

Exploring health literacy development in parents of children with significant disabilities through
an ecological systems and experiential learning framework

by

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B.A.S., Peru State College, 2009
M.S., Peru State College, 2011
M.S. Kansas State University, 2014

AN ABSTRACT OF A DISSERTATION

submitted in partial fulfillment of the requirements for the degree

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Department of Educational Leadership
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Abstract

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I am especially grateful for the 18 participants who trusted me with some of their most difficult and personal memories, experiences many cannot imagine.

Dedication

This dissertation is dedicated to my children, Lucille, Gabriel, Gavin, and Garrin, and to my husband, Scott. You provided both the inspiration and unwavering support that made this work possible. I love you, ‘forever and amen.’

This dissertation is also dedicated to all parents of children with significant disabilities, each navigating their own, unique learning journey.

Chapter 1 - Introduction

Parents and guardians (hereafter ‘parents’) of children with significant disabilities, a small subset of children with special health care needs (CSHCN), represent a heterogeneous and understudied group of adult learners. These parents often take on significant responsibility beyond what is typically expected of parents (Jacobs et al., 2019). Depending on their child’s condition(s), parents may learn to coordinate care and other social services, participate in shared decision-making within the medical home, perform advanced medical procedures, and respond to medical emergencies with life-saving interventions (Sterni et al., 2016). These responsibilities both necessitate and may lead to advanced levels of health literacy and often require professional-mediated education and self-directed learning. The Office of Disease Prevention and Health Promotion (n.d.) defines personal health literacy as “the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others” (para 3). This study applied a constructivist lens to this definition, such that health literacy represented a dynamic skillset (Pizur-Barnekow et al., 2011) developed through parents’ experiences within complex systems in the caregiving role, the primary focus of this investigation.

Background for the Study

Patient and family engagement, defined as “patients, families or their representatives, and health professionals working in active partnership at various levels across the health care system—individual care, organizational design and governance, and system-level policy-making—to improve health and health care” (Carman et al, 2013, p. 224) represents a widely discussed issue. For example, the World Health Organization’s ([WHO], 2025) Patients for Patient Safety (PFPS) initiative recognizes the need for collaboration among patients, families,

and communities to improve patient safety. In pediatric health settings, patients and their parents represent constants during the child’s health journey, offering insights important to the delivery of people-centered services and care (WHO, 2024). Patient, family, and community engagement across health systems can foster a more comprehensive understanding of social determinants of health (i.e., conditions in people’s homes, workplaces, and communities that affect health; Office of Disease Prevention and Health Promotion, n.d.) and contribute to the development of strategies to address immediate needs (Rhodes et al., 2021).

Developing health literacy may support patient and family engagement and health equity, both of which were emphasized in Healthy People 2030, the U.S. government’s ten-year public health agenda (Office of Disease Prevention and Health Promotion, n.d.). Previously, navigating the health care landscape was considered an individual responsibility. Normed health literacy measures primarily assessed individuals’ comprehension and pronunciation of common health-related terms (Agency for Healthcare Research and Quality [AHRQ], 2022), creating a potential gap between the knowledge assessed and the knowledge and skills needed by parents navigating complex systems. However, “...there is an increasing recognition that there are two sides to health literacy: the skills that individuals bring to health situations and the abilities of health professionals and institutions to provide health information effectively” (Ronson & Rootman, 2017, p. 109). For example, Healthy People 2030 expanded the definition of health literacy to include organizations’ responsibility for equitably enabling patient participation in health-related decisions (Office of Disease Prevention and Health Promotion, n.d.), positioning health care organizations as institutions responsible for educating patients and families. This updated definition emphasizes organizations’ responsibility “to address the skills that help people move from understanding to action and from a focus on their own health to a focus on the health of

their communities” (Office of Disease Prevention and Health Promotion, n.d., para 6). It also encourages researchers to explore new ways of studying health literacy (Office of Disease Prevention and Health Promotion, n.d.)—a primary consideration in the present dissertation.

Alongside calls for patient and family engagement across systems, community-engaged scholarship (i.e., partnerships among academics and community members in response to real-world challenges) has gained interest in recent years (Ojeh et al., 2024). These partnerships can take many forms, such as patient and family advisory committees (PFACs) or community-engaged research. Community-engaged scholarship recognizes the contributions of a community’s experiential knowledge.

