happy place, I guess because he is in there and getting some social interaction services, whatever he can get at the time. It’s good, it’s definitely good.”

During this time, Ashley’s biggest stressors for Landin are getting him ABA services, and she also wants additional speech services for him. Unfortunately, ABA services are difficult to find, and Ashley said that they have been on an “ABA waitlist forever, it just ... I don’t know ... it just doesn’t seem fair, there is just nothing available now.” So, after a year of being on a waitlist for ABA, Ashley said there are “still 12 ahead of us.” This was after she found a new place that was accepting new clients, and she said that was the shortest wait list that she could find. Mandy related that the experience of not being able to find ABA services for Landin after the negative online ABA experience has been exasperating for her.

Of all of the concerns Ashley has, her biggest concern for Landin is his inability to speak. Consequently, speech therapy is extremely important to her. She related that she is happy that he is in preschool and receiving speech therapy in person, but she is worried about it now that Landin is four years old:

Just not knowing if he is going to be able to communicate or not. I’m [still] not sure yet; he has said words before, but it’s so sporadic in between them. You

know, he's got a communication device and stuff which he is learning to use, but ... we keep trying to figure out the sign language or if we don't really need to push that until later.

So, she is trying to get him speech therapy from an outpatient clinic to augment the speech therapy he is getting at school. Ashley stated that the waiting lists for speech therapy are "like a year and a half out. Pretty bad, and I called around to all sorts of places." Ashley is on state Medicaid insurance, but she added, "it didn't matter if it was state health insurance or regular health insurances; it was all just the same." She describes the impact of Landin's speech delay like this: "it's very stressful, and it still is, well I just worry ... because well, I know he is getting farther and farther behind."

Structural Description

Structurally the external events that impacted Ashley's internal experience were COVID-19-related impacts, the isolation it produced for Ashley and Landin, and how the system worked for her transition between the center and the preschool. Ashley remembers the biggest problem with COVID-19 restrictions on professional services is that they were "actually keeping him from being in person. It was just COVID that was keeping him from being in person, you know. Otherwise, we would have gone to the facility, and that would have been better."

Moreover, the COVID-19 pandemic-related restrictions and precautions created an isolated time for a child and mother with no remaining family and a special needs child with no access to services except online. Ashley remembers this time as a period of isolation where she and Landin would not leave home for weeks on end. She talks about the isolation and stress in this way: "On top of that, we were there for weeks and weeks, it seemed like it, a long time, I

would only venture out if I have to. So, it seemed like it lasted forever.” Ashley also really worried about Landin’s socialization because of their isolation.

Lastly, Landin’s timing between diagnosis when he was one year old, and the beginning of his services was unfortunate. The center that provides in-home services for early intervention strategies for children with ASD only provides those services from birth to three years old. Children rarely receive a diagnosis of autism as early as Landin did. The fact that he did receive an early diagnosis is probably due to the level of severity and his presenting symptoms of autism. Landin was already two years old when he started receiving his services at the center, so he only had less than a year before he was too old for that program and was due to transition to the special education preschool program. Unfortunately, the preschool program did not have all the services that Landin needed, so Ashley had to try to find it in an outpatient setting, only to find out that there were no resources available. This meant that Landin would not receive ABA and the extra speech services that Ashley thinks he needs for over a year and a half. Ashley’s comment about that was:

I don’t know, but there is probably not much they could do about it; it was just the way it is, I guess. Seems like they should offer those services for maybe birth to five or something would be cool; I don’t know that just seems that is such a little time, but especially when they’re not diagnosed till, they are almost two or you know what I mean?

Conceptual Mapping Task

Ashley also ordered her conceptual map (Figure 4.2) loosely based on a time progression from initial services and the COVID-19 outbreak to where she and Landin are now on their journey. The first cluster of ideas that she organized on the top represented a missed opportunity for her regarding the professional services she received from March 2020 to the Fall of 2021. She describes it this way: “this is an area that could have been really beneficial but wasn’t because of the COVID ... like a star with a minus next to it.” It was an area that Ashley related that “I feel like it could have been better ... it just wasn’t as it was intended to be.” In this bubble, she also described her frustration with the way services were being provided.

In the middle cluster of thoughts, Ashley wanted to portray how stressful this time was for her and how she was still worried and disappointed. To represent her ongoing worry and disappointment, she drew an arrow pointing to the side to represent that it is still ongoing for her. In this cluster, she put her bigger feelings like “I feel like I’m failing,” “I know he is getting further behind,” and “mentally stressful.” In the bottom circle, Ashley drew a smiley face in the circle to represent how she feels better now that Landin is in his preschool and getting in-person services from the speech therapist. This bubble was her way of showing that there had been some relief from the extreme stress and isolation she was feeling earlier. Ashley is quick to point out, however, that she still is not getting all the services that she thinks are vital to Landin’s development.

Ashley had difficulty describing how these clusters of concepts intersect with one another because she had loosely ordered them in a time sequence. However, when she spent some more time thinking about it, she discovered that the middle bubble related to both the top and the bottom bubble as well as still ongoing.

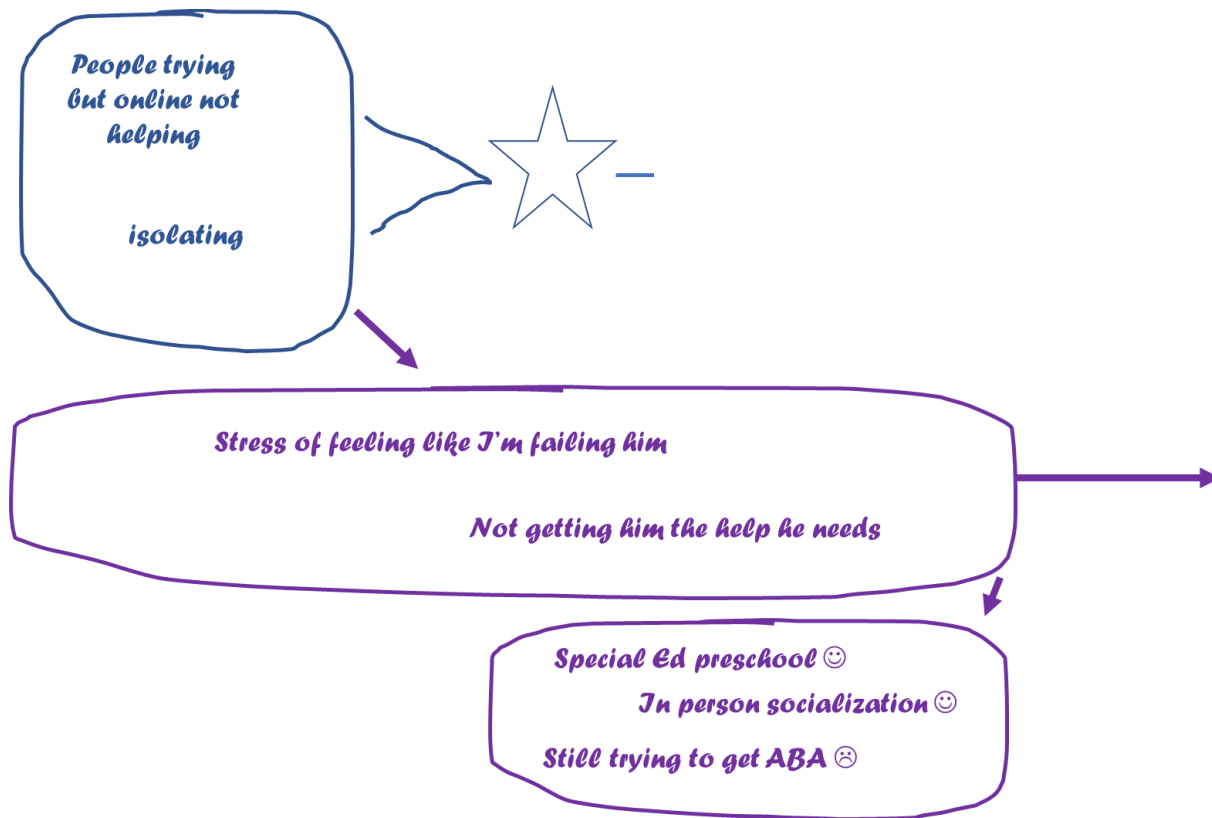


Figure 4.2 (Ashley's Conceptual Map Representation)

Richard.

Richard (pseudonym) is a Caucasian/American Indian man between 55-60 years old living in a suburban home in Western Washington with an annual family income of \$72K. Richard has grown children from a previous marriage who are not living in the home and has two children in their home currently who are ages two and four. Richard is also part of the “sandwich generation,” where he and his wife are caring for their children and for their disabled and aging mother, who is also living in the home with them.

Richard spoke freely about his learning disability which he said impacted his reading, writing, and organization skills. Richard has worked his whole life in labor-intensive jobs, and

he recently worked in a grocery store until 2019, when he stopped working to help care for Cayden (pseudonym), his son with ASD. As Richard stated:

I was determined to stay home with the kids because it was just better for them and for me, because working even at [a grocery store], it was a simple job and so, but it was ... it took a lot out of me during the day. So, when I got home there was less of me to go around ... and now Cayden has some special needs and stuff, I just want to make sure that he has a lot more of me, and he does.

Richard describes himself as a stay-at-home dad, and he cares for two sons, both with neurodevelopmental disorders. Cayden, who is four years old now, was diagnosed with autism spectrum disorder level 2 (requiring substantial support) by a mental health professional when he was between one and two. Richard's youngest son was born during the COVID-19 pandemic and is now being evaluated for ASD at age two. Cayden receives special education preschool, speech therapy, and occupational therapy currently. Richard is still trying to get ABA therapy for Cayden but has not been able to get the correct paperwork filled out from the medical facility that provided his diagnosis.

Richard requested to participate in this research in December 2022, and after several attempts to schedule and reschedule, Richard completed the semi-structured interview on January 9th, 2023. Richard conducted the interview in a private practice office setting, and the interview lasted one hour and five minutes.

Richard was on time for his interview and had some difficulty with the concepts during the interview that he attributed to his learning disability. His difficulties in the interview centered around reading some of the post it notes and conceptualizing the mapping tool and

concept. He was also not comfortable with writing anything down and he would use his phone to look up different symbols he could attribute to his concept clusters during the conceptual mapping exercise. However, with some re-reading of the instructions, he was able to complete all the tasks with seemingly little difficulty.

Regarding accessing, coordinating, and participating in the professional support services for Cayden during the COVID-19 pandemic, Richard saw his role as a supportive one to his wife as she worked with and coordinated with various providers and programs. Richard described this dynamic in their relationship this way: “I try to be as proactive as I can, [but] like I said, my wife does the majority of the stuff ... she is really good with the writing down and the doing, the remembering and all that stuff, but I’m not so much.”

Textual Description

Richard quit work shortly after Cayden was born, and it was apparent that Cayden had developmental delays. This, coupled with Richard’s learning disabilities and his wife’s autism diagnosis, led Richard to the conclusion that Cayden was going to need extra help. In 2019 the family was assigned a nurse who came to the home three to four times a week to support the family with Cayden and to support Cayden developmentally. Richard said that this support came from a program provided by the Washington Department of Health and Human Services. At the end of 2019, the nurse convinced Richard and his wife to have Cayden evaluated for autism. Richard remembers the professional support provided by this nurse as a tremendous boost to his and his wife’s ability to care for Cayden at the time. The services that she was providing were in-the-home support, where she could observe and assist with Cayden’s developmental needs directly as well as assist Richard and his wife with techniques for caring for Cayden’s unique needs.

Following the initial diagnosis of autism by a mental health professional, Cayden was referred to the center that provides birth to three years old support for children with developmental disabilities. Richard recalls “when it first started, you know when we first got the idea that we needed to get some help for our son ... okay, so, you know, there were some of the things open” and Cayden started to received speech and occupational therapy services at the local center. While Richard and his wife were getting Cayden set up at the center, the COVID-19 pandemic began in earnest.

March of 2020 Through Fall of 2021. In March of 2020 Richard and his wife lost the support of their in-home-care nurse due to COVID-19 restrictions. This impacted their family system in a significant way, taking away the professional resource that they relied on the most. Shortly after losing this family resource, they were just getting started with the early intervention developmental disabilities center, and they moved all their care to an online delivery system. Richard recalls the time when they were trying to explain and work out what Cayden needed without the support of their nurse:

They [the center] basically would talk to him about or talk [to my wife] about his different learning abilities; they first diagnosed what he needed, and then they would go over, you know, how can I help him best deal with, you know, his shortcomings. But again, it was hard work with that and try to express to them what he needs and have them express to us and just ... I felt it was harder experience to do with ... it being remote.

During this period, Richard’s wife was pregnant with and gave birth to their second son. Richard remembered that time as a very difficult time as they tried to navigate professional care for Cayden and OB/GYN care for his wife. This impacted both in the way described by Richard:

We could still get care for him; it just was more difficult. Again, a little more difficult for [my wife] and the fact that any appointments that she had with Cayden or even [our younger son], she was the only one who could go in, and a lot of times, she likes me being with her. So, it was more stressful for her because she would have to go into the appointment and do different things ... and it was hard for her to do that [alone], so it impacted her and therefore it impacted me because I tend to be a little empathic in that fact that I can feel other people's stress.

As Richard explained this time, he continued to emphasize how he was supporting his wife while she was participating in the speech therapy and occupational therapy that Cayden was receiving online.

The couple divided the responsibilities in a way that supported their differing strengths and weaknesses stemming from their own disabilities. In an example of the online support Cayden received, Richard explains their cooperating roles like this:

I was just helping to keep Cayden in the living room, you know, while they're trying to talk to [my wife], mostly with [my wife] with those conversations because I had to distract [our younger son] ... She communicates better than I do. I also have a learning disability; it's not quite the same, but it's a learning disability. So that's why I struggle with phone calls ... Her limitations go one way, and my limitations go another way.

For the remainder of 2020 through the fall of 2021, Cayden received speech and occupational therapy from the center through online platforms. Richard's experience of therapy

delivered online was this: “I felt it was a harder experience to do with it being remote. So, I don’t know if Cayden got as much out of it. I think he got a lot more when he could go.” When asked how Cayden responded to the online therapies, Richard said, “he did like talking to people ... or seeing people on the TV and having them talk to him. He didn’t necessarily talk back, but he just needed to make the gestures and be all happy and everything.”

Toward the end of the summer and into the fall of 2021, Cayden began receiving speech and occupational therapy services in the home. Richard said that when they did come over, they would conduct the therapies outside. Richard said, “There was a couple of different people that would show up, but sometimes at different times. I was like, you know? It was like crazy.” At this time, Cayden was approaching three years old, and soon, he would not be eligible for the services he was receiving from the center and would move into the developmental preschool. He thought, “by the time they got it all figured out and started getting regular sessions and stuff, he was approaching three years old, and he aged out of the [center’s program].” Richard also recalls that during the time when the services were provided in the home, when the service provider was there, everyone was required to wear a mask, whether they were participating in the therapy or not. Richard said, “I didn’t like wearing masks, but I did it because it was just to appease people.”

When asked how this experience of accessing and receiving professional support for Cayden during this time was, Richard explained it in the form of a comparison to his experience with his Celebrate Recovery 12-step group. He related that when it moved online, they had to shut down a lot of the subgroups that were really benefiting the members. He also related how isolating it was and how that was counter to the principles of recovery. He remembered it this way: “It just, it was hard, and I struggled with isolating when I was younger, so I know how hard

it is when you're trying not to isolate and they insist you isolate, for your betterment, and it didn't make sense."

Fall of 2021 Through December 2022. In early 2022 Cayden aged out of the center and began in-person special education preschool, where he received both speech therapy and occupational therapy. Richard thinks this is much better for Cayden, and he thinks that Cayden is developing better in this environment, but he adds, "If he has even a cough, it's just, you know, or just if he has any symptoms, you know he can't go to school for so many days until he is symptom-free, so that tends to be ...".

Richard and his wife are still trying to get Cayden services for ABA. Their problem is unique in that they are not yet authorized to receive ABA services based on their medical plan because they need more forms from their diagnosis to authorize the care. The preschool does not offer ABA services, so once they receive the authorization, Richard said that they would have to find a provider. Unfortunately, there are not enough providers in this area to address the need. This is a major concern and source of frustration for the family.

Structural Description

Much of Richard's stress came from structural impacts on the professional support system that they could utilize. Although Cayden received a diagnosis of autism, Richard said that the doctor who gave Cayden the diagnosis did not get the required paperwork completed and sent to their medical insurance provider. To make matters worse, Richard said that this doctor "ended up retiring or leaving or whatever." Consequently, Cayden is not authorized to receive ABA services, and the family is trying to find another doctor who can both re-diagnose and submit the correct forms so that Cayden can qualify for the programs that his diagnosis warrants.

Richard talks about the experience this way: “I think it was pandemic related because the guy was probably very overwhelmed with all the new systems that he had to deal with.”

Richard spent much time discussing how this impacted him and his family and how it impacted him:

The system is so tailored for people that can understand. I mean even people who are really smart struggle with this. So, when people you know already have their limitations, it just makes it that much harder ... the pandemic made it even worse. Like I said, me and my wife both have our special needs, you know, and the fact that we have had children that we want to take the very best care of them. You know it? It shouldn't be rocket science to get the services we need.

Richard talked about the pressure he felt from the “system” to fix the authorization issue.

Most everybody [providers] that was involved kept asking about going through, you know if he's got this paperwork done? ‘Unfortunately, we technically can't get paid until you get this done’ and whatnot, or like putting pressure on us to make sure that the doctor does what he's supposed to do. Yeah, it's like I don't know why the pressure would be on us if they're the ones who know it.

Richard continued to talk about how hard that was on him, giving the impression that he felt that this was his most important contribution to Cayden's care.

The other significant structural impact that the COVID-19 pandemic restrictions had on Richard was not being able to accompany his wife to appointments for Cayden's care. Richard expressed his frustration this way:

That's where I feel the system definitely was way overly cautious. I mean, we spend all day, all the time with each other. So, adding one more person in the room's not going to endanger anybody, but they had to be so strict on that then.

There was no common sense to it.

Yet at the same time Richard expressed how it was difficult for everybody and there was not a lot of good information on the pandemic out there.

Conceptual Mapping Exercise

Richard spent a long time trying to place the cluster of concepts in a way that illustrated his experience accurately. In the end, he clustered his concepts into three areas. The first area represented concern "with a little hope," which was on the top left of the page outlined with a circle, and he used a green marker to represent the hope. Richard wanted to draw a symbol that would represent each cluster but had difficulty coming up with the idea until he thought to use emoji symbols from his phone. He looked up each symbol and its meaning to accurately represent the cluster, as seen in Figure 4.3. Within his "concerned with hope" cluster, he added his thoughts about how the center helped them, even if he didn't think it was all that effective. He talked about how COVID-19 made everything harder, but everyone was trying. Lastly, he added how the online therapies confused Cayden but how he liked talking to the providers, also. In this cluster of concepts, he seemed to be representing a "both-and" concept of his experience.

In his second cluster of concepts, Richard outlined the cluster with a circle using a turquoise marker, then he used an orange marker to draw a "confused" emoji representing the cluster. He used orange because it was one of Cayden's favorite colors. Richard thought all the concepts in this cluster represented his confusion throughout the experience. His confusion

primarily revolved around systemic causes like “lots of mixed messages” about COVID-19 restrictions and their purpose. Moreover, he was confused about the paperwork needed for the state insurance to begin the ABA therapies. Additionally, he was confused because once the system started to work really well with the in-home visits from the early intervention center, Cayden lost those services because he turned three.