Community–academic partnerships are essential for high-quality, impactful health research, as such engagement enhances clinical trial design and delivery, increases research relevance and sustainability, improves participant recruitment and retention, and enhances external validity, as well as the public’s receptiveness to research. (Carter-Edwards et al., 2021, p. 558)

Investigators have reported challenges, such as difficulties developing relationships with patient and family partners, fostering co-learning, and resource sharing (Carter-Edwards et al., 2021), further illustrating the need to advance the knowledge base related to patient and family learning when engaging within these contexts.

Ideas such as shared responsibility and co-learning can also be identified at the individual level of care. Professional organizations, including the American Academy of Pediatrics (AAP), endorse the integration of patient- and family-centered principles across all levels of care delivery (Sterni et al., 2016). Patient- and family-centered care represents a “partnership approach to decision-making between health professionals and the [patient and] family in all

aspects of care” (p. e19). This approach to care encourages collaboration by acknowledging the uniqueness of individual patients and families and incorporating the patient and family’s perspectives into care planning and decision-making (Kuo et al., 2012).

Achieving the family-centered care ideal and involving parents in their children’s care decisions may require patient education and, subsequently, adult learning. In her work characterizing hospital patients as adult learners, Caffarella (1980) defined patient education as the process through which patients and families receive information, acquire skills, and develop attitudes to manage health conditions. ‘Adult health learning’ takes this a step further, stressing “the need to focus on adults as participants, critical thinkers, and agents of change” (English, 2017, p. 13). However, the recognition of patients, or parents in this case, as adult learners may be underutilized in the United States. For some, patient education represents knowledge transfer, where expert providers maintain responsibility for information sharing, with an expectation that patients will then comply with the given recommendations (Paterick et al., 2017). In the context of children with significant disabilities, this transactional approach positions parents as predominantly passive recipients of information (Fiala et al., 2024). Approaching parent education through an adult learning lens acknowledges each parent’s lived experience and positions them as active participants in co-constructing knowledge of their child’s condition and care plan. Advancing health literacy and the potential for patient and family engagement within these interrelated systems calls for further exploration of the dynamic spaces in which parents learn (Fiala et al., 2024).

Rationale for the Study

Understanding parents’ learning experiences in the context of the caregiving role holds promise for increasing parent engagement across the health continuum, potentially contributing

to improved health outcomes for children with significant disabilities, enhanced experiences for parents, and health literate systems better equipped to serve families. While “acquiring the requisite knowledge, skills, and organization necessary to raise a child with a chronic health condition creates many challenges and claims a significant portion of family resources” (Ray, 2002, p. 424), learning can represent a key coping mechanism in response to chronic illness (Baumgartner, 2011). A significant body of literature exists concerning the impact of supporting a child with significant disabilities on parents’ coping skills and mental health (e.g., Churchill et al., 2010; Drummond et al., 2012; Graaf et al., 2022) and employment and financial challenges (e.g., Foster et al., 2021; Loprest & Davidoff, 2004; Okumura et al., 2009; Ouyang et al., 2014). Understanding parents’ learning within the context of caregiving may support the development of interventions to reduce the burden resulting from their situation.

As introduced above, parents often take on substantial responsibility for providing care and support to their children with significant disabilities (Ray, 2002; Yu et al., 2022), yet their learning in this context remains understudied (Coady, 2013). For parents of children who require long-term mechanical ventilation, for example, health literacy (i.e., the degree to which they can use health-related information to take action) may be a source of empowerment when responding to tracheostomy-related emergencies. These parents must be able to identify, interpret, and respond to signs of respiratory distress (e.g., changes in work of breathing, color, vital signs) and solicit emergency services should their problem-solving efforts be unsuccessful (Sterni et al., 2016). As such the parents would serve as a key information source if the child were admitted to the hospital, a collection of responsibilities that positions them as important partners in their child’s health outcomes (Asuncion et al., 2022). The scope of parents’ responsibilities varies greatly depending on the child’s unique needs; however, these “tasks [often] require complex

cognitive and social skills, such as understanding medical terminology; evaluating treatment options; communicating with health care providers; locating community-based resources; and problem-solving barriers across health care, educational, and social service systems” (Mirza et al., 2018 p. 402). While limited research has been conducted examining the influence of parents’ health literacy on outcomes for children with significant disabilities (Keim-Malpass et al., 2015), links are suspected between parents’ understanding of their child’s condition and the quality of care provided in home, medication and treatment plan adherence, and the incidence of unnecessary emergency room visits or unplanned hospitalizations (Kun et al., 2010; Tschamper et al., 2023; Xiang & Miller, 2020; Yin et al., 2010). This is particularly important because of the increased risk for adverse health outcomes faced by children with significant disabilities (Sterni et al., 2016).

Understanding parents’ learning in the context of caregiving holds additional potential related to child health outcomes, including increased child participation and independence, such that children whose parents can find, understand, and use health information (i.e., health literacy) may be more likely to have their dynamic needs met (Lin & Gold, 2018; Yin et al., 2012). Children with significant disabilities often experience co-occurring medical conditions, each requiring separate health care visits and unique interventions that parents may coordinate or administer (Sterni et al., 2016). For example, children who receive long-term mechanical ventilation are often unable to consume all their nutrition orally and instead intake liquid feedings through a gastrostomy or gastrojejunal feeding tube (Sterni et al., 2016). These children may also receive therapies from allied health professionals, qualify for early intervention services through their school district, or rely on Medicaid for medical coverage. “In an ideal world, a child’s medical home would coordinate all services needed; however much of this

responsibility often falls on parents” (Pizur-Barnekow et al., 2011), and research suggests that lower health literacy levels contribute to difficulty accessing services, including early intervention (Harrison et al., 2024).

Understanding parents learning experiences may also provide insight related to supporting broader parent engagement and improving systems. Many parents describe themselves as experts in their child’s care, and this expertise that would bring considerable value to patient and family advisory committees (PFACs) or other academic/health care-community partnerships (Asuncion et al., 2022). For example, Conceição et al. (2011) described collaborating with an interprofessional team of experts (i.e., nurse and physician care coordinators, nurse educator, adult educator, and research coordinator) to develop a care coordination curriculum with advisement from parents of CSHCN. At a larger scale, family leadership and advocacy has brought about many policy changes that have led to programs supporting families’ access to resources (e.g., Parent Training Information Centers, Family-to-Family Health Information Centers). These programs demonstrate the power in parents sharing expertise with other parents, with peer support linked to better management of day-to-day responsibilities and reduced stress and anxiety (Ainbinder et al., 1998). These programs have also been described by parents as fostering meaningful learning about their situation (Ainbinder et al., 1998). As Diehl (2011) described adult basic education classrooms, these federally funded peer-support programs may lead to increased confidence among participants in addition to greater access to services (Rosen-Reynoso et al., 2016).

The present, exploratory study holds promise for future, larger scale research projects contributing to discourse among systems, organizations, professionals, and patients and families.

Problem Statement

Increased emphasis on collaborative practice has resulted in calls for patient and family engagement across the care continuum (e.g., Sterni et al., 2016; WHO et al., 2024), which can include individual care management, academic-community partnerships, and policymaking. Health care organizations have a responsibility to foster equitable participation of parents in health-related decisions (Office of Disease Prevention and Health Promotion, n.d.). Patient and family engagement can require the ability to find, understand, and use health information (i.e., health literacy) during encounters with systems beyond health care organizations (Mirza et al., 2018), such as schools, Social Security, Medicaid, and the Supplemental Nutrition Assistance Program (SNAP). Common normed health literacy measures focus on reading comprehension (AHRQ, 2022), which may not represent parents' knowledge and skill needs. Investigators have explored unidimensional aspects of health literacy and patient and family engagement (e.g., aspects of health literacy, empowerment, and community-engaged research; Yu et al., 2022). However, understanding parents' learning experiences as they engage with these systems requires additional research, knowledge that may contribute to improved child health outcomes and support organizations' efforts to address health literacy.

Statement of Purpose and Research Questions

The purpose of this study is to explore how parents perceive learning from encounters within complex systems in the context of caregiving. Specifically, it explored how parents of children with significant disabilities make meaning from engaging with these interrelated systems.