In his third cluster of concepts, Richard used a black marker to circle the concepts and used a red “angry” face to represent his feelings about this cluster. In this cluster, Richard placed the concepts that related to his increased struggles due to COVID-19 restrictions, primarily the inability to participate in appointments with his wife because only one person was allowed in. He also talked about personal things like how difficult the pregnancy was in a COVID-19-restricted environment and how he lost his support from his Celebrate Recovery group. The other source of anger that Richard discussed at some length was how disappointed he was that Cayden’s first experience of being in a swing was not until he was over three years old because all the parks and recreation areas were closed because of COVID-19. He talked about the care for Cayden in terms of how much more difficult it was.

When asked how the clusters intersected or were related to one another, Richard drew arrows going from the “concerned” cluster to the “confused” cluster and back to represent how they were intertwined. Then he drew an arrow from the “confused” cluster to the “angry” cluster to represent how one led to the other in his experience. At the conclusion of the mapping exercise, Richard was asked to reflect on the map and spoke mostly about the confusing paperwork and how that has prevented them from getting the care he wants for Cayden.

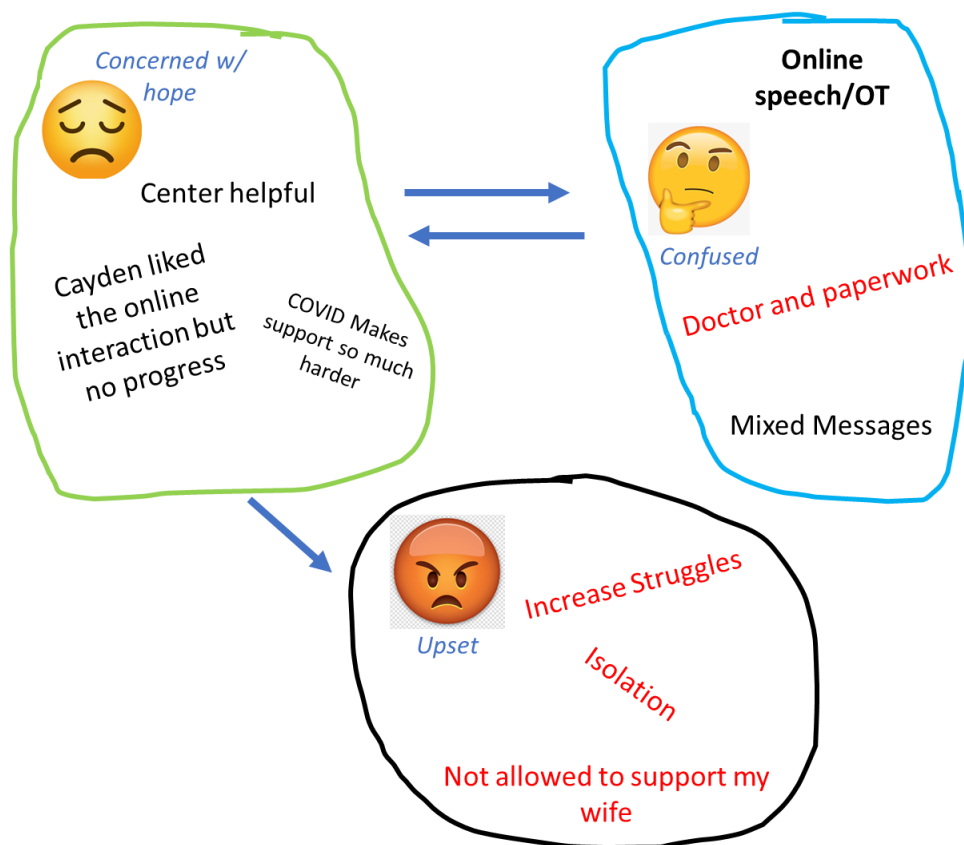


Figure 4.3 (Richard's Conceptual Map Representation)

Stacey

Stacey is a married woman aged between 35 and 40 years of age who lives with her husband and three children in a rural community in Western Washington. She works part-time, and her husband is active duty military; combined, they have a salary in excess of \$140,000.00. In her rural community, she has some resources for her children but does spend much time on the road driving her children to different events. Stacey is Caucasian, and in addition to working part-time, she was finishing her bachelor's degree during the researched time period. She received her degree during the pandemic and says she is in a better job now because of it.

During the COVID-19 restrictions, she was considered an essential worker, so she went to work four days a week.

At 13 years old, Kaleb is the middle child in their family. Kaleb was diagnosed with autism spectrum disorder when he was seven years old by a team in a local Military Hospital. They diagnosed him with a level 2 severity based on the DSM-5 scale; thus, he requires substantial support. Before the onset of the COVID-19 pandemic, Kaleb was ten years old and in 5th grade receiving outpatient occupational and ABA services.

Stacey was referred to this study from an occupational therapy clinic in the area. The interview was conducted at a local library in a room that could ensure confidentiality on November 28th, 2022. Stacey could understand the instructions and the conceptual mapping exercise quickly; however, she did require prompting and reflection to provide more detail to her experience. Stacey sometimes would have to stop to gather herself when she thought about the stress of the more difficult times during the pandemic. Stacey was most fearful about bringing COVID home and what would happen if Kaleb got the virus because of his extremely negative reaction to anything medical. Stacey was able to continue, but her pauses reminded her that she could benefit from addressing her fears and processing them. The interview lasted 1 hour and 26 minutes.

Textural Description

Stacey described the services and the way that she was coordinating care for Kaleb before the pandemic. She lives 30 to 40 minutes away from the services Kaleb needs, so there was much driving. He was receiving occupational therapy from an outpatient clinic two times a week and ABA therapy from another outpatient clinic three times a week. She added that sometimes

he would have to be at ABA until six o'clock at night, and she related how that was hard on the family. Stacey was working part-time and attending college full-time, as well as being a mom of three with an active-duty husband. The constant demands of the therapies were very hard on her. He attended a local elementary school with the general population, but on an IEP with a number of accommodations like pacing, extra breaks, wearing hats, fidgets, and teachers allowed to send him on an errand (break) if they see him escalating; he also had a resource room he could go to.

Stacey said that just before the pandemic, she was trying to get Kaleb into mental health counseling. She described it this way:

Right before the shutdown [Family Services] had a counselor and I'd gone in and done his intake with her ... then the shutdown happened and when they went back up, they were only doing virtual and they were only doing established clients and because she hadn't met him in person yet she didn't want to meet him over Zoom, so that got cancelled.

Stacey then related that everyone was shut down and not accepting clients that were not a threat to themselves, so they "just kind of stayed in limbo" regarding finding a mental health provider for Kaleb.

March of 2020 Through Fall of 2021. Stacey described her experience of the COVID-19 restrictions on Kaleb's professional support by emphasizing that "he doesn't do well with unscheduled changes." She thought it was fortunate that he was already receiving care from OT and ABA providers because their initial closure, while they were planning their support in the new environment, felt like breaks they had taken in the past. Stacey remembers that "OT previously over the summer because they can go stagnant, kind of, and so, they wanted to give

them a nice break, and they came back so they could track the impact.” Therefore, Stacey felt the initial closure by both the OT and ABA clinic which lasted about three months or so, was hard for Kaleb but not extremely hard. She said it was “just waiting for them to open back up again and show us how those services would be provided in the environment.”

The closing of his school Stacey remembers as more difficult:

That was hard. So, he ended elementary school with the pandemic and entered middle school, so we weren’t able to do a face-to-face meet with his [IEP] team. His evaluation was done virtually, which did not capture what we needed it to. That whole environment had a big impact on his IEP that we’re just now coming out of as he is leaving middle school.

The impact that Stacey is referring to is that because of the difficulty interacting with the IEP team from Kaleb’s school, he did not start speech and OT services in the school until 2022, a delay of almost two years.

Right at the beginning of the shutdown in April 2020 and during the governor’s stay-at-home order, Stacey’s family planned a vacation where both parents had time off from work (they were both essential workers). Instead of canceling it, Stacey remembers:

We just stayed home. We actually cut everybody off from electronics that week, including my husband and I, and we went like no screens for a week. We started family dinners, like actually sitting at the table, all of us together, and we still do that now ... I feel like it brought us together. Yeah, in a good way.

Stacey also said they shifted as a family, and she shifted her work schedule saying, “I work half as much, so there’s less work and more home.” These major shifts, Stacey recalls, helped them

adjust to the changes the pandemic caused, specifically the move from in-person school to online school for her children.

Stacey described her experience of switching to an online education this way:

School was hard, we were virtual. I guess the whole shift to virtual was hard.

They kind of were trying to figure out how to end that school year, but with the expectation that they were going back to school, which, as we all know, they never did come back until the next year, April [2021], and then only half days ... September 2021 was when they came back really.

She switched her work schedule from starting at 10 a.m. and going till 3 p.m. to starting at 6 a.m. and going until 10 a.m. so she could go home and be with Kaleb as he did his schoolwork. She would get home just after his Zoom calls and help him while she worked on her schoolwork too.

She remembers that he was thriving through the online medium and going from getting mostly B's to getting straight A's in his classes. However, she recalled, "it took a lot of one on one to get him through stuff ... to keep him focused. He likes to drift on his computer and go play games or watch YouTube and not stay focused on stuff." She thought there were two main reasons for his improvement in grades: first, the one-on-one attention, and second, the school didn't require as much. As Stacey puts it:

I think part of the excelling is that ... how does it ... the workload, the expectation of work to be completed, was less than it is now that they're in school ... they kind of like bare-boned everything.

Another thing that helped Kaleb with his at-home study that Stacey mentioned was that Kaleb was able to close the computer when he needed a break or switch rooms or roam around. She

recalls that type of freedom worked for Kaleb, but she is quick to note that it is not all that realistic in a school environment.

In terms of her experience with ABA and OT services starting back up in person, Stacey recalled that “It went pretty well. He was super excited to do so. OT was a little more of a challenge because they went down to only having one child in the clinic at a time.” In both ABA and OT, Kaleb moved back to in-person following the initial closure of the services for three months, albeit with less frequency. Stacey viewed the OT experience this way: it “ended up working great for him, he loved it, it was just him. He had the run of the place.”

When she recalled the transition back to in-person ABA, she related that “it was rough because they tried to keep six feet distance when they opened between kids and the provider if possible ... they would sometimes shut down for positive COVID-19 tests.” Stacey thought they shut down maybe four times from the Summer of 2020 to the Fall of 2021, and each time it was for a positive COVID-19 contact. Stacey said they would shut down for three days to do a deep clean because they wanted to make sure everyone stayed safe. For Stacey, this was a huge relief, “I loved it that she did that; it made me feel safe in sending him in there every day.”

While attending ABA and adhering to the safety protocols, there was one issue that caused some anxiety for Stacey -- Kaleb’s refusal to wear a mask during his time there. Stacey said that Kaleb “hated the mask, but eventually got used to it, but he [would say], you know, ‘I don’t like breathing my own breath.’ Not cool.” Stacey was not as worried about his mask-wearing in that environment because she said, “the providers kept six feet away ... [and] because of everything they were doing like I said, it felt like a safe spot, and they were very cautious.” However, she noted that “they couldn’t do it 100% of the time because people move and kids

with ASD, you can't always contain them." She said that Kaleb did not wear his mask until one day, his dad took him to ABA and told him he had to, "so then he started wearing it every time."

Stacey described her greatest source of anxiety and stress came from her worry that she was going to "bring it [COVID-19] home" because she worked in a large chain grocery store and had contact almost daily with the public. She recalled that:

I was an essential worker. So, the worry, you know, catching it from work and bringing [it] home and knowing that he does not do well in medical settings. He doesn't respond well. So, the worry of him getting it, and then reading all the articles of kids with ASD getting COVID and um ... just a huge detrimental impact that it can have ... and the terror ... yeah, yeah, if he did get it.

COVID-19 impacted Kaleb's extreme reaction to medical settings through his vaccination, mask-wearing, and COVID-19 testing. Stacey recalled the experience of getting the vaccine for Kaleb, "we went twice the first time. I don't think we even checked in before he turned around and left." To help him, Stacey said for the next time, "a doctor prescribed him a medication ... set up lots of good rewards ... and so that worked out well". Stacey said the second time they went to get a vaccine didn't go well at all:

He took his [the same prescribed] medicine, we went in, and the clinic was closed. Yeah, which we were upset about because they said come back on this day ... so we ended up doing it at Rite Aid ... and we got in the room, and he screamed and yelled and hollered and hid in the corner ... then his brother got his first one, and we're like, okay, see you can do it, and he ended up saying 'I'm not gonna be able to do this unless you hold me.' I said, okay, so here's what we're

gonna do, restrain him. Yeah, I said, you'll sit on my lap, I'll hold you really, really tight, and no matter how much you scream, we're gonna give you the shot. Are you okay with that? He said, 'yes, I need it. I want to make it happen, even if I say no, even if I yell and scream.'

Stacey said that he was able to get the vaccine this way, but there was much resisting and screaming, and when they walked out of the room, "there was a line of people waiting with their eyes huge due to his screaming, and she [med tech] goes, I promise, I promise I didn't hurt him." Kaleb's extreme reactions to the vaccine added to Stacey's worry over him getting COVID-19.

Stacey remembered a positive impact of the COVID-19 online education experience was that Kaleb's father got to see more of him and began understanding some of his behaviors. She said, "Dad was able to see more, so that was his dad has become a bigger advocate for him in school ... he was there at the last two IEP meetings, advocating for him". She recalls this change "made it less stressful, yeah, having an ally."

Fall of 2021 Through December 2022. Starting in the fall of 2021, Kaleb was in his second year of middle school, and he was beginning full-time in-person school with restrictions. He was required to wear a mask at first and get tested and quarantine if he had contact with a COVID-19-positive person. His OT and ABA were still being conducted through outpatient clinics that Stacey drove him to most days a week, although less than before the pandemic and she remembers that took some pressure off her.

Stacey recalled frustration at the school IEP process that "looked over" Kaleb's need for OT, and because of this oversight, Kaleb did not receive in-person OT from the school until the end of the 2021-2022 school year. She remembers that oversight as a direct result of having to

do the IEPs over zoom. She recalled that after a referral from Kaleb's primary care doctor, he began speech therapy through the school and had that as a pull-out but through telehealth; and in the fall of 2021, he started receiving these services in person. Stacey said that his speech therapy was for communication and social cues with facial expressions. She talks about how it has been better for him in person because now "he's able to make a connection and a relationship with her easier," and she said that she can see his improvement now because "he seems to be making friends now; it's getting him invited to go places."

As for mental health services for Kaleb during this time, Stacey said that in the fall of 2022 they were finally able to get mental health services for Kaleb through the ABA clinic that he goes to. When she recalls the sessions with the counselor she said, "I think he did a couple of weekly sessions and then we flipped to every other week, then we took a break because he was in track ... he's going back but he says that he feels obligated to be there." She said they stopped going, but maybe they will try again with another therapist in the winter.

A difficulty that Stacey addressed during this time was how Kaleb did not want to test for COVID-19 if he was in contact with someone who tested positive. This meant he had to stay quarantined from school for ten days instead of three if he had a negative test. Stacey would say to him, "You can stay home, or you can test and come back in three days, and he was like, I'm not getting a test. They're not gonna touch my brain with that." She tried to reassure him that they would not touch his brain with the test, but she said he remained unconvinced.

In addition to the negative impacts that COVID-19 restrictions placed on the care from professionals for Kaleb, Stacey notes that:

I think it was a positive because our schedule was so busy with all his services. It [COVID-19 restrictions] gave us a chance to not have anything planned and for him to really connect with his siblings again. Instead of, you know, school and then ABA, OT, and ABA, you know, all the busy, busy days in the schedule, so it gave us a nice, forced break from everything.

When asked what advice she would give herself now if she had to do it over again, Stacey responded, “Yeah, what I would tell myself, that, that, he is going to be safe with those providers. You’re right ... and that he is going to gain services that can be very impactful in the end.”

Structural Description

Stacey seemed to take all of the interactions with the school professional providers, the providers of OT, speech therapy, and ABA, with a sense of calm and understanding with their many changes. There were two structural influences that she had much greater difficulty with. The first was the school’s IEP assessment meetings held during COVID-19, and the second was Kaleb’s interactions with the medical system.

Stacey remembers the first IEP in 2020 that was for Kaleb’s first year in middle school, and she was very concerned about getting it right because there were already so many changes with leaving elementary school and entering middle school. Moreover, those stressors for Stacey were compounded by the “not knowing” that COVID-19 interjected. Stacey said that she had to fight for OT services for Kaleb in the first IEP meeting with the middle school in the summer of 2020 and that she was told by the OT doing the assessment that he could not provide services until he assessed Kaleb. Stacey recalled at the second meeting in 2021:

The [OT] came to the second one and said, Oh yeah, I'm gonna go check out Kaleb and see what I think he can do to help, and I was like, wait, you said you were gonna do that at the last meeting ... it just so happened that the SPED (supervisor for special education) was actually in the IEP meeting as well for the district, and he came off of mute and apologized.

Stacey's interaction prompted the school system to provide OT services for Kaleb both in the late spring of 2021 and again starting the 2021-2022 school year, but the net effect was that Kaleb lost a year of OT that Stacey said he was authorized for.

As described above, Kaleb's interaction with the medical system, or in Stacey's experience, just the thought of him getting COVID-19 produced a great amount of stress on her. When she talked about this stress her emotions were heightened, she had a catch in her voice, and she would have to pause to gather herself to move on. At the end of the interview, when she reflected on her conceptual map and looked back at all that had happened, she had an emotional response. When asked about it, she haltingly said, "I guess it kind of ... I almost want to say, it kind of, it feels like I'm back there."

Stacey said that she hadn't sought any care for herself, but she added:

I know I need to do that, but I've been trying to just keep, I guess everybody running ... I need to find somebody just to talk through all of that ... just to process ... but I've been wanting to make sure that the kids are okay.

The thought that Kaleb might get COVID-19 and must interact with the medical system was so impactful for Stacey that she said that she ordered many of her activities and work schedule to avoid that possibility in any way that she could.

Stacey also wanted to emphasize that she “feels like we lessen the busyness because of this [COVID-19 changes] outcome ... I was more intentional about the times that I picked [for professional services] and how often I let him go.” Stacey believed that this empowered her to have more time with his family and still get the benefit of the services.

Conceptual Mapping Exercise

As Stacey began to organize her concepts into clusters to represent her experience of accessing and receiving professional support for Kaleb during the COVID-19 pandemic (Figure 4.4), she initially organized them into a timeline. However, this was only a loose association as she continued building her conceptual map. The initial cluster that she created on the top left of the poster represented the initial closing down events, then she had another cluster that was associated with that by representing the stress and difficulties of those first months when there was no professional support available for Kaleb.

Stacey drew another small concept cluster on the far right top that represented Kaleb’s move back into OT and ABA in person at the outpatient clinics, and she labeled it “Good.” Directly under these top clusters and linked to one another were two clusters, one representing her experience of the ABA and OT services and how she felt safe with them. The other cluster represented her experience of online school for Kaleb and the services provided by the school in 2020 and 2021.

In a cluster below those, she drew a line to them, which seemed to represent the difficulties with vaccines and finding mental health counselors for him, and she outlined it in yellow because it was in the summer. None of the other colors were meant to give meaning to the clusters, except the brown box she drew around Kaleb’s initial counseling. When asked what

the brown color represented, she replied, “I’m not going to make a comment about the brown color.”

She had one concept in the center that all the others were linked to that simply said, “schedule changes hard,” which seemed to imply Kaleb does not do well with change, and it impacted everything else. Her last cluster represented positive things that happened in 2022 and throughout the experience, like “OT at school in 2021-2022,” “Switch to live in 2022,” and “dad’s change made less stressful.”