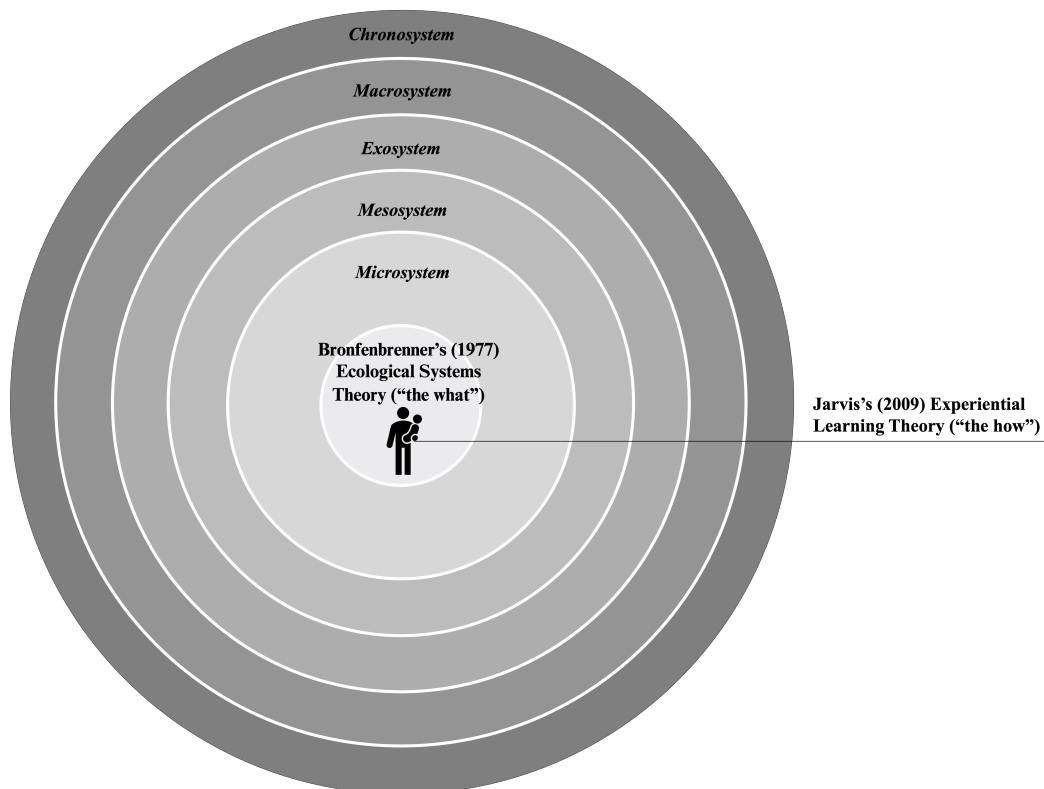
This study aims to address the following research question:

- How do parents of children with significant disabilities describe learning from their experiences in the context of caregiving?

Theoretical Framework

Exploring parents' learning experiences in the context of caregiving requires examination of their encounters with these complex, interrelated systems and their processes for interpreting the experiences. Ronson and Rootman (2017) posited that "health literacy arises from the interaction of the individual and the health context" (p. 109). As such the theoretical framework for this study, depicted in Figure 1.1, layers Bronfenbrenner's (1977) ecological systems model and Jarvis' (2009) experiential learning theory to examine interactions with systems (the "what") and the internal processes of learning from those experiences (the "how").

Figure 1.1. Multi-Theoretical Framework



Note. This figure depicts the theoretical framework for this study, which layers Bronfenbrenner's (1977) ecological systems theory and Jarvis' (2011) experiential learning model.