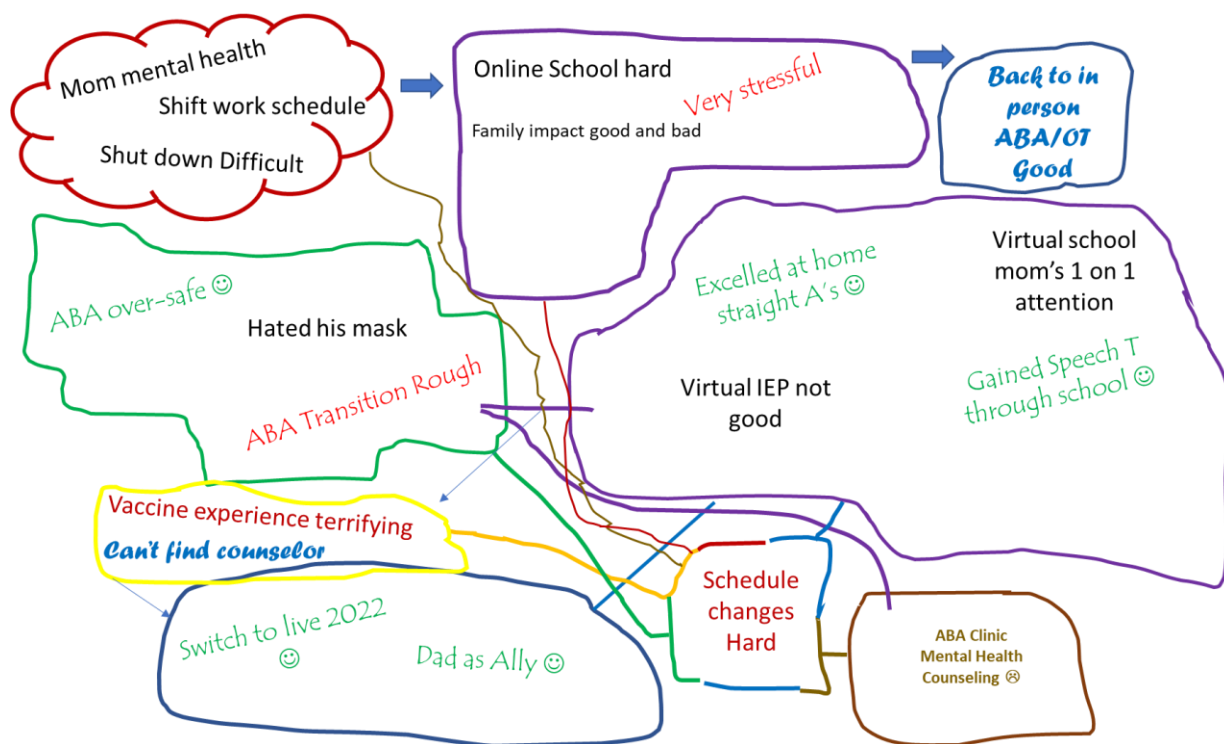


Figure 4.4 (Stacey’s Conceptual Map Representation)

Caitlin.

Caitlin first learned about the research project when the early intervention center for children with developmental needs reached out to her and informed her of the research. Caitlin

is a 35–40-year-old mother of three children who works as an in-home caregiver to her mother through a program supporting in-home elder care. Caitlin’s husband is on disability and looks after their two sons, who are still in the home. She is Caucasian and Native American and lives in a suburban setting in Western Washington with a combined income of around \$70,000.00.

Caitlin disclosed that she has Asperger’s (ASD), PTSD, anxiety, and depression and, as a child, was diagnosed with ADHD before it was re-diagnosed as autism. Although completely independent and able to function in most areas, Caitlin’s husband is diagnosed with a learning disability. Caitlin’s second son, Connor, who is now four years old, was initially diagnosed with autism in 2019 and then again in 2021 to meet her insurance requirements. Connor’s ASD diagnosis severity is level 2, requiring substantial support. It is not unusual for ASD to be transgenerational, and as such, Caitlin’s sister has a daughter diagnosed with ASD, level 3, and her brother has a son diagnosed with ASD, level 3. Caitlin also expressed concerns that her youngest son is showing signs of ASD, and she plans to have him assessed.

The interview was conducted in a mental health private practices office setting on December 28, 2022 and lasted 1 hour and 52 minutes. Caitlin stated parking was difficult for her, so the location had to be adjusted to accommodate this. Although Caitlin referred to her ASD often and its effect on her scattered thoughts, she had little difficulty in answering the open-ended questions in the interview. Caitlin easily grasped the conceptual mapping task while organizing her concepts in two clusters and labeling them. She seemed nervous about saying the “right” things and appeared eager to tell her story while staying engaged throughout the whole interview.

Textural Description.

Before the COVID-19 pandemic, Caitlin was learning to care for Connor, who had ASD, while also struggling with a difficult pregnancy where she remembers her “ hormones shot through the roof.” Due to Caitlin’s exceptional needs, she was provided a nurse to assist with her pregnancy and to assist with Connor’s developmental needs when he was one year old. She said that the nurse would come into the home weekly. Caitlin described her support this way:

She was doing all those beginning evaluations like every six months, she was doing an eval on Connor, and it was just super helpful having her there. I was a lot less stressed because I didn’t have anything to worry about [because] she was able to like see everything right there [with Connor], and I was able to focus on what I really needed to focus on, that was learning what I could do for my son ... she’s the one that helped me initially understand how to get set up with the [early intervention center].

She coordinated with the early intervention center for children with developmental disorders and Connor was evaluated by this center and found in need of speech therapy and occupational therapy. During the time before COVID-19, Caitlin remembered that “he like trained us in the beginning, before even we got set up with the [early intervention center], he would try to find ways to communicate what he wanted.” Caitlin described her son as “excelling in a wide variety of areas, but there were definitely difficulties in receptive communication.” Connor did not receive services other than the nurse assistant visits and evaluations before the COVID-19 outbreak.

March 2020 Through Fall 2021. Caitlin described her experience of accessing and receiving care from professional providers during this time as one of frustration, stress, and loss. Caitlin described her biggest loss as they moved from the nurse in-home visits to online. She

remembered that Connor “first started reacting to the fact that the nurse wasn’t coming in person to see him; that was our very first experience of Connor really showing signs.” Caitlin describes Connor as very social, and he would look forward to the nurse’s visits.

Caitlin also described a sense of loss for her because the nurse partnership also provided her with a kind of mental health support and said, “It’s just very difficult when my support that have kept me stable for so long just ended up changing so much; it was scary, it was very difficult, it was traumatizing.” Caitlin also received mental health support for herself, but when COVID-19 restrictions were in place, the sessions were changed to an online platform:

I had to switch to just being on the phone to talk about my wellbeing, that was a huge difference, and not as helpful at all. Many times, she was trying to do FaceTime, I, my phone would end up going nutty or crashing, turning off and I’m a techy person ... so it was just not the greatest experience to be able to get that help that I’m majorly dependent on especially after things finished with my nurse partnership.

Caitlin said she “had a lot more anxiety and some depression, I ended up getting put on medication for it, and I had not needed that for quite a few years.” She remembers being in a constant state of worry over the care her son was getting.

Caitlin recalled that Connor received speech therapy for receptive communication and occupational therapy from the early intervention center once a week through an online platform for the first year or so of the pandemic. When she describes her experience with this online therapy, she said:

So there were a lot of breakdowns, mental breakdowns, and stuff; I was going through a lot of problems with Connor being able to be involved and pay attention. He treated it like [the therapist] was a YouTube. There wasn't a lot of that interaction, personally, that he was used to from us at home, and that was really needed for him, so it just stressed us out. I just got really nervous and frustrated all the time about that, and I just kept asking, when can we do this in person? Because I was always concerned he wasn't showing enough.

One of Caitlin's difficulties with the online experience was her anxiety over setting the Zoom call up correctly on her end so that the therapist on the other end could really get a sense of what was going on with Connor. She describes it this way:

Yeah, so definitely, I had some mental breakdowns; I call them episodes, my autistic part. Because I had to like follow around with the camera, and it was hard for me to do like two things at one time. I was trying to make sure they can see him, but I don't have all the right stuff. I tried to use my iPad, my camera, my iPhone, you know, so I was like a nervous wreck every time we were having to meet ... and like when they tried to communicate to him, there was nothing really that, you know, it just was so different to him than what he was used to, with how we were interacting.

Caitlin describes a major difference for her in her and Connor's in-person experience with the nurse partnership and her negative online experience with the center this way: "I mean, that's why I got to see the difference with Connor between my nurse partnership gal and then what didn't get to happen with the center."

During Connor's speech and OT sessions, they identified the need for ABA therapy. As Caitlin attempted to set up this service, she discovered that she did not have the correct diagnostic paperwork from the doctor who diagnosed her son. This meant that Caitlin could not access these services under Molina Health Care. Caitlin remembers how helpful the center was in trying to fix this problem and how they worked with her to try to provide ABA services as a part of Connor's other professional caregiver's time. However, it was not until later in 2021 that Connor would receive ABA therapy, even though the paperwork was not completed.

Caitlin recalls some anxiety unique to her situation regarding ABA: "I didn't want it to get worse because my sister and my brother didn't have their kids in ABA, and I wanted him to be in ABA." Caitlin stated that it was toward the end of 2021 when they were able to fully engage with Connor in ABA therapies. Until that time, they were seeing him over Zoom and she stated, they "couldn't proceed past that surface part ... but they [the center] tried everything, I know they did".

Caitlin describes how both she and Connor are impacted by change when she discussed how therapists would either "change jobs or something". She said,

It takes a long time just for me to get used to someone, especially on a personal level ... when things are not consistent, and it's like the whole house gets affected emotionally, mentally, psychologically because I also have my mom that lives with us and I care give for her.

By the fall of 2021, things started opening in the state of Washington, and Caitlin could begin in-person services for Connor. Unfortunately, this represented another change that Caitlin would have to adjust to.

Fall of 2021 Through December 2022. Caitlin recalled being able to go back to the early intervention center for ABA, speech therapy, and occupational therapy when “the shutdown started finalizing and closing, and we were getting back into the flow of being able to go out.” She said that the ABA therapists wanted Connor to come in for his therapy four times a week, but Caitlin told them that they could only bring him for three visits. She said, “they wanted four, but it was really hard. Yeah, it was just really hard to transport him.” Caitlin explained that it was hard because she had difficulty driving, and the center was 30 minutes away, so she was only able to drive him there three times a week, along with his appointments for speech and OT.

Although Caitlin really wanted in-person appointments for Connor, this experience was not without its own difficulties. Caitlin recalls the COVID-19 pandemic restrictions on in-person visits this way:

So, they’re either the people that couldn’t see him because they tested positive ... or Connor ... if he had the sniffles, cough, all the regular things outside of any COVID related, we couldn’t go, you know, go into have him treated, just, I mean, like a slight cough. You know it was a big deal, and I was trying to understand about it all.

Caitlin also had difficulty with wearing masks due to what she describes as a claustrophobic condition; she said: “So with my condition, I have some claustrophobia, but I wear the mask, I am obedient to that when I need to, but I did not want to have to do any of that.”

In the spring of 2022, Connor began preschool in a special education preschool where he has an IEP that provides speech and occupational therapy services and preschool activities four

days a week. Caitlin is happy for this service because Connor gets socialization through this process. She described how she feels about it this way:

I feel really good about him, and I mean, he's super excited to, like, jumping up and down, can't wait to get on that school bus, and we hear from his teacher that he is doing really good with the progress that he's making, and you know, it's because he's in that environment.

Caitlin pointed out, however, that Connor is no longer receiving ABA therapy because the diagnostic paperwork that Molina requires is still not complete. The ABA therapies are not offered in the preschool that Connor attends. Caitlin said that she has now been assigned an advocate to help her figure out all the paperwork she has to prepare to have the services authorized.

Caitlin has many regrets about the whole experience as she recalls how COVID-19 impacted access and receiving professional care for Connor: "My son really, really did not get everything, and so that's what we're paying for now. In the long run with him, he is still behind with speech, he has about ten words". Moreover, she feels "just there's been so much that's been missed and care that he has not got."

Structural Description

Caitlin and her family have a unique situation, with the prevalence of ASD, pregnancy, learning disabilities, and the need to care for an elderly mother while trying to access and receive care for her son's ASD symptoms. Of all her challenges, Caitlin expressed that her biggest challenge with accessing and receiving care was her interaction with the medical system.

Specifically, the changes in care at her local medical care facility and the problems with the paperwork for her son's care.

Caitlin described an interaction with the hospital that was so troubling for her because she could not bring her son with her while she was breastfeeding that she told herself she would not go to the hospital for any reason after that. She said, "So I had that experience and told myself, I'm only going to the hospital if I almost like can't breathe or really, really badly and in pain." Unfortunately, she remembers how that caused severe complications, and a lot of her care went unmanaged. This was also a problem for the family when she was trying to care for her mother.

Caitlin describes the difficulty she has had with the limit of only one person allowed during visit. She described the situation this way:

I can go into stores [with difficulty], most of the times, like I said, I have to have my husband with me, I feel better and calmer having him, and like I mentioned, like, none of that was possible when we were going to doctors, clinics, hospitals, and I was so so bad ... it was just awful. My mom has a cognitive disorder ... memory loss ... chronic anxiety and depression ... a lot of times they wouldn't let me go back into urgent care with her because of the restrictions ... and she is very dependent on me to verbalize things ... because of the cognitive, she doesn't always interpret the way she used to.

She says it has gotten better where she can go in with her mom now, in late 2022, but there are still places that will not allow it.

The other challenge for Caitlin is her frustration with the required documents from the medical provider for her insurance to authorize her to access services for her son. This structural

impact, as Caitlin describes it, affects some of Connor's care and not others. For instance, Connor can receive special education, speech, and OT, but not ABA. Caitlin believes the reason for not receiving ABA is only that the form that the doctor completed for those services directly following the diagnosis was lost by the medical provider. They have not been able to find or recreate this form because the doctor has since left the group practice.

Caitlin also acknowledged that COVID-19 and the restrictions impacted everyone. She said of the center that was helping her before Connor went to preschool,

I really experienced a wonderful team of people that were trying to do everything they could. They totally understood [and] they were fighting for me and Connor to be able to get everything we needed and even allowed me to reach out to them there [now]. They were upset too ... I, just, I never was upset with them.

Caitlin recalled her frustration with the system and how it was impacting Connor, but she also showed a deep appreciation for the professional providers giving the care.

Conceptual Mapping Exercise

Caitlin clustered her concepts roughly in the temporal way they happened while grouping them into things that were hard for her. These hardships that represented themes for clusters were the "online therapies and their impact on Connor," the "changes to her normal supports and the impact on the family," and lastly, her "own experience with the medical system." She ended her conceptual map with a heart to represent things improving in 2022 but added a "never-ending" cluster of circles to represent the "crazy cycle" and still needing to get the authorization for ABA.

In describing her conceptual map, Caitlin said, “this is all pertaining to what I noticed with Connor and what things affected him throughout the course of the COVID shutdown, and the other is all related to how it affected us as a family and household.” When she was describing her online therapies and their impact on Connor, Caitlin said

I did this like a river because, like it, it felt really good to have [the early intervention center]. I mean, I really experienced a wonderful team of people ... trying to figure out how to make it safest for people. I understand that level from, you know, understanding that from a medical point of view.

When Caitlin was describing the column representing her own experience with the medical system, she outlined it in black and said that it was “the beginning of all the fear, yeah, I should, I was going to do red, but black is just to indicate how dark and scary I mean just to get that feeling how scary it was.”

When she described the cluster representing the impacts on Connor, she said she drew a foot around it in an orange color to represent Connor’s individuality. Caitlin expressed it this way:

In the midst of all this going on, he was, you know, he was still trying to be him. But I could see how confused he was at times how; I mean, it’s hard not to go into tears when I think about how alone he must have felt inside.

This had special meaning for Caitlin because she could remember her own feelings of being alone when she was growing up due to her autism.

When describing how the family was affected, Caitlin drew a brown object around the cluster, saying that brown for her is “like a valley or like you’re in between.” Caitlin referred to it

as a road where “immediately we had all these extra family difficulties and stuff happening and everybody being affected by everybody.” Caitlin finished by discussing why she put a heart around the 2022 preschool cluster. She believed that the “whole outlet has helped me.”

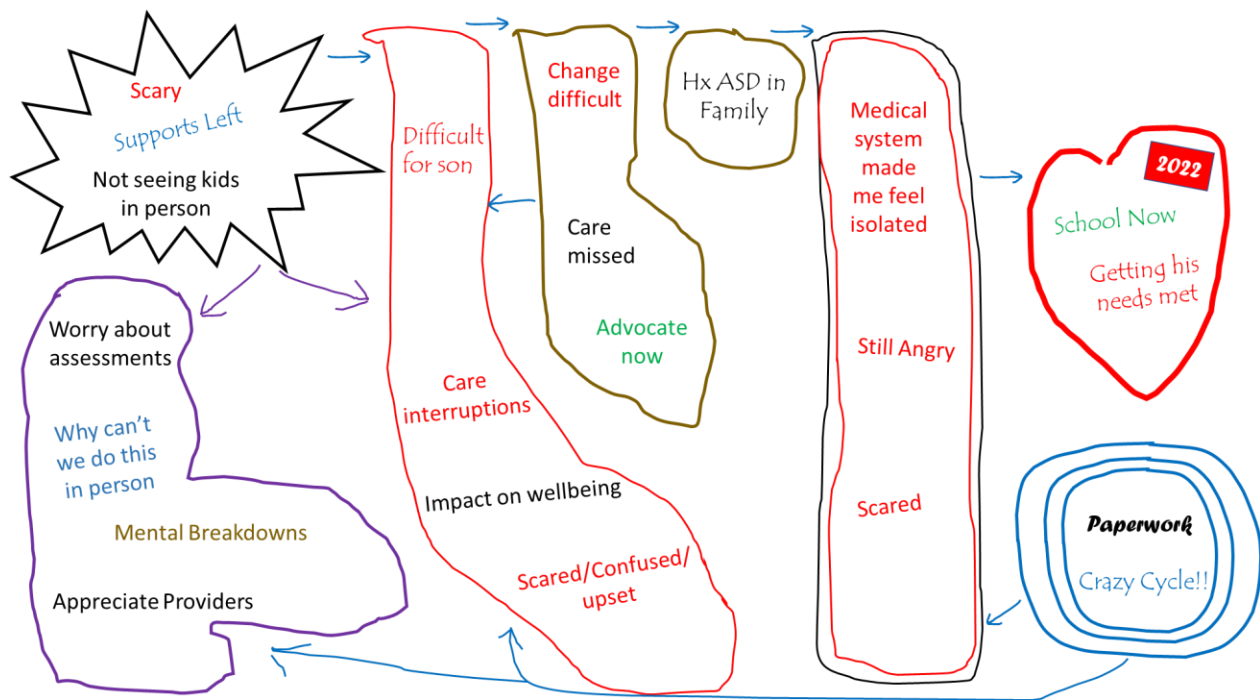


Figure 4.5 (Caitlin's Conceptual Map Representation)

Results

In analyzing the results from the participant interviews, the text was captured using Otter.ai, advanced transcription software, and then checked and re-written by the researcher, where conflicts occurred. The pictorial representations of the participant conceptual maps are found in Appendix K, and visual summaries of each participant's conceptual map were added to the participant description above and used in the development of themes (Figures 4.1 - 4.5). Researcher memoing was added to the Atlas.ti qualitative data analysis software to record the

researcher's thoughts and experiences during the interviews, data analysis, and participant confirmation discussions. The research validity and trustworthiness were significantly increased by utilizing multiple data collection methods such as interviews, drawings, memoing, and participant confirmation (Creswell & Poth, 2018; Heppner et al., 2016; Moustakas, 1994).