Ecological Systems Theory

The health care landscape is comprised of multifaceted, interconnected systems spanning personal interactions (e.g., child, parents, providers), environments (e.g., home, clinic, hospital), organizational practices (e.g., protocols, scheduling, electronic health record, insurance rules), community resources (e.g., home-away-from-home housing, community foundations, free clinics), state and national policies (e.g., laws such as the Affordable Care Act, Medicaid eligibility criteria, free and reduced lunch program), and societal expectations (e.g., values related to participation, stigma related to certain conditions, access to care; Carmen et al., 2013). Exploring issues within this complex context requires a framework that supports the consideration of intersecting influences. In his ecology of human development, which was heavily influenced by Lewin, Bronfenbrenner (1977) sought to connect human development to the broader social environment. He posited that a child's interactions across various nested systems (i.e., microsystem, mesosystem, exosystem, and macrosystem) within their changing environments shaped them over time (i.e., chronosystem; Bronfenbrenner, 1994). Bronfenbrenner's ecological systems framework has underpinned numerous studies related to education, child rearing, and caregiving (e.g., Sherman et al., 2024; Polfuss et al., 2019) as it "facilitates organizing information about people and their environment in order to understand their interconnectedness" (Algood et al., 2013, p. 128).

Experiential Learning Theory

Ecological systems theory provides a framework for organizing parents' diverse experiences, while experiential learning theory provides the framework for examining the

internal processes of interpretation and learning (or nonlearning) from the experiences. Informed by Lewin, Dewey, and Piaget, Kolb's (1984) experiential learning cycle remains popular, as evidenced by its contributions to simulation-based education and training in health professions, including psychiatry (Meyer et al., 2021), nursing (Watson et al., 2025), and dental hygiene (Lundquist et al., 2021), for example. Using Kolb's model, health care educators posit that the experience motivates learners who construct knowledge through reflection (Ker et al., 2011). Health care providers have recently incorporated simulation-based training into training for parents of children with tracheostomies (Truitt et al., 2025). However, results from a cross-sectional questionnaire study showed no statistically significant difference in knowledge of tracheostomy-related emergencies between parents who had completed the high-fidelity simulation and those who had not (Truitt et al., 2025). This evidence aligns with Jarvis' (2011) criticism of Kolb's model, which suggested that generalization of learning only occurs after the opportunity to practice the resolution on multiple occurrences. Other criticisms of Kolb's model include its oversimplified, linear depiction of learning, the lack of clarity around what constitutes a "concrete experience," and its overemphasis on cognition (Morris, 2019). Jarvis' (2011) model attempts to address these criticisms and expand upon Kolb's work to consider how people learn in the context of their lifeworld (2009), a model conducive to inductive qualitative research.

Building on tenets of Knowles (1980) andragogy and Kolb's (1984) experiential learning cycle, Jarvis (2011) posited learning to be a lifelong process occurring through primary experiences (i.e., originating from direct interaction with the world) and secondary experiences (i.e., facilitated by others, such as patient education). Primary and secondary experiences can strengthen a person's understanding of their world or contribute to feelings of disjuncture, which

Jarvis described as tension between one's prior experience and their current situation. To illustrate:

A parent's expectations for their 18-month-old child's language development might be influenced by previous primary experiences with the child's older sibling and secondary experiences, such as information shared by the child's pediatrician or online resources.

Disjuncture occurs when the parent's life experience (e.g., the 18-month-old not meeting the same milestones as their sibling) differs from life as they know it (e.g., expectation for children to talk early). (Fiala et al., 2024, p. 3-4)

This type of disharmony can contribute to feelings of uncertainty and may lead to explicit questions regarding the appropriate course of action (Jarvis, 2009).

Resolving a minor discrepancy between one's prior knowledge and current situation may result in a small shift in understanding (Jarvis, 2009). Continuing with the previous example, "soliciting advice from the child's pediatrician might help a parent reframe their expectations for the child's speech and language development" (Fiala et al., 2024, p. 4). Responding to a more significant mismatch may lead to shifts in parents' understanding (i.e., cognitive transformation), feelings (i.e., emotive transformation), or actions, habits, or skills (i.e., practical transformation; Jarvis, 2009). Following the example further, "the parent may seek information online, contact the child's pediatrician for guidance, or be referred to a developmental psychologist and speech-language pathologist for further assessment and intervention but still not have resolved the disjuncture" (Fiala et al., 2024, p. 4). At this point, learning and growth may be episodic as the parent integrates meaning from the experiences into their developing biography. Resolving disjuncture and returning to a state of harmony can require significant practice of the identified resolution (Jarvis, 2009). Returning to the example, substantial practice with an intervention

(e.g., speech generating device) may be necessary to support the parent's resolution of the disjuncture (Fiala et al., 2024). Over time, these tasks may become routine, and the parent may internalize the role as part of their identity (Jarvis, 2009). However, parents who perceive the gap as being too large may instead rely on their previous understanding of the world (i.e., nonlearning; Fiala et al., 2024).

Although there is limited research on parents' development of health literacy in the context of caregiving, insights from previous research support grounding this study in Jarvis' experiential learning model (Fiala et al., 2024). For example, parents participating in a qualitative study in Norway described gaining knowledge through their experiences caring for their children with epilepsy (Tscharper et al., 2023). Developing and maintaining health literacy in this context "was described as a continuous emotional, cognitive, and social process" (Tscharper et al., 2023, p. 5). The researchers' analysis of the interviews includes examples of what Jarvis (2009) coined as disjuncture, such as the period following diagnosis, and suggestions for supporting parents' unique learning journeys (e.g., co-co-creating a follow-up plan; Tscharper et al., 2023).

Methodology, Methods, and Data Collection

This study seeks to understand parents' learning experiences by employing a methodology and design rooted in the constructivist notion that "meaning is constructed based on people's understanding of their worlds, experiences, interactions with events, and circumstances in their lives" (Bhattacharya, 2017, p. 2). Aligning with this ontological and epistemological position and the multi-theoretical framework underpinning this study, a general basic interpretive methodology was selected to support the translation of theoretical insights to practical application (Merriam & Tisdell, 2015). As such the methodology for this basic

qualitative study involves conducting in-depth interviews by posing open-ended exploratory research questions, collecting verbal reports and observations, systematically analyzing this data, carefully representing their meaning, organizing them into clusters, disclosing the researcher's perspectives, and presenting the clusters in a model (Elliot & Timulak, 2021).

Participants were recruited through my professional and social networks, which include more than 65,000 family members of children who experience autism spectrum disorder (ASD), 47,000 mothers of babies who spent time in a neonatal intensive care unit (NICU), 8,000 parents of children living with tracheostomy tubes, and more than 1,500 parents of individuals with developmental disabilities. Interested parties completed a screening process to determine their relationship with a child experiencing significant disabilities. Before participating in the study, participants were informed of the associated risks, according to the informed consent procedure approved by Kansas State University's Institutional Review Board (IRB).

Data was collected from 18 parents of children with significant disabilities through a series of semi-structured interviews held via web conferencing software. Participants were asked to consider their experiences within the complex systems of caregiving, including those before and on behalf of or with their child. To acknowledge the expertise parents brought to this study, participants received a \$20 stipend, payable by virtual gift card, for completion of the information checklist and initial interview, \$20 for the participation in the second interview, and \$10 for validating interpretations during the member checking process. Interviews were recorded and transcribed, and this data was housed on Kansas State University's encrypted software systems. Inductive analysis was used to code and categorize the deidentified transcriptions (Saldaña, 2021). Analytical memos and field notes were kept throughout the process to support

researcher subjectivity, and participants were invited to provide feedback on the findings through member checks (Saldaña, 2021).

Significance of this Study

Children with significant disabilities (Zablotsky et al., 2019), including those with medical complexity (Cohen et al., 2011), represent a growing population of people who often require specialized care and services. Most of these children live at home with family caregivers who support daily living tasks, provide medical treatments, and coordinate care and other services (Yu et al., 2022). There is a paucity of literature exploring parent experiences within the complex, interrelated systems they navigate, particularly in relation to how these experiences influence learning. Instead, the knowledge base on the parental caregiving experience is largely comprised of unidimensional studies (Yu et al., 2022), such that they focus on health literacy or parent engagement within a single system (e.g., hospital; Anderson et al., 2021), explore the development of parent health literacy related to a specific diagnosis (e.g., epilepsy; Tschamper et al., 2023), highlight an isolated element of the caregiver role (e.g., medication administration; Yin et al., 2010), or attempt to evaluate the impact of parent health literacy on outcomes (e.g., DeWalt & Hink, 2009; Hassan et al., 2010; Lawrence et al., 2021). Studies have also assessed targeted technology-based interventions, such as a chatbot with integrated gamification (Bui et al., 2022) and a voice-activated note recording and transcription application (Sezgin et al., 2022), parents' coping skills and mental health (e.g., Churchill et al., 2010; Drummond et al., 2012; Graaf et al., 2022; Holmes et al., 2024), employment and financial challenges (e.g., Foster et al., 2021; Loprest & Davidoff, 2004; Okumura et al., 2009; Ouyang et al., 2014), and perceptions of care (e.g., Bellin et al., 2011; Kenney et al., 2011; Kerfeld et al., 2011). No studies were found

that conceptualized parents as adult learners to investigate their perceived learning experiences related to engagement within systems in the context of caregiving, the aim of the present study.