This technique naturally flows from the research process described by Moustakas (1994) in the phenomenological reduction step, where the participant looks at the experience, describes it, looks again, and describes it again (Moustakas, 1994). In this process, the researcher explored the systematic varying of the potential structural meanings that underlie textural meanings using both researcher rigorous analysis and Atlas.ti qualitative software to determine themes. The researcher read and re-read each transcript numerous times, and during this process, initial themes emerged. After recognizing foundational themes that accounted for the phenomenon, the researcher used the analysis of concepts from the qualitative software and synthesized them into key concepts that related directly to the research questions. These concept words are directly related to statements by participants and are represented in a "concept cloud" produced by Atlas.ti, shown in Figure 4.6.



Figure 4.6 ATLAS.ti Concept Cloud

The “cloud” is a pictorial description of the number of statements associated with each concept. The larger the word, the more often the word or concept was used by the participant. The numerical representation of this “cloud” is presented in Figure 4.7.








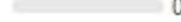






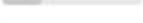
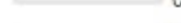


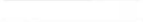























Name	Grounded	Density
○ ◆ ABA	 34	 0
○ ◆ care	 9	 0
○ ◆ change	 13	 0
○ ◆ COVID	 27	 0
○ ◆ dad	 11	 0
○ ◆ doctor	 15	 0
○ ◆ family	 16	 0
○ ◆ health	 14	 0
○ ◆ Holly Ridge	 1	 0
○ ◆ home	 32	 0
○ ◆ husband	 12	 0
○ ◆ impact	 11	 0
○ ◆ OT	 19	 0
○ ◆ person	 32	 0
○ ◆ provider	 14	 0
○ ◆ school	 49	 0
○ ◆ speech	 21	 0
○ ◆ stress	 12	 0
○ ◆ support	 20	 0
○ ◆ therapist	 15	 0
○ ◆ therapy	 23	 0

Figure 4.7 Numerical of Code Representation

During the analysis, the researcher identified participant key imagery, either visual or exemplary text that vividly illustrated the participant's description of the phenomenon (Moustakas, 1994). In describing and classifying the codes generated by ATLAS.ti, the researcher decided on the most appropriate themes to synthesize text and conceptual data collected from the interviews into experiences central to the phenomenon. Many of the participants organized their reflections on their experience in a time-ordered manner, from the start of COVID-19 through what they felt as relief from it. However, it is important to note that some participants are still working through the impacts COVID-19 has had on their ability to access and receive care for their child with ASD.

Theme Development

The researcher formulated the above concepts and meanings and clustered them into common themes and aided by the qualitative software. The themes and subthemes representing the data from participant experience in accessing and receiving professional care for their child with ASD during the COVID-19 pandemic in Washington State were: 1) Online delivery of professional supports led to increased isolation, increased parental demand, and decrease in efficacy, 2) parental and systemic family stress, 3) loss of momentum/developmental progress, 4) difficulty in accessing professional support, 5) relief of returning to in-person school, and 6) fathers increased involvement.

The statements associated with each code were selectively chosen by the researcher and paired with each theme. Table 4.2 represents the number and type of statements selected by the researcher and aided by qualitative software associated with each theme from the participant portion of the interview transcripts.

<i>Statement Count to Theme Association</i>		
	# of Statements from Concept Codes	
Theme	Negative	Positive
Increase in isolation, parental demand, and decrease in efficacy from online delivery of professional supports	50	4
Parental and Systemic Family Stress	32	0
Lost Momentum/Developmental Progress	25	1
Difficulty in Accessing Professional Support	34	0
Return to in person schooling a relief	0	12
Fathers increased involvement	3	10

Table 4.2

In this table, the statements that were selected for each theme are separated by the theme described as having a negative impact on the participant or a positive impact. Therefore, there are positive statements about a father's increased involvement and a few negative ones.

Moreover, there are many more negative impacts of online delivery of professional support than positive impacts. Except for the father's increased involvement theme, where one participant had no contact with the father, all themes were present with each participant and reoccurring.

Theme 1: Online Delivery of Professional Supports

The theme of online delivery of professional support was prominent in each participant's experience. This theme was further divided into three subthemes to better represent the participants' experiences. The first subtheme is one of the participants feeling isolated from the lack of in-person contact with providers either in their homes or at a center. The second subtheme was an experience of increased demand for the parent through the online application of

professional support. The final subtheme was the participant's experience of a lack of efficacy of online professional support compared to their in-person experience.

Subtheme: Feeling of Isolation. Participants felt isolated during the COVID-19 pandemic due to the closing of schools and parks and worrying about contracting the virus. Participants who could receive in-person therapy early on reported less isolation in their experience than those who only received support from an online platform. Mandy reflected on her experience of isolation:

... the therapist was once a week for an hour. I was thankful for that, because we could actually go and see people, you know, because it was just us three in the house by ourselves. We didn't interact with our neighbors; we followed the protocols. And we didn't we don't have any family here or anything we, we really did stay, that we really isolated. Because my husband worked at the, at the grocery and I didn't want to be a super spreader.

Ashley describes her experience of this also:

... because we all just kind of kept ourselves during that time, you know. We really didn't know what was happening with that virus. So, we all just kept separate. Which is actually very isolating for a two-year-old. Social skills picture could have been much improved if he had it. Visitors and stuff like that. I think that his being in school right now. It's definitely impacted better. Yeah, versus him being home with me all the time Okay. Social interaction, it's always good for kids. They have to have that.

Caitlin described this feeling of being isolated and alone while creating her concept map and discussing it.

So, I could represent that there, there was like ... I just know in I did feel alone, and I felt like ... I was boxed in, so I chose a box for that on the outside it had everything to do with the new traumas that had taken place, being scared because now I, you know, I ... I did not get that new person support till this past month or so. So, I was I was doing a lot of that navigating by myself.

In the above descriptions, the participants describe the experience of not having in-person contact with providers as isolating. The COVID-19 pandemic led some to self-isolate because of the fear of an extreme reaction from their child with ASD if they were to get COVID-19. Stacey recounts this fear by explaining how her son reacts to the medical system giving an example of when he was administered the COVID-19 vaccine.

And we got in the room, and he screamed and yelled and hollered and hid in the corner... But that's typically how he responds in medical situations, which is why if he got it, it was going to be worrisome. So, the worry, you know, catching it from work. And bringing home and knowing that he does not do well in medical settings. He doesn't respond well. So, the worry of him getting it ...

Subtheme: Increased Burden on Parents. Online delivery of professional support for children with ASD required the participants to arrange their lives around supporting the online activities. That presented itself in changing their work schedules, quitting work, rearranging their house, or just trying to learn the various skills taught to them and their children online. The participants describe their experiences this way.

Richard said:

They basically would talk to him about, or talk to [my wife] about his different learning abilities, they first diagnosed what he needed, and then they would go

over, you know, how can I help him, best deal with, you know, his shortcomings. But again, it was hard to work with that and try to express to them what he needs and have them express to us and just ... I felt it was harder experience to do with ... it being remote.

Caitlin expressed the additional burden:

I had to like, follow around with the camera and it was hard for me to do like two things at one time. I was trying to make sure they can see him, but I don't have all the right stuff. I tried to use my iPad, my camera, my iPhone, you know, so I was like a nervous wreck every time we were having to meet ...

Mandy describes her experience of online additional burdens too:

Because then I'm in all of these different roles that I didn't sign up for either. I knew that I knew I couldn't homeschool her. I never wanted to homeschool her because that our relationship isn't like that. Like some parents are really effective. And I am not effective at getting her to do it. I want, I mean, it's just not a place that, I'm disorganized ... I just appreciate the teachers and what they do, they can get so much done out of it. I didn't go to school for that.

Stacey recalls having to shift her work schedule to be home for Kaleb when he was doing online schooling because he needed the extra help to keep him engaged.

Okay, and so it's just that I shifted my work schedule. And I worked 6am to 10am Yeah, on. I think I only work two or three days a week. So, I was, would be back home to help them Just after he got out of his first Zoom calls.

Ashley, with her younger son described her experience of online parental burden:

Um, well Yeah, I mean, trying to get a two year old to stare at the computer for an hour and a half or so ... It's not that easy. So, a lot of times it was me and them, you know, when it's supposed to be about him. It's pretty stressful. Just in person is much better for somebody like that.

Subtheme: Decrease in Efficacy Using Online Platforms. All the participants discussed a decrease in efficacy using online support. However, the degree to which they felt the decrease depended primarily on the age of the child with ASD and somewhat on the method used.

Mandy described this phenomenon:

... cuz my daughter would just have it up and she can't, she has ADHD as well. She would sit in front of the camera for about, I don't know, 10 minutes, and then run off. And then you know, I would come up [to and it] doesn't give the daughter, my daughter, a lot of privacy either, right? Because when you have a mental health therapist, they're in this session where they get to play that in Zoom land you, you're in the family kitchen, with the that's where we had it.

Then she describes a time where it worked for her daughter:

So, speech therapy. We worked on the skill of getting directions without becoming frustrated. Okay. And they did that through drawing she likes to draw, so that was pretty effective over Zoom.

Ashley described the reduced efficacy also:

Let's see, speech therapy feeding therapy, OT and ABA therapy through the computer, and he's two at this time so for him to want to pay attention to computer screen ... Really didn't work that great. Yeah. I feel like that he would

have benefited a lot more in person for sure ... I had ABA for him online. Yeah. But its not ... like I said it's like trying to get a two-year-old to focus on a computer screen ... He just wanted to push all of the keys and do other stuff.

Caitlin described her experience with her younger son attempting to receive professional support through an online platform like this:

So, the majority, I would say about 80% of our time with them ended up being through Zoom and so there was a lot of breakdowns, mental breakdowns and stuff, I was going through a lot of problems with Connor being able to be involved and pay attention, he treated it like he was a You Tube. So, there wasn't a lot of that interaction, personally that he was used to from us at home. And that was really needed for him.

When Stacey talked about her older son, she described an experience where her son seemed happier at home and more focused with the one-on-one attention that his mother was able to give him. She described him as also being able to avoid people at school and rules that he did not like. She said:

He excelled at home. Yeah, he went from B's to straight A's which I was extremely shocked by.... he still didn't like writing but ... He was at home. So basically, whatever he needed to get work done. That meant on the couch, laying in his bed, laying on the floor, [or] sitting at my desk versus the dining room table. Kind of, he had that freedom to just move around and go wherever he wanted.

But she did add:

I think part of this part of the excelling is that..... how does it..... the workload, the expectation of work to be completed, was less than it is now that they're in school.

Theme 2: Parental and Systemic Family Stress

An increase in stress that the difficulty of accessing and receiving care for their children with ASD during COVID-19 the participants experienced was another important theme. Some of the participants were seeing mental health therapists or experienced limitations from existing disabilities themselves. In recalling their experience, these challenges were also discussed by the participants. All the participants described increased stress both in the family and individually.

Stacey describes the increase in stress this way:

That shift from the COVID ... starting in that first couple of weeks into ... the next few months ... where we had ... like the impact and lengthening of the stress and shifting everything and the school staying virtual ... and then we transition back from those few months kind of to the schedule. Starting back up again. Staying busy.

She also described her stress in terms of needing mental health support for herself for the difficulty over the last two years:

I still haven't sought care for me, someone to talk to. So, I know I need to do that. But I've been trying to just keep I guess everybody running. Now I know. I'm, in fact I was just talking to my stepmom this weekend. I was like yep; I need find somebody just to talk through all of that. And everything that happened.... just to process. If you don't sit and process through it, then it's just gonna sit here so I

guess I still have to do that. But I've been wanting to make sure that the kids are okay. Before could now and everything seemed to settle.

Mandy and her family describe their increase of stress resulting from COVID-19 restrictions that moved all their daughters' professional services to online and at home:

We didn't get the supports that we needed, we had to provide them at home, we were not prepared. No one was prepared. And there was a lot of stress due to change transitions, and roles and learning new skills all of us all at the same time. Like, you know, when someone goes to therapy, that one person, they, they change and evolve. And you know, the family learns to change and evolve around them. But we all had to learn to do things at the same time. And it was not pretty there was yelling, and you're not doing this and you're not doing that and pull your weight and why. Why, Why aren't you doing your work child? You know, just do it. We just, yeah, just a lot of harsh words, and not a lot of kind words in the beginning ... There's a high stress, [my husband] said 'I cannot do this anymore'. I was stressed out. Then. I got fired ... Yeah. That's when, I went, I, it went down. Yeah ... In the beginning, there was just so much stress was so many different things occurring at the same time for the family that it just seemed unlivable.

Richard remembers the struggle of trying to help his wife in situations where only one person could go to appointments with their son, while also dealing with both his disabilities and his wife's.

So, it was more stressful for her because she would have to go into the appointment and do different things and then come back and try to explain to me

what they explained to her. And it was hard for her to do that. And so, it impacted her and therefore affected me, because I tend to be a little empathic in the fact that I can feel other people's stress. You know, I'm in a room full of really stressed-out people. It can be hard for me, because I can feel it, everybody's stress.

Caitlin's experience was different because, at the beginning of the pandemic, she had a nurse who would come to the home and could see all that was happening with Connor. So much of Caitlin's stress stemmed from trying to demonstrate what the nurse and she were seeing with Connor in person previously to a new provider over an online platform.

I remember in the beginning, there was a lot of difficulty getting it in person. There's a lot of frustration about that ... because I was always concerned, he wasn't showing enough, where he needed help, things like that they did walk us through in, like, setting up toys, you know, the everyday, they ADLs and things like that, that we can show them a lot, a lot of times I was I was like setting things up in a way for them to see where his challenges were, because I was just so scared. We weren't going to get any help for him in those areas.

Caitlin also talked about how the stress was impacting her own mental health:

Yeah, so the wellbeing ... starting with me, I had a lot more of anxiety and some depression, I ended up getting put on medication for it. And I had not needed that for quite a few years.

Ashley explained her stress differently:

It's just, I mean, it just ... It weighs on my mind a lot, I mean it's just very mentally, stressful and challenging. And you know I get on line and look for ABA things I can do at home, stuff like that, but it's just not quite the same

without that instruction you know the ... I don't know ... I feel like I am failing him I guess, in a way.

Theme 3: Lost Momentum/Developmental Progress

The participants talked about a loss of momentum in their child's developmental progress due to the change in services provided during the COVID-19 pandemic. The lost momentum ranged from participants believing that there was no progress during the entire two years to just minimal loss of momentum in certain areas that professionals supported compared to progress they witnessed before or after the COVID-19 restrictions.

Ashley thought the greatest loss of momentum came from the ineffectiveness of online therapies for her son. She said:

I feel like that he would have benefited a lot more in person for sure. And by the time the whole thing was over, the COVID pandemic, the occupational therapist is the only one that actually came to see us twice. And that's it. He was three by then so ... It really put a damper on the stuff that he could benefit from, I think.

Caitlin explains her experience of lost developmental progress with Connor like this:

You know, it was a big deal. And I was trying to be understanding about it all, I just, my son really, really did not get everything. And so that's still what we're paying for now. In the long run with him, he's still behind with speech, he has about 10 words, he is going on four years old ...

Mandy describes her daughter's lack of progress in behavioral development due to her experience of a revolving door of ABA therapists at the center she went to. Mandy believes the staff changes were a direct result of COVID-19 impacts.

There's a little bit of grief because that ABA would have been really helpful when she was younger when we could have got her before she matured. They're and those years are important for [development of] their brains. So that's like critical development. Yeah, those are critical development years that that impacted her. And it really showed, for instance, when she came back to school, she got into fights. And the principal said, Yeah, this is common now. Whereas before, it wasn't common. And she, they, they're, I just, it seemed like everyone had stunted social-emotional growth for them. Like you're in a, you know, for a year and a half, like everyone is a year and a half behind socially and emotionally. And we won't even talk about academics.

Stacey said:

Umm, counseling wise, right I've been I've been searching for a counselor for him for a year. And actually, didn't get one until three months ago ... So, we just kind of stayed in limbo. Okay.

In contrast to this experience with mental health, when asked about what advice Stacey would give to herself experiencing the COVID-19 pandemic for the first time with her son, her advice was:

What would I tell myself, that that he is going to be safe with those providers.

You're right.... and that he's going to gain services that can be very impactful from the end.

It should be noted that Stacey's son saw his providers in person during all but two months of the pandemic. Stacey's greatest fear was that Connor would get COVID-19 and react badly to it.

Theme 4: Difficulty in Accessing Professional Support

All the participants had trouble in accessing professional support for their child with ASD during the COVID-19 pandemic. This theme was a major theme in all the participant interviews.

Mandy stated:

So, I was really looking forward to ABA because everybody said you because and I saw from TV show parenthood, what ABA look like. And I thought that's what I was going to get. And it was going to be intense. And we were going to get training and we didn't get that we didn't get the Hollywood ABA ... staffing shortages. And we are authorized for 20 hours only got 10 Right, maybe ... and then it closed because the staffing was COVID related.

Ashley had a very difficult time finding both speech therapy resources and ABA therapy resources once her son entered the special education preschool.

Yeah, the only place that I have him signed up for, for ABA, it's actually a brand-new place and [in the city] called [omitted]. Yes. And as ... I call it right away, and there is still 12 kids ahead of him. There's no way of predicting how long that will take. That's the shortest for any academy for ABA. And speech therapy is just nah ... Like a year and a half out. Pretty bad. And I called around to all sorts of places. And it didn't matter if it was State health insurance, or regular health insurances it was just all the same.

Ashley added:

But there's just nothing available now they are all full and they all have wait lists, so ... he got shorted a lot of that type of therapy and not just, just this county, but other kinds of counties, let's see, the state I guess I mean, I don't know if it's like

that with every state but we need a lot more services are out here. I just wish there was more resources that's all, more people to do the therapy.

Caitlin talked about the difficulty she had in getting ABA services for her son because of a shortage of doctors who could complete the paperwork necessary for her state medical insurance. She described the experience like this:

The paperwork surrounding that I never had that kind of experience before where my son couldn't get everything he needed. Because we were told with Molina [insurance company] everything would be covered. And we didn't know what that meant, in the underlining factors, what they needed in terms from doctors, which you always assume. I mean, anybody would assume that, you know, doctors know what documents they need to give in, you know, the insurance, medical billing kind of stuff. Those areas. I am, it's going to take me a while to regain trust there. Yeah, to regain trust that some big changing for the whole world like this, that that wouldn't happen again.

Stacey had difficulty accessing OT care through the school for Kaleb because of a “virtual loop” she was in. The OT providers would not see him until they could evaluate him, and they could not evaluate him until he was back in school and then they would discuss it in his annual IEP review. Stacey described the experience like this:

Fight, to get the services to OT..... OT would only come virtually when he was new. And when I requested documentation that Kaleb had been receiving services. He couldn't provide it because he started in February so he couldn't provide me anything prior to that, but then he couldn't provide me anything from when he started until the IEP meeting, either because they had not been working

with him. Even thought they were supposed to. And he said he was gonna go and visit Kaleb and see what he thought that they could do to help website to IEP meetings last year. And he came to the second one and said, oh yeah, I'm gonna go check out Kaleb and see what I think he can do to help and I was like, Wait, you said you're gonna do that at the last meeting. And all the teachers were there and I was like, so am I hearing things did he say this? And they were like, yeah, he said he was gonna do that. He actually left the meeting on his computer because he was upset that I called him out on it.

Stacey experienced a similar scenario with the military health care she requested for Kaleb:

Oh, mental health? So that's right just before the shutdown [the military] had a counselor and I'd gone in and done his intake with her ... So, I've done his intake, and then the shutdown happened and when they came back up, they were only doing virtual, and they were only doing established clients and because she hadn't met him in person yet she didn't want to meet him over zoom. So that got cancelled. And then everybody [other military and civilian counselors] was just shut down or not accepting new patients or not accepting anybody that wasn't a threat to themselves.

Richard expressed his experience in difficulty accessing care this way:

And so, on top of that with the different struggles getting a new doctor and stuff, technically, we don't even have a new doctor for him yet. It it's always interested now the people that go there and that I think was probably pandemic related

because the guy was probably very overwhelmed with all the new systems that he had to deal with.

Theme 5: Return to in-Person Schooling a Relief

The participants all described how the return to in-person schooling as well as in-person therapies as a relief to the stress they were experiencing prior. Their experience of this relief came from the changes that they were required to make during COVID-19 that they thought were going to be temporary but realized that it was a complete reordering of their lives from online therapies, difficulty getting therapies to rearranging or quitting their jobs because their children were no longer in school. Their relief was palpable in their descriptions of their experience of it.

Mandy's experience of this was: The school was in person spring of 2021, and then I could, and then yeah, spring of 2021 is when things got relaxed because she was in school. Yeah. She got to go to school. And I got a break. We got a break from each other. And she got to have friends ... and then when school went back in person, September of 2021, I could get a job. Okay, a real job. And like to work and go back to work. And then as we moved through the New World, and things did start to open up and we did have opportunities for being in person. There was less stress on the family. And then when they finally opened up, were the bright spots.

Stacey's experience was similar:

They switched to live last school year; 21 to 22 school year is when they did it in person ... I think he's able to make a connection and a relationship, he seems to be making friends now. It's getting him invited to go places ... He has more services now, because we went through it. Speech in school and OT in school is what I'm referring too. Those he didn't have prior, so he's gained services going

through and they think that's because of advocating and seeing and realizing, Hey, when he goes back to school full time he's gonna need more than you guys have provided him ... Now I'm an Operations Coordinator for [omitted]. I got my degree, and I got a nice job.

Ashley described Landen going to school as:

The school would be a happy place I guess because he is in there and getting some social interaction services, whatever he can get at the time. It's good. It's definitely good. I think that his being in school right now. It's definitely impacted better. Yeah, versus him being home with me all the time Okay.

Theme 6: Father's Increased Involvement

An interesting theme that became evident while analyzing the participant interviews was how fathers became more involved in the lives of their children with ASD because of the COVID-19 restrictions. For all but the single mother, fathers, either because they were home or because their child was home involved in virtual school, had more visibility or contact with their children. The result for all four married couples was a greater sense of involvement and a relief that mothers had an ally.

Stacey described this experience:

So, his dad was able to see more. So that was his dad has become a bigger advocate for him in school. Prior to COVID His dad didn't go or invest in any of the services or IEP. But now post COVID He's, hey, you know, I think this would be a good goal for him. These would be good accommodations. He was there at the last two IEP meetings, advocating for him and helping set up his educational

goals. So that was a huge win on that front ... And made it less stressful. Yeah, having an ally.

Mandy's experience started when she was working from home but in a very stressful job so her husband was the primary parent helping Olivia during the day with her online schooling from 8 a.m. to 4 p.m., after which he would get ready for his job in the evenings. The first year was difficult as Mandy describes it because she felt he handled Olivia wrong, but she describes in the end how that time together was so helpful.

And even though we're all in the same house, we're all in different schedules. So, it's like, Oh, your turn to take care of her. I'm in my room working and then switch. And then I would take over ... It's, it's shifted a little more back to me, but not like it was before. David is very much in like, telling her when chores are due and things like that. And she listens and stuff like that. Whereas before, it was all me. We came through this experience improved, because David is now a para, and he's going to school to be a teacher, and they have now they have a relationship that is more like a parent, a father, daughter, instead of fun dad, like, I know that I know the parent to go to, to get, you know, to get out of doing things. Kind of thing. That takes a lot of stress out of off of me.

Richard describes his involvement even though he lives with what he referred to as his "limitations."

But I was determined to stay home with the kids because it was just better for them and for me, because working even at [a grocery store], it was a simple job and so, but it was ... it took a lot out of me during the day. So, when I got home, there was less of me to go around. So, I figured it's ... I'm already getting

disability. I could stay on disability and still care for the kids. So, one of the things I wanted to do anyway is that my first generation of kids didn't have a lot of my time because the jobs I did were very labor intensive. And when I got home, like I said I didn't have much of me left. Yeah, and so they didn't get a whole lot of me ... So overall, I just didn't want a repeated of that. And now that Cayden had some special needs and stuff, I just want to make sure that he has a lot more me. And he does.

Caitlin had this to say about her experience of her husband's involvement:

My husband was a wreck. Still kind of is he's very frustrated and angry about what's going on even to this day because he was the one that was just really trying to make sure Christian got the help. I mean, he saw it before me ... My husband is also my support person for my autism because I also got diagnosed with PTSD. And, and I have anxiety. So, all of it plays together, especially when changes are happening a heck of a lot of changes, obviously, for everyone, but it like intensified by 10.

Research Question Responses

Each participant was asked an open-ended question at the beginning of the interview:

Let's take 15-20 minutes, and in that time, can you please describe your experience of accessing and receiving professional care for your child with ASD from either, special educators, ABA therapists, occupational therapists, speech therapists, mental health experts, and medical support during the COVID-19 pandemic? A follow up question was asked to each participant to thicken the description of their experience and further address the third and fourth research

questions, the follow up question was: *Can you please describe how the change in care during the pandemic impacted your own well-being, your child's, and your family's?*

Directly following the participant completing the conceptual mapping task, they were asked to reflect on it through another series of questions designed to gain more insight into their experience.

- *“Now that you have created this conceptual map about your lived experience of accessing and receiving professional care for your child with ASD during the COVID-19 pandemic, take a few minutes to reflect on it. (Pause until participant indicates they are done reflecting.)*
- *What strikes you as you look at your conceptual map?*
- *How have things changed for you during the pandemic because of your experience in accessing and receiving care from professionals?*
- *What advice would you give to yourself back in February of 2020 to make things better in accessing and receiving care for your child with ASD now that you have lived through it?*
- *“Where are you now in your story?”*
- *“Is there anything else that you feel compelled to say from this whole experience?”*

Through the participant answers to these interview questions, all the research questions were answered, some more thoroughly than others. Research questions that were not as fully answered are addressed in the recommendations section of Chapter 5.

R1 - How do parents of children with ASD describe their experiences of accessing and receiving professional services for their child in the midst of COVID-19 mitigation efforts in Washington State?

This question focuses on the lived experience of the parent; their answers represented their subjective experience and provide insights into the challenges and successes they experienced over two years with the system of professionals they came to rely on. Each research participant gave a rich description of their experience with this question. Participants described how being unable to access care or transitioning to online supports and back again increased their sense of isolation while caring for their child with ASD. One participant experienced this way when describing her experience with the one service that was not online during COVID: “Then the therapist was once a week for an hour. I was thankful for that because we could actually go and see people, you know because it was just us three in the house by ourselves.”

They spoke of an increased burden of reordering their lives to support online schooling. The participants described feeling overwhelmed by the multiple roles they were asked to fill through online therapies that they felt underqualified for. Parents of younger children experienced this burden more significantly than parents of older children. A parent of a younger child with autism said of her experience with online therapy:

Okay, yeah, so definitely I had some mental breakdowns. I call them episodes, my autistic part. Because I had to, like, follow around with the camera, and it was hard for me to do like two things at one time.

They described their experience with online delivery of care and how it was largely ineffective for their child’s development except in some circumstances. One participant’s experience was, “So I don’t know if [my child] got as much out of it. I think he started getting a lot more when he could go.” Another participant had this experience with online therapy, “We receive counseling services from the school. Okay. That was not effective because it was over Zoom.” However, a few of the participants did experience positive improvements with select

online therapies. One participant described one session with mental health therapy online for an older child:

One session was effective, where she told me about social stories, this was to help with getting homework started. Because my daughter would run when it was time to do homework. And she told me about a social story and how I could use that I, I'm not I don't want to it's time to do homework. I don't want to do it. But I know at the end, there will be a reward for it. And that seemed to help.

The participants all described the increased stress felt either by not being able to access the care they wanted for their child or fear of their child getting COVID-19 or spreading it themselves. As one participant described it, “We didn't get the supports that we needed, we had to provide them at home, we were not prepared. No one was prepared. And there was a lot of stress due to change transitions.” They also described the added stress of losing in-person support and social interaction for their child with ASD. One participant with a younger child said,

“... and then because of that, that already started with feeling scared, being traumatized and that way, we had a lot of areas that were not being met because of that. And then that also around that time was when I lost, I finished the support that I had from WIC.”

Each participant described a different level of stress for largely different reasons. One thing that stood out among others is the decrease in mental health that many experienced and that there were transgenerational patterns of mental health disorders. The participants also described a loss of developmental progress for their child with ASD due to online therapies that they

believed were not efficacious or inability to access the care they needed due to COVID-19-related complications.

In addition to the difficulties in receiving care that participants experienced, they also experienced a lack of access to care. This mainly applied to the area's ABA services for younger children new to the early intervention preschool programs. “We are still on wait lists. He doesn't have ABA ... We've been on a waitlist for ABA forever.” It also was present in older children needing more mental health support. A participant with an older child describes it: “And then everybody was just shut down or not accepting new patients or not accepting anybody that wasn't a threat to themselves. So, we just kind of stayed in limbo”.

Participants felt a sense of relief as the school opened back up and their child with ASD could receive care through the school system. This treatment was important to the family system because it allowed the primary caregiver to return to work and not have to stay home with their child to provide services to them while they were online. It also gave the parent a sense that their child was socializing with other children their age, and they felt that was important to their development.

I'm taking off, our family is going, I got this really great job as [omitted] and I help a lot of people, and so I found a job that I, I like a lot of meaning and a lot of meaning whereas before I was working in [omitted], which is not a great place for a person that is not detail-oriented. Yeah, is a very high-stress position. And now [my husband] is going to be a teacher and [my child] has friends.

Participants described the experience of having an ally in their children's fathers because their children were home more, and the fathers were interacting more with them. Although for some it was a difficult beginning, the result at the end of the pandemic was nearly universal in

the fathers' increased involvement and knowledge of the intricacies of their child with ASD.

One participant described this phenomenon,

So, his dad was able to see more. So that was his dad has become a bigger advocate for him in school ... He was there at the last two IEP meetings, advocating for him and helping set up his educational goals. So that was a huge win on that front.

R - 2: How do parents describe their interactions with professional services for their child with ASD during the pandemic?

In answering this research question, the participants had positive and negative interactions with professionals caring for their children with ASD. Participants expressed a universal understanding that all providers were trying to do their best in the environment that they were in, and the constraints placed on them due to the COVID-19 pandemic. Their empathy seemed to match their appreciation of how providers were really trying new things and ideas.

One participant expressed an example of this,

And I mean, I really experienced a wonderful team of people that were trying to do everything they could. They totally understood they were fighting for me and [my son] to be able to get everything we needed; they even allowed me to reach out to them there.

Three participants had negative interactions with either providers directly, or they had negative interactions with a seemingly impenetrable wall of bureaucracy blocking access to care.

A participant had this to say about his experience:

And that's where I feel the system definitely was way overly cautious. I mean, we spend all day, all the time with each other. So, adding one more person in the

rooms, not going to endanger anybody. But they had to be so strict on that then there was no common sense to it.

During the COVID-19 pandemic, a center providing ABA therapy closed in the area where the participants were located. Seemingly the shutdown was a result of COVID-19 restrictions and staffing shortages. One participant expressed her regret:

There's another issue is that staffing changes, she received three different site therapists. They're all things, yes. Oh, yeah. Which was COVID related. So, you have to establish rapport with a person that you never met. And she's seven. Yeah, forget it. Because they just never got fully staffed. Even though we were in person, they still struggled.

One of the participants was so appreciative of the way an ABA center was so thorough in their sanitizing and the care they took to lessen exposure to the virus. She described her sense of relief at their professionalism:

I loved it that she did that; it made me feel safe sending him in there every day. They did. I forget how often, but I know that they tested all of the providers regularly. Everybody kept kids home if they were sick; it was, it felt safe sending him there.

R - 3: How do parents describe the difference between accessing and receiving professional services before the COVID-19 pandemic and during the pandemic?

The research participants answered this question in varied ways depending on how old their child was and how established their services were before the pandemic impacted their support providers. Three of the five participants already had established support and had been using that support for multiple years. The other two participants had just begun receiving

support and had less established experience with the providers before the pandemic. However, the participants could discuss their experience of receiving services when the pandemic restrictions were mostly lifted versus when they were in effect and impacting provider support.

One of the participants described the difference in receiving her own mental health counseling before the pandemic as a real support for her to help her with key relationships and with the difficulties her son was displaying. She said:

So, I couldn't. I had to stop going in to see her; I had to switch to just being on the phone. So, to talk about my well-being that was huge difference, and was not as helpful at all. Many times she was trying to do FaceTime, I my phone would end up going nutty or, or crashing turning off because Wi Fi signals or whatever.

Another described her experience with her daughter's play therapy that was in person before the pandemic and how it changed with the lockdown and restrictions.

Because when you have a mental health therapist, they're in this session where they get to play that in zoom land you, you're in the family kitchen, with the that's where we had it. We didn't have her in the room, you know, it wasn't exactly private.

A participant described the change for her this way:

She was receiving speech and OT and resource room and transcription and para educator. The big changes with that were speech therapy was over Zoom, and that seemed to work okay. OT with mom didn't work as well. There are just too many things that they had in person that [child's name] wanted to do and that's where her mind was.

One of the participants had a nurse who would help them in the home before the pandemic started then when the COVID-19 restrictions started, she no longer came to the home, and the parent said of her child, “He first started reacting to the fact that the nurse wasn't coming in person to see him. That was our very first experience [our son] really showed signs.”

Another participant discussed the changes from the ABA sessions her son was receiving before the pandemic to the ones he received during the pandemic.

ABA the transition back in ... I think that was rough because they tried to keep six feet distance when they opened between the kids and the provider if at all possible. There would be sometimes shutdowns for positive COVID tests, and then we had to do the close contact thing if he was in close contact ... they couldn't really do the group sessions.

The only positive comment about the transition from before the pandemic restrictions to during was from a participant whose son went from a B average grade to an A average grade when the school went to virtual. She described another surprising result of taking more control of her scheduling of professional supports through this ordeal, “Yeah, and I feel like we lessened the busyness because of this outcome. Yeah, like that, transition back, was good, but I was more intentional about the times that I picked and how often I let him go.” She described this experience as spending more time with the family and her other children.

R-4: How do parents of children with ASD describe the impact on their family system while accessing and receiving care from professional ASD service providers during the COVID-19 pandemic?

This final research question is a primary research question that attempts to understand the systemic impact on the family system by the change in accessing and receiving professional care

for their child with ASD during the COVID-19 pandemic. This question allowed the participants to explore the circular causality of the impact on the family system, considering systems theory.

Each participant describes an increase in family systemic stress. One participant who had her own mental health challenges was caring for a husband with learning disabilities and a mother with dementia, a son diagnosed with ASD, and gave birth to another son during the pandemic who is now showing some signs of ASD. She discussed the impact her son's meltdowns had on the family:

My mom already has trouble with kids in general. She had it with us, with us growing up. She's has also OCD. So anytime [my son] is outside of his norm and she sees those differences, it sets her off to stay on that topic ... Yeah, that's fine. So yeah, my mom just reacts to that, same with my husband just in those same kind of ways ... When things are not consistent and it's like the whole house gets affected emotionally, mentally, psychologically.

She addressed the impact on her, too:

When I was talking about like, all those experiences since I had that were changing for me too ... affected me being the mom I needed to be because when I go through those episodes I shut down. Then it takes me a while to like, get back to myself again.

As mentioned in one of the themes that emerged during the interview analysis, a change in most of the participant family systems is an increased involvement of fathers with their children with ASD. Participants describe this increased involvement in a positive way where they are more of an ally, or less of the "Fun Dad" and more of a partner in caring and understanding their child better, helping with them more at home, and advocating for them more

at school and other places where they receive professional supports. As a participant of an older child shared her experience of her husband's increased support, she expressed, "And made it less stressful. Yeah, having an ally."

Some of the participants described how adjusting for changes in support from professionals impacted their family functioning.

And even though we're all in the same house, we're all in different schedules. So, it's like, oh, your turn to take care of her. I'm in my room, working and then switch, and then I would take over. Actually, I did the schooling; it didn't end at four because there was music and PE that he didn't get to. So, we so, then it switched, and we would switch so really it was her school did go till eight [at night].

Most of the participants talked about the added stress and pressure that the changes in care for their child brought on the family. One participant described the change in their family system and said:

We didn't get the supports that we needed, we had to provide them at home, we were not prepared. No one was prepared. And there was a lot of stress due to change transitions, and roles and learning new skills all of us all at the same time.

Summary

The research findings represent the voice of the participant's experience as they accessed and received care from professional caregivers during the COVID-19 pandemic. The interviews were presented with participant quotes so the reader could hear directly from the participants. Each participant completed an in-depth interview and created a conceptual map that deepened the description of their experience and added a pictorial representation of it.

The data was analyzed, coded, and thoroughly reviewed multiple times, where important themes emerged and were presented. These themes and the research questions were discussed, and quotes from the participants were presented in support of both the themes and the answering of the research questions. These procedures were used to increase the validity of the study and so that the participants' voices would come forward to provide a deep, rich, full-bodied description of their experience.

Chapter Five: Conclusion

Overview

The purpose of this transcendental phenomenological study is to describe the experience of parents caring for a child with ASD as they are accessing and receiving professional services for their child during a global COVID-19 pandemic in Washington. The sections in this chapter will consist of a summary of findings, discussion of the findings, implications, delimitation and limitations, and recommendations for future research. In addition, the researcher will make specific recommendations to primary stakeholders treating and funding treatment for children with ASD. The systemic focus of this study is a key feature of this last chapter and is applied in many of the sections.

Summary of Findings

The research participants gave a rich description of their experience in accessing and receiving professional support for their child with ASD during the COVID-19 pandemic. In summary it was largely a struggle for them. The times they were unable to access care or transition to online supports and back again. This struggle increased their sense of isolation because they and their child did not have the contact with their providers that was so important to them. Due to the online delivery of care in most areas, participants felt an increased burden of reordering their lives to support online schooling. They also described the feeling of being overwhelmed by the multiple roles they were asked to fill through online therapies. This increased their stress in feeling like they were failing their child because they felt underqualified to provide the multiple professional therapies to their children or were frustrated when they could not recreate for the therapist their child's behavior over a telehealth platform.

Those who exhibited the greatest burden for care were parents of younger children. They described their experience with online delivery of care and how it was largely ineffective for their child's development. This was primarily because of a toddler's short attention span, a factor which left parents feeling like they were not helping in a way that supported their child. Participants all described the increased stress felt either by not being able to access the care they wanted for their child or fear of their child getting COVID-19 or spreading it themselves. Participants also described the added stress of losing in-person support and social interaction for their child with ASD.

One prominent theme was how most participants struggled with a decrease in their mental health. There were obvious transgenerational patterns of mental health disorders or learning disabilities within the sample population. Moreover, the most difficult thing for a parent already concerned about their child's normal development was the observed loss of developmental progress for their child with ASD due to online therapies that they believed were not efficacious or the inability to access the care they needed due to COVID-19-related complications.

Participants universally expressed joy and hope at reopening schools and services in person. This allowed the participants to return to work and for many professional supports to be delivered through school with professionals present and working with their children in person. The one exception was that ABA therapies were not offered in any of the schools, and there needed to be more resources in the area for ABA. Also crucial to parents was that the school offered their child a venue to socialize with other children their age, and they felt that was important to their development.

There was an increase of systemic family stress on the parents of children with ASD. Although it is outside of the focus of this study, general systems theory would suggest that this increase in stress would negatively impact the child with ASD's behavior which in a circular causality would also increase systemic family stress.

The participants noted some positive events. Although only one father was interviewed, most participants stated that fathers seemed to gain a closer relationship with their children with ASD because they were home more and going to therapies less. This increased participation was most helpful in advocating for their child's needs along with the mother and gave the mother a sense of an ally and relief.

During the height of the pandemic shutdowns and the move to online and other novel therapy practices, it was apparent through participant comments that providers were attempting new therapy approaches and working hard to deliver the care the children required during this unprecedented event. This outcome was recognized and appreciated by the participants.

Discussion

The findings in this study confirm much of the empirical and theoretical literature from previous research explored in Chapter Two. However, the research findings also provide novel contributions that point to an increased adverse impact on families with theoretical implications through systems theory as it is applied to the participants' lived experiences.

Confirmation of Previous Research

This study confirms much of the demographic research on ASD. Specifically, males are four times more likely to be diagnosed with ASD than females, ASD is 30% hereditary, and parents have an increased burden of coordinating multiple professional services for their child with ASD (Depape & Lindsay, 2015; Fletcher et al., 2012). In this research, four out of five

children with ASD were male, 25% of parents had a diagnosis of ASD themselves, and 60% had other mental health disorders. Most parents in this study coordinated at least three different weekly services for their child.

This study confirms and emphasizes the impact the COVID-19 pandemic has had on parents while they attempted to access and receive care for their child with ASD. Previous research demonstrated that a more significant family burden for those caring for a child with autism is positively associated with the number of unmet professional supports (Lopez et al., 2019; White et al., 2021). This was a significant finding in this study, with many parents commenting on their increased burden. The two professional supports, ABA therapies and special education, that created the most significant burden for the participant sample were the therapies most significantly affected by the COVID-19 restrictions.

Previous studies found that ABA and RBT therapists experienced job insecurity, increased burnout, and reduced productivity with their therapies (Jimenez-Gomez et al., 2021). For the participants in this study, four out of five parents interviewed either lost or could not access ABA therapies, and one of the larger ABA providers in the area closed. One of the participants had ABA therapy online for a short while and evaluated it as ineffectual, and two continued ABA therapies in person with only a brief interruption. Three of the five parents interviewed are still trying to access ABA therapies and cannot.

Moreover, in previous studies on special education by Tokatly (2021), parents express the difficulties of shutting down special education systems, dealing with multiple logistical problems for their families, and detailing the regression in behavior and social skills of their children. Previous studies found that children who were being treated at ABA schools or at public schools in special education environments were now required to stay home, and parents, out of necessity,

had to stay with their children instead of work (Bhat et al., 2021; Dahiya et al., 2022; White et al., 2021). This study confirms those findings as all participants had to rearrange their care for their child and their employment to meet the demand of staying at home with their child for schooling. This impacted the family system financially and reordered roles in the family until the child could return to their in-person education.

The most compelling confirmation of previous research is the impact on parent well-being. In nearly all studies conducted between 2020-2022, parents caring for a child with autism during this time were significantly impacted in well-being and mental health (Dekker et al., 2022; Masi et al., 2021; Pecor et al., 2021; Reicher, 2020; White et al., 2021). This was true of the participants of this study as all five interviewed indicated a decrease in participant mental health, with two participants believing they had acute stress reactions similar to PTSD symptoms from the experience. Moreover, the anxiety from the pandemic and difficulty in accessing and changes in receiving care negatively impacted the family system by hindering the parents' ability to provide support and resources to their vulnerable children leading to a lower quality of life for both parent and child.

Divergence From or Extension of Previous Research

Although this study confirmed previous research in many cases, it did diverge from it in surprising and unexpected ways. One previous finding in educating children with ASD was that many parents would homeschool after trying to work within the school system and found it too emotionally and financially difficult (Samsell et al., 2022, Song et al., 2018). This finding was different in this research. This study demonstrated a direct contradiction to the previous research as one of the themes was how relieved and hopeful parents were when their child with ASD either returned to their special education or general education in-person instruction or entered it

for the first time. This was even true for the parent of a teen with ASD who improved academically with online instruction because the parent was extremely worried about their child's socialization.

An extension of previous research revealed in this study was that in initial studies at the beginning of the pandemic, nearly all families reported a loss of at least one educational or professional support for their child with ASD, with 74% of parents reporting a loss of access to one or more therapies and 36% reported a loss of a healthcare provider (Jeste et al., 2020). In this study, 100% of participants lost or could not access the professional supports they were authorized through their insurance or state programs to treat the symptoms of their child with ASD during the pandemic. As mentioned, three out of five participants could not access ABA therapies. Two out of five could not access the mental health therapies they needed. One could not access speech therapy, and one could not access OT for nearly two years. One participant lost all therapy services for two months, but it was in person when they returned.

One outlier study by Pollard et al. (2021) found that moving ABA to telehealth was successfully transitioned from in-person with minimal service gaps. In that study, participants indicate high levels of satisfaction with the online ABA treatment. This study directly contradicts that finding. Finally, it should also be noted that special education was available to all who qualified for it, albeit primarily online, from March 2020 to the Fall of 2021.

Another extension of previous findings related to parent evaluation of the effectiveness of online therapies provided to their child with ASD. In previous studies, researchers found that about a quarter of children with ASD and their families who moved to online learning reported positive impacts, and nearly half reported a negative experience with online learning with their child receiving “no learning” or “bare minimum” (Dos Santos, 2021; Jeste et al., 2020; Simpson

& Adams, 2022). All parents in this study reported a negative experience with the online delivery of professional support for their child with ASD. The following is a more detailed analysis of this finding because it deserves to be unpacked, for the details are revealing.

First, parents with younger children reported receiving the least benefit from online therapies, consistent with previous research. The three parents with younger children all reported no developmental improvement with online speech and occupational therapy. Moreover, they only saw an increase in their child's development in these areas once they could access in-person services again.

Second, parents with older children in elementary school experienced some benefits with speech therapy and special education services online for the oldest. Both parents of older children experienced little to no improvement through online mental health. However, that was likely because one was play therapy, and the other could not access care as no care provider was available for the two years they were looking. Furthermore, the older school-aged children in the study received in-person professional care much earlier than the younger children, in most cases, nearly a year and a half earlier. This likely had a positive impact on their overall functioning, obscuring the impact of online services. In the area researched, there were more in-person resources for school-aged children during the pandemic than for preschool children. The existing preschool services were mainly in-home and discontinued during the pandemic.

New Contributions from this Research

In addition to the divergence from previous research, this study is the first to examine the systemic family impacts on parents and children with ASD as they interacted with their essential professional support during the COVID-19 pandemic. This approach views the child with ASD

as residing in a system that is an identified whole composed of many interrelated individual parts. The entire family system was impacted by the quality, quantity, and expenses of caring for the child with ASD. Unmet professional service needs influenced the family system. With many professional support systems shutting down during COVID-19, the feedback loops that family systems relied on to balance the family were also shut down. From parents having to quit their jobs, alter them, or get fired, the impact on families as they attempted to achieve their homeostasis was felt by both child and family.

The increased burden and isolation noted in the participant results also impacted the family and system in terms of decreased mental health, increased stress, or, in some favorable cases, more time with their child. Reciprocally, caregiver anxiety levels correlate with the severity of ASD-related behavior problems and the child's ability to thrive.

Participants described the experience of having an ally in their children's fathers because their children were home more, and the fathers were interacting more with them. One previous study acknowledged this phenomenon (Russell et al., 2020), but no other research exists on parents caring for a child with ASD. As noted in the results section, by the end of the pandemic, those interviewed experienced the fathers' increased involvement and knowledge of the intricacies of their child with ASD.

Theoretical Family Systems Illuminations

The design of this study has its theoretical roots in systems theory and focuses on how the access and receiving care for a child with ASD during the pandemic impacts the larger family system. Specifically, as an individual interacts with others in the family system, the whole family system changes slightly, and consequently as the family system changes it will naturally

gravitate towards a homeostatic or “stable” state (Von Bertalanffy, 1951, 1968; Hecker et al., 2015). That is until it is moved out of that homeostatic state and forced to adjust to novel changes to the family system, either by changes in individuals in the system or by influences from sources outside of the family e.g., change in professional supports, special education, community changes, or other professional providers. This multisystem theoretical approach was developed primarily to address inadequacies in simple cause and affect models used for explaining the complex social behavior that transpires in the family (Balswick & Balswick, 2014).

Research suggests these changes in social and professional supports increase the risk for mood and anxiety disorders, which are co-occurring for many ASD children (Bhat, 2021; Diamond et al., 2020). This study has demonstrated and supported that research. Moreover, it supported the premise of systems theory as participants detailed their experience of heightened stress and anxiety in themselves and how that had an impact on other members of the family system in a circular way, as theorized by general systems theory (GST).

In agreement with Bronfenbrenner’s (1979) social ecology theory, Haehnel et al. (2021), found a significant association between the various aspects of individual health and a comprehensive measure of family health. Specifically, depression had the strongest association in its interaction between individual and family health. In this study, participants discussed their sadness and anxiety, as well as feelings of being overwhelmed and scared. Systems theory encourages examination of how these increased negative emotions have impacted the overall functioning of their child with ASD, of how the access and receiving of professional supports has impacted the negative emotions, and how those negative emotions have impacted the access or desire to access and receive care for their child with ASD. As noted by some of the participants,

they just gave up on some of the services believing they were not worth the effort. Viewing participant experiences through the lens of family systems theory, illuminates the interrelatedness of all the systems that the parent of a child with ASD interacts with.

Implications

The theoretical, empirical, and practical implications of this study are explained in this section. Additionally, this section offers an explanation of how this study has been guided by fundamental Christian principles and a Christian perspective of the importance of family. There are also recommendations for various stakeholders, specifically those providing the professional support and the government agencies supporting them.

Theoretical Implications

Many of the findings in this study confirm findings in both qualitative and quantitative studies that have been conducted previously. While the theoretical implications from the results represented the experience of the primary stakeholder and the parents of a child with ASD, it widened the aperture to the family system. When examining children with ASD and the efficacy of their professional supports, research should consider the circular causality experienced in the family system.

There is little doubt that parental distress impacts children with ASD, and child distress affects parental well-being. Research in the development of children with ASD should examine this fundamental premise.

Empirical Implications

A key observation from this research is that the demand for professional services in this area far exceeds the availability, a factor noted in multiple studies. There are many reasons, including education requirements, credentialling, compensation, and difficult working

conditions. Regardless of the reasons, parents, have experienced difficulty accessing ABA, speech, mental health, and OT for their children. However, they did not have trouble accessing special education programs.

All the participants in this study preferred professional support, therapy, and medical providers, who saw children in person during the pandemic. However, it was also important to them that the offices followed safety measures like frequent sanitizing, screening clients before the waiting room, and turning away clients for pandemic-related reasons until their symptoms or contact had enough time to dissipate. As one participant noted, even during lock down they had to go to the grocery store, work, ride the bus, and other things where they had no idea of the health/contact status of the person next to them. At least in the therapy office there were precautions and screening making it a much safer place which gave them a sense of calm.

Most of the participants talked about the added stress and pressure that the changes in care for their child brought on the family. Families caring for children with ASD have an increased prevalence of depression and anxiety. Every participant described an increase in family systemic stress and that can be related to increased baseline of stress prior to the pandemic as noted in other studies and corroborated in this study. When treating the child, participants appreciated a whole family approach where they were included in the therapy process but were not compelled to provide the therapy.

Besides the single mother, all the participants were in households with two income earners. In that setting, daycare or care outside of the home is essential for the functioning of the house. Therefore, it was unsurprising that when schools closed, the entire family system had to adapt to this new environment. When the schools opened or children could attend preschool, the system returned to homeostasis. In a world where both parents work outside the home, or even

work remotely, full-time care outside of the house is important for reducing the stress in the family system.

Previous research has established that families of children with ASD often isolate from social situations and even from extended families due to misunderstanding their child's behavior. With isolation already a feature of the experience within these families, the further isolation that lockdowns and the move to online therapies, online schooling, and shutting down of parks and other venues had an outsized impact on families participating in this study. Consequently, in-person therapies were essential to these families in relieving some of that felt isolation, reducing some of the stress in the family system.

Practical Implications

A practical implication, based on participant experiences to this study is that researchers evaluating the efficacy of online speech, OT, ABA, and mental health therapies are not seeing actual results of improvements in client development but instead an expectancy effect. Although difficult to differentiate the two, research can add validity to studies by including caregiver input.

Recommendations for Stakeholders

Preschool state programs can add, partner with, or fund ABA providers in their developmental preschool programs. Partnering would eliminate the gap in ABA care between the early intervention programs and state school programs. Additionally, state funding authorities of early intervention programs could take a clear-eyed view of compensation, work environment, and other factors that lead to burnout of ABA providers and difficulty staying in business. Moreover, if developmental preschools (3 - 5 years old) are providing the function like that of ABA therapies, then that can be communicated to parents through studies and analysis of their efficacy.

State health departments could also consider that most therapies children with ASD access are outpatient. Outpatient therapy and medical offices can screen, sanitize, and mask to allow in person visits. Those outpatient clinics can ask patients/clients to return when they are potentially not contagious, or they can move online for a brief time. Through this screening and flexibility, outpatient clinics can reduce much of the risk from viruses. This differs from hospitals that provide emergency care and must accept patients regardless of their exposure status. Therefore, policy from the health department can recognize this difference in potential future pandemics and limit grouping all medical under one umbrella allowing more access to in person care in settings that can screen and reschedule.

For providers of telehealth therapies, it is important to note how telehealth is viewed by parents and its efficacy for younger children. Parents of children with ASD may not be cognitively prepared or emotionally available to receive training on therapies and provide treatment for their children. An assessment of parent capabilities, and emotional strength, along with their willingness or desire to participate could be an excellent addition to parent led therapies. These assessments could be considered in programs that promote training parents to provide treatment for their children, limiting the burden and stress on the family system.

Moreover, the participants seemed to be in unison when they expressed how telehealth was helpful in a few circumstances and not beneficial in most. Older children who could interact through this medium responded much better to telehealth, but even that had its limitations. Because some therapies are more difficult over online platforms, professionals should always be looking for ways to provide the most efficacious therapy method for their clients. It goes without saying that safety and exposure, where screening has demonstrated higher risk, necessitates a move to online therapies, or when providers are compromised themselves.

However, a wholesale move to online therapies is something that would not be supported by the implications of this study.

Christian Worldview Considerations

This study is not specifically a study of how Christianity cooperates with a parent's experience as they access and receive care for their child with ASD. However, the Christian view acknowledges the positive and inevitable nature of dependence in a family relationship (Vitz, Nordling, & Titus, 2020). A Christian worldview postulates that all are dependent on others in crucial ways for one's wellbeing, and ultimately all are dependent on God. Moreover, personality is fulfilled in freely chosen self-giving love and not in isolation and development occurs in relationship to others (Vitz, Nordling, & Titus, 2020). The family system is the most common place that these principles are developed and shared.

The professional supports that care primarily for a child with ASD engage and enrich this crucial family system, a system that relies on their support. Humans live in relationship to one another as God lives in relationship within the Trinity (Balswick & Balswick, 2014). His example demonstrates a unity of oneness in three through relationship. Relationships are the primary way humans reflect God's image (*imago Dei*).

Family is the primary building block of any civilization and children, in the Christian sense, are at the center of the family. As Peter Kreeft (2021) states:

Children are the masters: parents are the servants. The parents' life, their time, their lifetime, their money, their attention, *everything*, changes, and orbits like a planet around the sun of their children's needs. Having children is the single most generous, charitable, loving, unselfish, saintly Christian act that a society can perform for itself (pg. 5-6).

Consequently, this study serves at the pleasure of the parents who are caring for their children and supporting their families, while also providing for their child with ASD and desperately attempting to provide the support they need to thrive.

Delimitations and Limitations

In researching a parent's lived experience of accessing and receiving care for their child with autism, the research focused only on hearing the parent's voice. This desire to answer the research questions from only one of the stakeholders, albeit the primary one, was a conscious decision that also brought bias into the research. Parents are an excellent source of information because they see the development and behaviors of their children on a near constant basis. However, they are not trained to understand what normal development is, nor what is expected development given the severity of a child's ASD. Understandably, parents will likely be impatient with their child with ASD's developmental progress. They are not experts on speech development, motor skills, behavioral development, and so on. Therefore, only hearing from one stakeholder regarding developmental progress reduces the study's validity.

However, development is only a part of the experience, and the scope of this research had to be limited to the funds and time available to the researcher. Therefore, a decision was made to honor a parent's voice only in researching the accessing and receiving professional support for their child during COVID-19 because the primary research question is about a parent's experience. Therefore, prioritizing their voice seemed prudent.

An additional delimitation was to use the conceptual mapping task and the built-in validity checks in only one interview/engagement with the participant. Another validity check by participants was considered at the onset of the research to check if participant agreed with the

six themes that were developed and provide feedback at the end of the analysis. This additional validity check was not included and may present a bias not accounted for in the results.

There may also have been an element of volunteer bias because the participants had their own motivations for completing such a lengthy and involved interview with no monetary compensation. It should be noted that paying for participant time also adds potential sample bias. Additionally, parents had to be willing to meet in person and some potential participants could have been reluctant and didn't answer the flyer call.

All research will have limitations, and this study is no different. One limitation on the study was having only one male participant, and a higher male-to-female ratio may have increased variance between interviews. The study also needed to be more extensive in answering the third research question about the difference between the care before and during COVID-19 because three of the five participants had only a few months of service before the outbreak and changes. However, this was mitigated by hearing about the services received following the lockdowns and most of the significant pandemic restrictions affecting care.

This study was also limited in geography to one county in Western Washington State. This was necessary to complete the semi-structured interview with the conceptual mapping task in person.

Further limitations involved the setting and race of the participants. This county does not have a large urban area. Therefore, none of the participants were from a metropolitan area. In this study, only Caucasian and Native American races were represented. Experiences from other races may have impacted the themes.

Recommendations for Future Research

The research sample was small with only five parents of children with ASD considered. Additionally, it considered improvement in development from only the parents view of their child. Future research that was a mixed study with qualitative exploration of a parent's experience and a quantitative evaluation of the developmental progress of the child as assessed before the pandemic by professionals and assessed again at the time of the research by the researcher might yield more validity to the scope of the child's developmental progress. This could be compared to children in similar pre-pandemic conditions with similar symptoms and cross tabbed to compare the extent of progress across groups.

Future studies could also focus research on early intervention from ages three to ten or from ages 11 to 18. These two age groups typically require vastly different involvement from parents as they access and receive professional supports for their children and the texture of each study would likely yield very different results from the participants.

Lastly, a study that cast a wider net on parent experiences in different states and counties would be illuminating and an essential source of information for each geographical area. Throughout the research it was apparent that the struggles that parents experienced with accessing and receiving care were both pandemic restriction-based, which was applied differently throughout the states, and based on the services available in the area. Services vary significantly based on local funding of state and county programs, saturation of providers, and required need in the area.

Summary

This study was phenomenological research focused on the lived experience of parents as they attempted to access and receive care for their child with ASD during the COVID-19

pandemic. The study demonstrated the circular nature in which parental distress impacts children with ASD and in turn how child distress impacts parental wellbeing. A key feature in all the participant experiences was that the demand for professional services in this area far exceeds the availability. Access to care was limited and it did impact families caring for their child.

Another important takeaway from this study was that parents and children preferred professional supports that were in person. Additionally, when treating the child, participants appreciated a whole family approach where they were included in the therapy process but were not compelled to provide the therapy. Parents added that the further isolation that lockdowns, move to online therapies, online schooling, and shutting down of parks, and other venues had an outsized impact on them.

The experience of parents of children with ASD during the COVID-19 pandemic was marked by increased stress and isolation. The systemic family impact of COVID-19 mitigation efforts by providers of professional supports were significant to parents and varied across delivery methods, age of the children, parental transgenerational challenges, and other factors. If the findings are applied by stakeholders, then providers can assess and address some of these factors in their treatment, potentially improving symptoms for the child they are treating.

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Appendices

Appendix A

Letter to Professional Care Providers of Children with ASD

Dear Professional Care Provider for Children with ASD,

As a doctoral student in the School of Behavioral Sciences Department of Community Care and Counseling at Liberty University, I am conducting research to better understand the impact of the COVID-19 pandemic on the of parents and families of a child with ASD while they were trying to access and receive professional support during COVID-19. The title of my research is A PHENOMENOLOGICAL STUDY OF PARENTS ACCESSING AND RECEIVING PROFESSIONAL CARE FOR THEIR CHILD WITH AUTISM SPECTRUM DISORDER (ASD) DURING THE COVID-19 OUTBREAK IN WASHINGTON STATE. The purpose of the research is to provide an opportunity for parents to share their experiences and feelings concerning the changes implemented in Washington State by professional care providers of children with ASD and how that impacted their family system. This research is designed to give an in-depth understanding of the lived experience of parents of a child with ASD to aid further research and decision-making from professional caregivers and officials.

As a professional care provider for children with ASD, you interact with parents daily and therefore would be an excellent source for recommending qualified parents who could participate in this study. In honor of client privacy and HIPAA requirements constraints, I am only requesting that you allow the posting of recruitment flyers or, ideally, that you provide recruitment letters to qualified parents. I am not asking for any information about your clients. Information about the study and researcher is listed on the recruitment letter, where parents will be directed to make contact through text, email, or phone with the researcher if they are interested.

For the participants, the researcher will conduct only one in-depth, semi-structured interview lasting around 60 - 90 minutes in a private setting selected by the participant or in a therapy office. Parents or primary caregivers will be screened to maximize diversity, but they must be the parent of, or primary caregiver of a child under 18 with a diagnosis of ASD prior to 2020.

Contacts and Questions: The researcher conducting this study is Patrick Barry, phone: or by email. You may also contact the researcher's faculty chair, Dr. John King, at

Thank you in advance for your assistance in finding qualified participants for this study. Your professionalism and care for children with ASD are greatly appreciated. If you choose to grant permission and to provide material about this research to potential participants, please respond by emailing.

Patrick M. Barry
LMFT, doctoral candidate

Appendix B

Recruitment Letter

Dear Potential Research Participant:

As a doctoral student in the School of Behavioral Sciences/Department of Community Care and Counseling at Liberty University, I am conducting research to better understand the impact of COVID-19 on the parents and family of a child with ASD (autism spectrum disorder) while they were trying to access and receive professional support for their child during the pandemic. The purpose of my research is to bring the parent's voice forward in our attempt to understand how changes to care may have impacted both children with ASD and their families. This research is designed to give an in-depth understanding of the lived experience of parents of a child with ASD to aid further research and decision-making from professional caregivers and officials. I am writing to invite eligible parents or primary caregivers to join my study.

If you are over 18 years old, a parent or primary caregiver for a school-aged child formally diagnosed with ASD before 2020 (who is not high functioning enough to not require at least two professional services on a weekly basis) and are willing to participate, you will be asked to participate in an interview which will include creating a Conceptual Map (CM) representing this experience and then reflecting on and discussing the symbols and ideas on the map to deepen your description of the experience. The interview should take approximately 60 to 90 min for you to complete. Your name and other identifying information will be requested as part of your participation, but the information will remain confidential in strict adherence to ethical guidelines.

To participate, contact me via voice or text to schedule an interview at or email at.

A consent document will be given to you at the time of the interview. The consent document contains additional information about my research. If you choose to participate, you will need to sign the consent document and return it to me at the time of the interview.

Sincerely,

Patrick Barry, LMFT
Doctoral Candidate, lead researcher

Appendix C

Research Participants Needed

A Phenomenological Study of Parents Accessing and Receiving Professional Care for their Child with Autism Spectrum Disorder (ASD) during the COVID-19 Outbreak in Washington State

- Are you a parent or primary caregiver of a child under 18 yrs. old and diagnosed with ASD prior to 2020 (who requires at least two professional services on a weekly basis)?
 - Are you over the age of 18?

If you answered yes to both of these questions listed above, you may be eligible to participate in a research study

The purpose of the research study is to bring the parent's voice forward in an attempt to understand how changes to care during the height of the COVID-19 pandemic may have impacted both children with ASD and their families.

You will be asked to complete a one-on-one interview which should take approximately 60 to 90 minutes to complete.

A consent document will be given to you at the time of the interview.

If you would like to participate, please contact the researcher at *-***-**** or email at @liberty.edu.**

*Patrick Barry, a doctoral candidate in the School of Behavioral Sciences Department of Community Care and Counseling at Liberty University, is conducting this study. Please contact Patrick Barry at ***-***-**** or by email at @liberty.edu for more information.*

Appendix D

Participant Screening Instrument (Phone)

Hello, and thank you for your time and willingness to participate in this study. My name is Patrick Barry, a Doctoral Candidate at Liberty University, and I am in the research phase of my dissertation entitled A PHENOMENOLOGICAL STUDY OF PARENTS ACCESSING AND RECEIVING PROFESSIONAL CARE FOR THEIR CHILD WITH AUTISM SPECTRUM DISORDER (ASD) DURING THE COVID-19 OUTBREAK IN WASHINGTON STATE. You were selected by professionals in the field of ASD care and given this phone number to begin the participant process. I have a few follow-up questions to ensure your participation would be a good fit for this study. I am hoping we could take about 10 to 15 minutes to talk now, or if we can schedule another time for me to contact you that would be more convenient.

If nominee says they can talk now, then proceed with protocol. If nominee is not available to talk now, say: “Then let’s schedule a time that is convenient.” At the conclusion of the conversation, thank nominee for their time.

As we begin, I have a few questions I would like to ask you:

1. Are you over 18 and a parent or primary caregiver of a child under 18 who has been diagnosed with autism spectrum disorder?
 - *If nominee answers no to this question, then say, “Thank you for your willingness to talk with me. Being a parent or primary caregiver of a child with ASD is a qualifying factor for participation in this study. Thank you for your time.”*
 - *If nominee answers yes to this question, then go on to question #2.*

2. Have you been the parent or primary caregiver to your child diagnosed with ASD prior to 2020 and during the COVID-19 pandemic to the present?

- *If nominee answers no, then say, “Thank you for your willingness to talk with me.*

Parenthood or primary caregiving of a child diagnosed with ASD prior to 2020 and during the COVID-19 pandemic to the present is a qualifying factor for participation in this study. Thank you for your time.

- *If the nominee answers yes to this question, then go on to question #3.*

3. Is your child with ASD receiving two or more professional services a week; this can include special education services, ABA therapy, occupational, speech, physical, or mental health therapy, respite care, specialized daycare, social skills training, family counseling, social worker services, neurology, pediatrics, psychiatry, or other medical assistance?

- *If the nominee answers no, then say, “Thank you for your willingness to talk with me.*

We are selecting participants who have at least two professional services provided each week for their child with ASD, and it is a qualifying factor for participation in this study. Thank you for your time.

If nominee answers yes to Question #3, then say, “To make sure that the study includes participants from different social locations, I have a few demographic questions I would like to ask you, would that be okay? What is your current family situation in terms of partner relationship status, number of children and other family members in your household, your age, approximate annual income, whether you live in a rural, suburban, or urban area, the way you describe your race, ethnicity, and sex, when your child was diagnosed with ASD and by whom, what severity your child with ASD was diagnosed with?

If nominee is a potential participant, then say, *“Thank you for your information. I will get back to you and let you know if you have been selected to be a part of the study or not. Various factors are going into who will ultimately be chosen as participants for my study based on demographic factors. My goal is to choose people that fit the best for my research, so if you are not chosen, it in no way reflects on your ability or capabilities. I would like to make sure that I have your contact information (double check on e-mail and phone number from nomination form). If you are chosen to be one of the participants, I will be in contact with you soon. If you have not heard from me, then you can assume that you have not been chosen. Do you have any questions for me? (Answer questions, thank nominee for their time).*

Continue Conversation (if nominee is chosen for the participant pool): I would like to talk with you further about this study. May I continue? (Obtain verbal consent). The process of my research will occur through one lengthy interview that will likely last between 60 to 90 minutes.

I would like to schedule a time for our interview which will last between 60 and 90 minutes. Do you have any questions for me at this time before I go on with more information? (Answer questions).

Thank you for your time and willingness to talk with me and participate in my research. Let’s schedule a time and place for us to meet, making sure that we have 90 minutes of uninterrupted time should we need it. I will also need an e-mail address (preferably) to follow up on our phone conversation.

- Obtain contact information, meeting time, and location.

Then say, “Thank you for your time. I look forward to our conversation soon.”

Initial Phone Screening Report

First Name:

Phone Number:

Date:

Marital Status_____. Number of children in the household _____.
 Number of other household members _____. Parent/caregiver age _____. Approx.
 household annual income _____. Geography _____. Race _____.
 Ethnicity _____. Sex _____. When child was diagnosed with ASD and by
 whom _____. Severity of ASD Diagnosis? Level 1: Requiring
 Support _____. Level 2: Requiring Substantial Support _____ Level 3: Requiring Very
 Substantial Support_____.

General Impressions of Nominee:

Is this Nominee a participant in study?

YES NO Maybe (will consider in the future)

E-mail (or regular mail) address of Participant:

Appendix E

Participant Demographic Information Form

Date:

Participant Pseudonym and Number:

1. What is your current relationship status with the ASD child's other biological parent?
2. When was your child diagnosed with ASD and by whom?
3. What severity has your child with ASD been diagnosed with? (Level 1: Requiring Support; Level 2: Requiring Substantial Support; or Level 3: Requiring Very Substantial Support).
(DSM-V severity levels for ASD p. 52).
4. How many professional ASD services does your child require? (Special Education, ABA, OT, PT, Speech Therapy, Mental health counseling, neurology, other medical providers, special camps/schools)
5. What is your age now?
6. How many other children or adults live in your household and their relationship to you?
7. What is your approximate average annual income for your household?
8. Do you live in a rural, suburban, or urban area?
9. How do you describe your race, ethnicity, and sex.

Appendix F

Sample E-Mail to Participant Before First Interview

Date
Name
Address
E-Mail

Dear _____,

Thank you very much for your willingness to participate in my study entitled A STUDY OF PARENTS ACCESSING AND RECEIVING PROFESSIONAL CARE FOR THEIR CHILD WITH AUTISM SPECTRUM DISORDER (ASD) DURING THE COVID-19 OUTBREAK IN WASHINGTON STATE. Based on our recent conversation, we are scheduled to meet at the following place and time:

I will do my best to make sure that our time together is no longer than two hours for this meeting. A consent document is attached to this letter for your convenience. The consent document contains additional information about my research. You will be asked to sign the consent document at the time of the interview.

Thank you for your time. I look forward to our meeting.

Sincerely,

Patrick Barry

Patrick Barry, LMFT
Doctoral Candidate, Department of Community Care and Counseling
Liberty University, School of Behavioral Sciences, Community Care and Counseling

Appendix G

Consent

Title of the Project: *A Phenomenological Study of Parents Accessing and Receiving Professional Care for their Child with Autism Spectrum Disorder (ASD) during the COVID-19 Outbreak in Washington State.*

Principle Investigator: Patrick M. Barry, MA, LMFT, and Doctoral Student at Liberty University, School of Behavioral Sciences/ Department of Community Care and Counseling

Invitation to be Part of a Research Study

You are invited to participate in a research study. To participate, you must be over 18 years old, and a parent or primary caregiver of a child diagnosed with autism spectrum disorder (ASD) prior to 2020. Furthermore, your child must not be high functioning enough to not require at least two professional services on a weekly basis. Taking part in this research project is voluntary.

Please take time to read this entire form and ask questions before deciding whether to take part in this research.

What is the study about and why is it being done?

The purpose of the study is to understand how the changes in professional care for children with ASD, required or influenced by the COVID-19 pandemic, impacted the parents and family of that child. The information discovered during the research will be used to better prepare care providers in similar future events to meet the needs of children with autism and their families.

What will happen if you take part in this study?

If you agree to be in this study, I will ask you to do the following thing:

1. Participate in an interview which will be conducted with specific questions allowing the participant to tell his/her story and experience. During the interview, participants will create a Conceptual Map (CM) representing this experience and then reflect and discuss the symbols and ideas on the map to deepen your description of the experience. Time will be allowed for you to reflect on the map and make corrections or adjustments as needed. This should take approximately 90 minutes. The interview will be audio recorded and then transcribed by the researcher.

How could you or others benefit from this study?

Participants should not expect to receive a direct benefit from taking part in this study.

However, this study may affect the local and state community of ASD care providers by bringing parents' stories/experiences to them and providing them with concentrated feedback on the impact of their policies/changes during the pandemic. This study could have significant applications for the state of Washington, which was one of the most stringent states regarding lock-down and COVID-19 mitigation efforts, either supporting their decisions or encouraging them to consider new approaches

What risks might you experience from being in this study?

The risks involved in this study are minimal, which means they are equal to the risks you would encounter in everyday life.

As a mandated reporter, I am required to report any disclosure of child abuse (abuse or neglect of a child currently under the age of 18), or elder abuse. I am also required to report any specific threats of harm to other individuals to that individual.

How will personal information be protected?

The records of this study will be kept private. Published reports will not include any information that will make it possible to identify a subject. Research records will be stored securely, and only the researcher will have access to the records. Data collected from you may be shared for use in future research studies or with other researchers. If data collected from you is shared, any information that could identify you, if applicable, will be removed before the data is shared.

- Participant responses will be kept confidential through the use of pseudonyms. Interviews will be conducted in a location where others will not easily overhear the conversation.
- Data will be stored on a password locked and encrypted thumb drive and may be used in future presentations. After three years, all electronic records will be deleted. Data will be locked in a 3-lock system: 1. Locked in a file cabinet; 2. Locked in the office; 3. Locked in the building. Data in spreadsheet form and audio recordings on the thumb drive will be encrypted, password-locked and password timed out.
- Interviews will be recorded and transcribed. Recordings will be stored on an encrypted thumb drive that is password locked for three years and then erased. Only the researcher, chair, and reader will have access to these recordings.

Is study participation voluntary?

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with Liberty University or the organization that referred you. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

What should you do if you decide to withdraw from the study?

If you choose to withdraw from the study, please contact the researcher at the email address/phone number included in the next paragraph. Should you choose to withdraw, data collected from you will be destroyed immediately and will not be included in this study.

Whom do you contact if you have questions or concerns about the study?

The researcher conducting this study is Patrick Barry. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact him at ***-***-**** or by email at patrick.barry@liberty.edu. You may also contact the researcher's faculty chair, Dr. John King, at john.king@liberty.edu.

Whom do you contact if you have questions about your rights as a research participant?

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, **you are encouraged** to contact the Institutional Review Board, 1971 University Blvd., Green Hall Ste. 2845, Lynchburg, VA 24515 or email at irb@liberty.edu.

Disclaimer: The Institutional Review Board (IRB) is tasked with ensuring that human subjects research will be conducted in an ethical manner as defined and required by federal regulations. The topics covered and viewpoints expressed or alluded to by student and faculty researchers are those of the researchers and do not necessarily reflect the official policies or positions of Liberty University.

Your Consent

By signing this document, you are agreeing to be in this study. Make sure you understand what the study is about before you sign. You will be given a copy of this document for your records. The researcher will keep a copy with the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.

☐ The researcher has my permission to audio-record me as part of my participation in this study.

Printed Subject Name

Signature & Date

Appendix H

Full Interview Protocol

*Thank you for your willingness to meet with me. As we begin, I would like to share an **INFORMED CONSENT DOCUMENT** with you, and for the next few minutes we will walk through this document and answer any questions you may have. (Read through Appendix G and answer questions. Sign consent form and make a copy for the participant and for the researcher.)*

I will now start our audio recording. (Turn on audio recording. Test the equipment to make sure that it is working properly.) We are now going to spend roughly the next 60 to 90 minutes in an interview where I will be asking you questions and probe for more information from these initial questions, and we will walk through a conceptual mapping exercise, which is simply a very easy visual exercise that will help you organize your story. There are no wrong answers to questions, and you are encouraged to take your time and think deeply about your responses. As a researcher, I am very interested in your story of your experience. I will ask some questions, solicit some answers, and then probe deeper for more information. Are you ready? (Make sure participant is ready and that there are no further questions.)

During this phase of our interview, I will be recording key ideas, concepts, and events on Post-it notes® while you are sharing your story. I will first give you a statement that I would like you to reflect on for a few moments, and then when you are ready, please let me know, and you can proceed while I record some of your thoughts.

Let's take 15-20 minutes, and in that time, can you please describe your experience of accessing and receiving professional care for your child with ASD from either, special educators, ABA therapists, occupational therapists, speech therapists, mental health experts, and medical support during the COVID-19 pandemic?

Once the participant completes answering this question, ask the following question:

Can you please describe how the change in care during the pandemic impacted your own well-being, your child's, and your family's?

(For each question, pause after the asking to allow the participant to gather their thoughts and to ensure you are encouraging them to tell their story. Moreover, while participant is speaking, be prepared to ask further clarifying questions. When they indicate they are complete, then say:)

"I would now like you to take a look at each of the details I wrote on these Post-it notes® and make sure that these details are accurate and a proper reflection of your experience. Are there any other details you would like to add?"

Conceptual Mapping Task

Now that we have all the details checked and reviewed, I will give you the easel pad which can be placed in your lap or on the table for ease of use. I would like you to take each of these Post-it notes® and arrange them on the pad in a way that represents your lived experience of accessing and receiving professional care for your child with ASD during the COVID-19 pandemic, and how the concepts on these notes relate to each other.

"Wonderful! Thanks for doing that. I am now going to give you some colored markers. I would like you to draw a shape around each of the clusters of concepts; it can be a circle, triangle, square, star, a heart, a tree, etc. These shapes should represent the meaning of your cluster of concepts in a way that is important to you. Please feel free to make any comments you like about the process or the concepts as you are working."

Pause while the participant completes this and use reflective listening skills and process observations. *Now, I would like you to draw lines or arrows indicating how these concepts*

interact with each other or how they are related to one another. If there is directional flow in the concepts, please feel free to use arrows or other symbols to depict that flow."

After the CMT has been created, ask the following questions:

- *"Now that you have created this conceptual map about your lived experience of accessing and receiving professional care for your child with ASD during the COVID-19 pandemic, take a few minutes to reflect on it. (Pause until participant indicates they are done reflecting.)"*
- *What strikes you as you look at your conceptual map?*
- *How have things changed for you during the pandemic because of your experience in accessing and receiving care from professionals?*
- *What advice would you give to yourself back in February of 2020 to make things better in accessing and receiving care for your child with ASD now that you have lived through it?*
- *"Where are you now in your story?"*
- *"Is there anything else that you feel compelled to say from this whole experience?"*

(Once the participant has had the opportunity to answer the questions, conclude the interview by saying:)

- *"Thank you very much for sharing your experience with me. Your commitment of time for this project is very important, and I am very grateful. As mentioned previously, this interview has been audio recorded, and I want to remind you that this audio recording and your conceptual map will be described in a way that will protect your confidentiality. If there ever comes a time when you have concerns about confidentiality regarding the conceptual map and your audio recording, please feel free to contact me and we can*

discuss your concerns and take further steps as necessary to ensure your confidentiality.

Thank you again for participating and sharing your experiences.”

Appendix I

Sample Letter to Participant After Face-to-Face Interview

Date
Name
Address
E-Mail

Dear _____,

Thank you very much for your willingness and your time as a participant in my study entitled *A Phenomenological Study of Parents Accessing and Receiving Professional Care for their Child with Autism Spectrum Disorder (ASD) during the COVID-19 Outbreak in Washington State*. Your information is very valuable to this research, and I look forward to reviewing your responses, along with those of other participants in this study.

As mentioned previously, your interview was audio recorded, and I want to remind you the audio recording and your conceptual map will be described in my dissertation in a way that will protect your confidentiality. If there ever comes a time when you have concerns about confidentiality regarding the conceptual map and your audio recording, please feel free to contact me and we can discuss your concerns and take further steps to ensure your confidentiality.

Thank you again for your time.

Sincerely,

Patrick M. Barry

Patrick Barry, LMFT
Doctoral Candidate, Department of Community Care and Counseling
Liberty University, School of Behavioral Sciences, Community Care and Counseling

Appendix J

IRB Approval Letter

LIBERTY UNIVERSITY.

INSTITUTIONAL REVIEW BOARD

October 13, 2022

Patrick Barry
John King

Re: IRB Exemption - IRB-FY22-23-200 A Phenomenological Study of Parents Accessing and Receiving Professional Care for their Child with Autism Spectrum Disorder (ASD) during the COVID-19 Outbreak in Washington State

Dear Patrick Barry, John King,

The Liberty University Institutional Review Board (IRB) has reviewed your application in accordance with the Office for Human Research Protections (OHRP) and Food and Drug Administration (FDA) regulations and finds your study to be exempt from further IRB review. This means you may begin your research with the data safeguarding methods mentioned in your approved application, and no further IRB oversight is required.

Your study falls under the following exemption category, which identifies specific situations in which human participants research is exempt from the policy set forth in 45 CFR 46:104(d):

Category 2.(ii). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording).
Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation.

Your stamped consent form(s) and final versions of your study documents can be found under the Attachments tab within the Submission Details section of your study on Cayuse IRB. Your stamped consent form(s) should be copied and used to gain the consent of your research participants. If you plan to provide your consent information electronically, the contents of the attached consent document(s) should be made available without alteration.

Please note that this exemption only applies to your current research application, and any modifications to your protocol must be reported to the Liberty University IRB for verification of continued exemption status. You may report these changes by completing a modification submission through your Cayuse IRB account.

If you have any questions about this exemption or need assistance in determining whether possible modifications to your protocol would change your exemption status, please email us at irb@liberty.edu.

Sincerely,

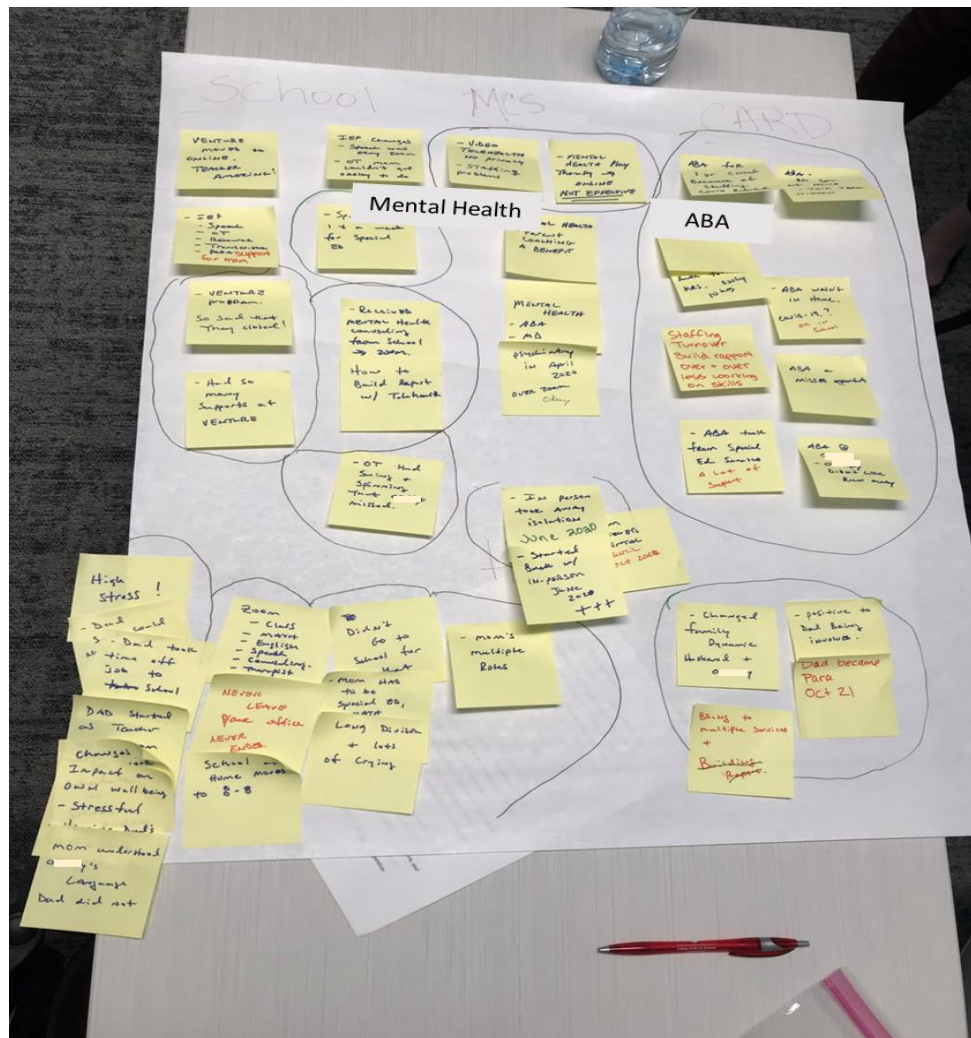
G. Michele Baker, MA, CIP

Administrative Chair of Institutional Research

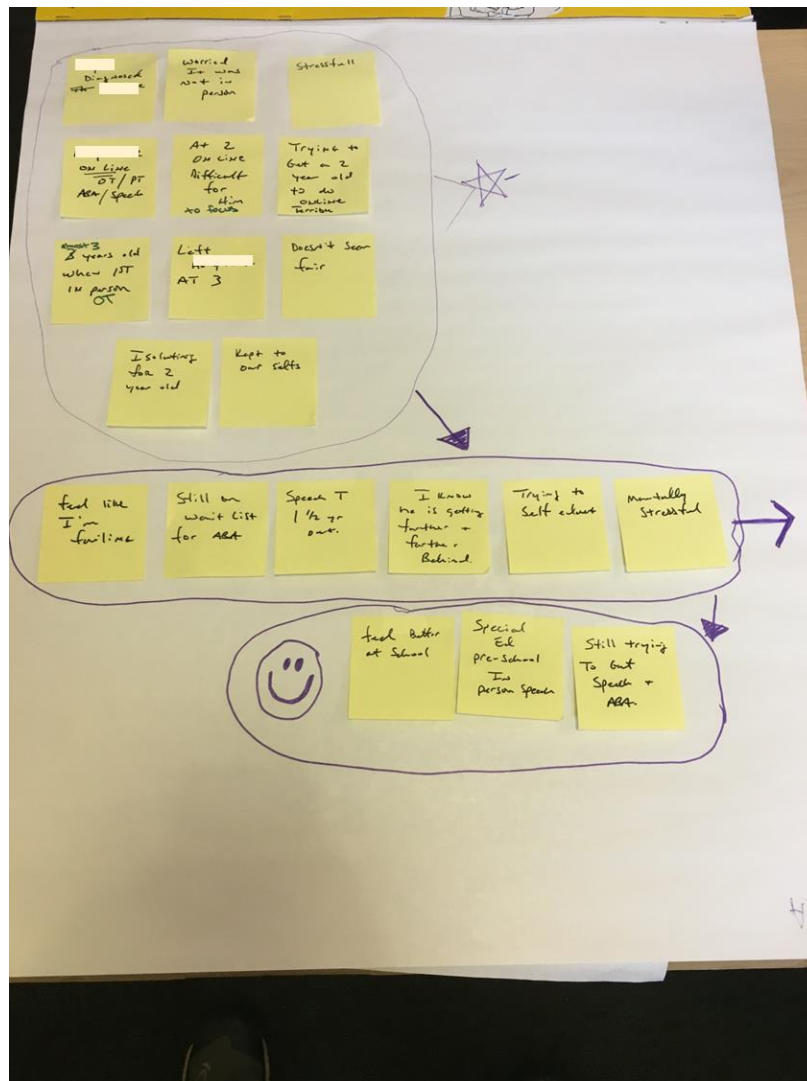
Research Ethics Office

Appendix K

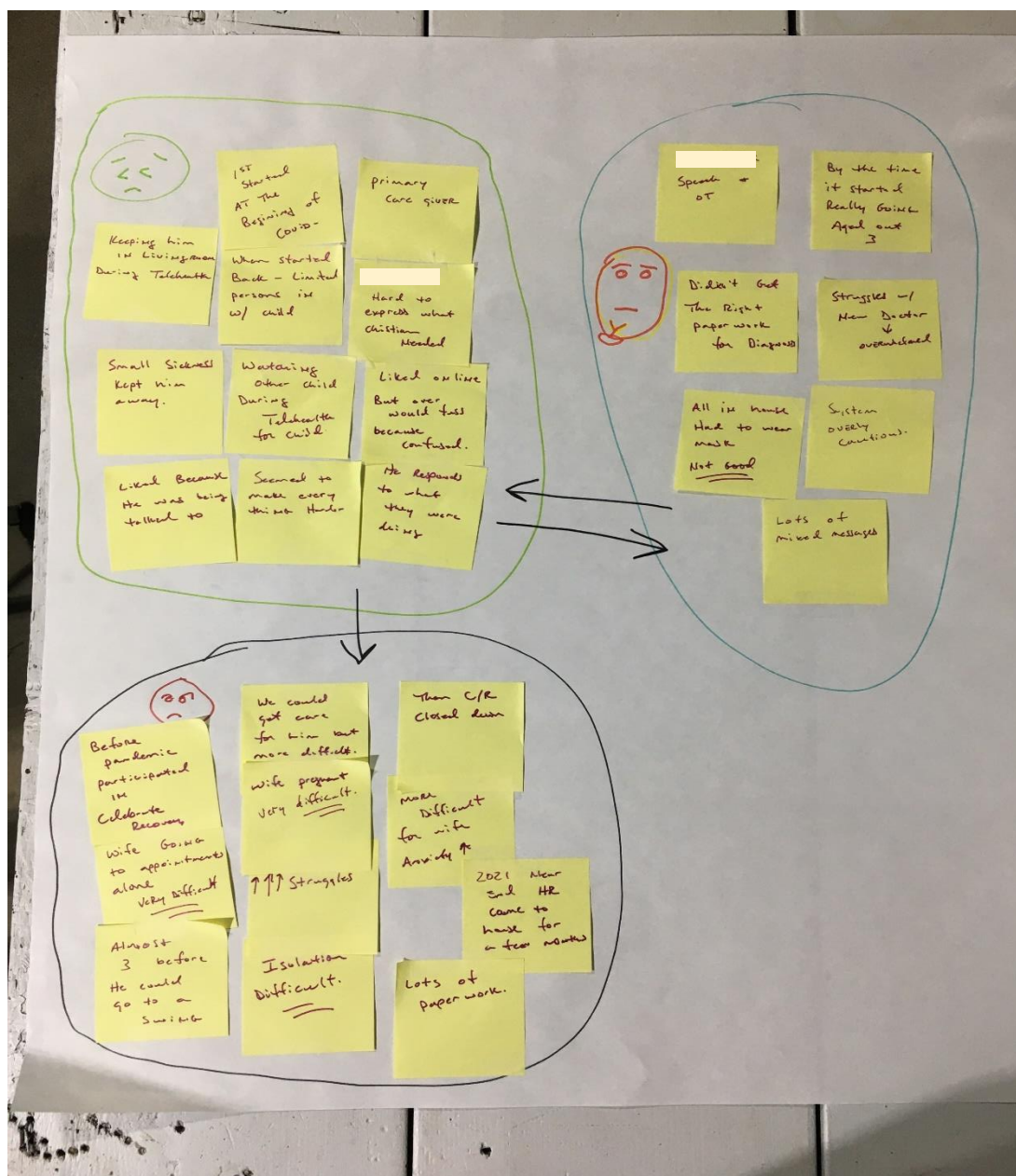
Pictures of the Participant Conceptual Mapping Task



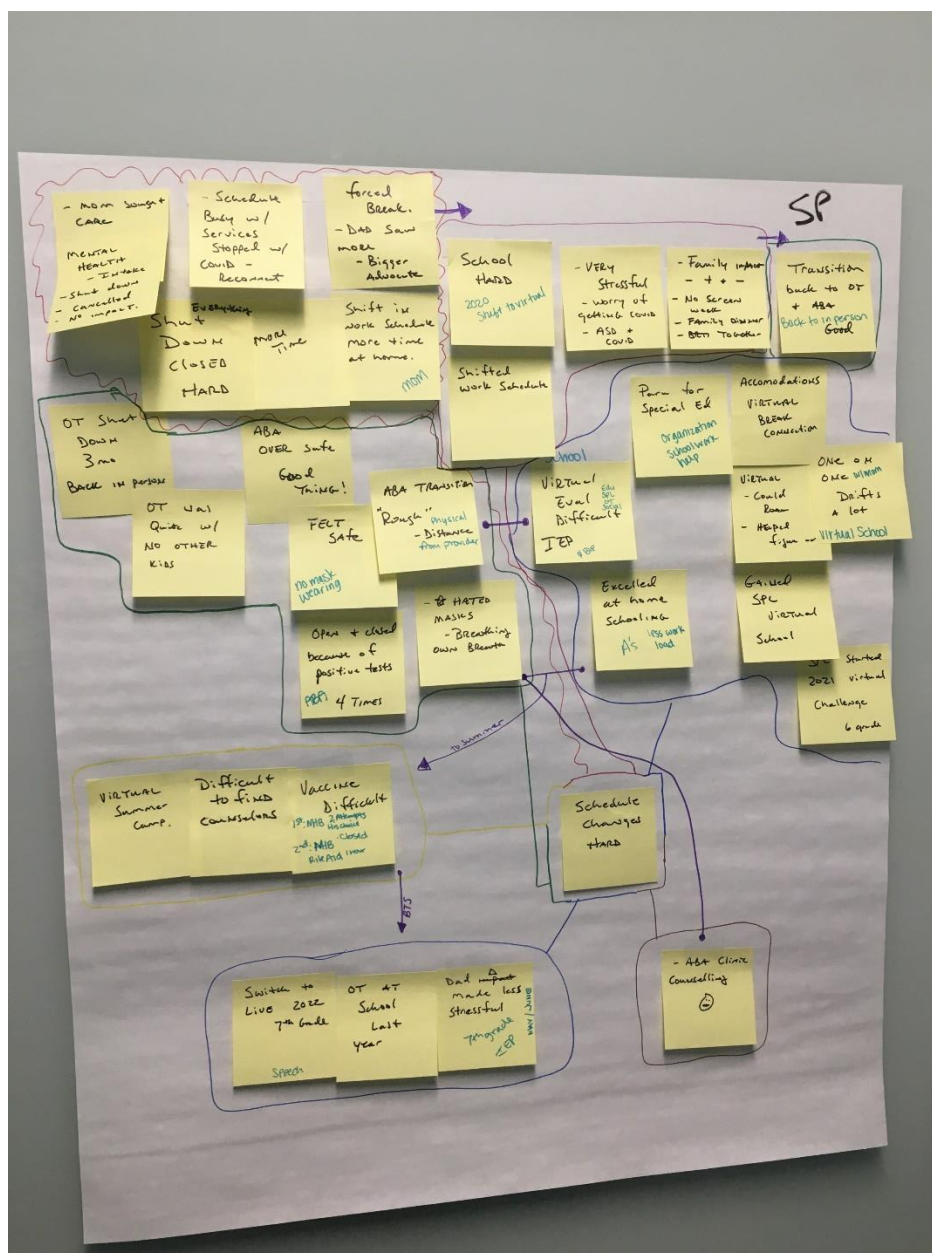
Mandy's Conceptual Mapping Task



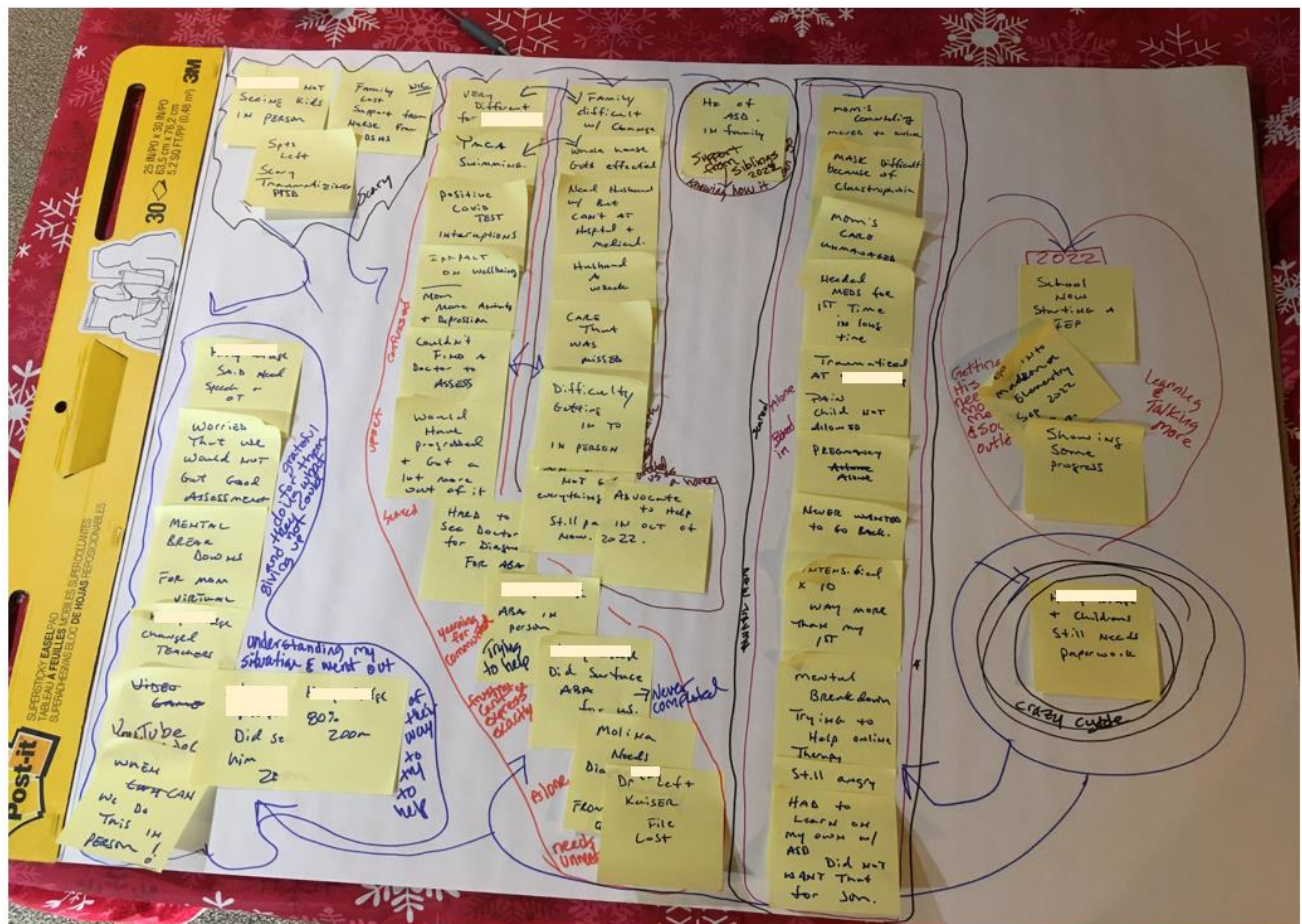
Ashley's Conceptual Mapping Task



Richard's Conceptual Mapping Task



Stacey's Conceptual Mapping Task



Caitlin's Conceptual Mapping Task