Delimitations and Limitations of the Study

Delimitations describe the boundaries of the study set by the researcher (Roberts & Hyatt, 2024). The time frame, participant characteristics, and the data sources bounded this dissertation. First, this study was conducted between September 2025 and February 2026. Next, study participants were limited to parents or guardians of children with significant disabilities, living in the United States, who did not have formal clinical education before taking on the caregiver role. Gaps in existing literature regarding parents' learning experiences and the potential for parent health literacy to influence the outcomes of children with significant disabilities (Keim-Malpass et al., 2015) support this delimitation.

Limitations represent constraints beyond the researcher's control (Terrell, 2022). Parents came from diverse backgrounds and with experience supporting children with different conditions and unique needs; thus, their experiences may have been heavily influenced by specific institutions or systems, potentially limiting the transferability of the findings. Additionally, this qualitative study relied on participants' conscious memories of their experiences navigating complex, interrelated systems in the context of caregiving, which research suggests may be stressful for parents (Holmes et al., 2024).

Definitions

This study relied on the following definitions of terms:

Caregiving—Care and support for a child with significant disabilities, beyond that what is typically expected of parents, such as coordination of resources and providing aid to meet a child's health and developmental needs (Teicher et al., 2023).

Children with Significant Disabilities—People under age 18 with health conditions lasting 12 months or longer who cannot do things most children of the same age can do, and/or their daily activities are substantially affected by a chronic health condition (Yu et al., 2022). Children with medical complexity refers to a small subset of children with significant disabilities “who experience multiple severe health conditions, extensive health service needs, and elevated health care utilization, in addition to disability and functional limitations” (Yu et al., 2022, p. 1489).

Health Literacy—Sometimes referred to as personal health literacy, meaning one’s ability to find, understand, and use health information to inform decisions and actions (Office of Disease Prevention and Health Promotion, n.d.). Organizational health literacy refers to the level at which health care services and information organizations address personal health literacy (Office of Disease Prevention and Health Promotion, n.d.). This study applied a constructivist lens to these terms such that they are seen as dynamic (Pizur-Barnekow et al., 2011) developing through and in response to experiences.

Learning—A complex, lifelong set of processes in which one interprets and integrates meaning from their primary and secondary experiences into their developing biography in the context of society (Jarvis, 2009).

Parent—A person with primary responsibility for raising a child, including a biological parent, foster or adoptive parent, or legal guardian.

Chapter Summary

Parents of children with significant disabilities often assume responsibilities beyond the typical tasks associated with the parental role (Jacobs et al., 2019). Layering Bronfenbrenner’s (1977) ecological systems theory and Jarvis’ (2009) experiential learning theory, this dissertation

will explore how these adults perceive learning from encounters within the complex systems of caregiving. Calls from the WHO (n.d.) and the American Academy of Pediatrics (Sterni et al., 2016) encourage patient and family involvement across the health care continuum, and the inclusion of organizational health literacy in Healthy People 2030 extends responsibility for equitably involving patients in decision-making to health care organizations (Office of Disease Prevention and Health Promotion, n.d.). This shift, alongside gaps in the existing literature and a potential mismatch between patient education and normed health literacy measures and the knowledge and skills parents may need, underscores the importance of this study.

Organization of the Dissertation

This dissertation is organized into five chapters, including the introduction. In Chapter 2, I examine the literature related to this study's multi-theoretical framework. In this chapter, parents are positioned as adult learners learning through primary and secondary experiences framed by Bronfenbrenner's (1977) ecological systems theory and Jarvis' (2011) experiential learning model. In Chapter 3, I describe the study's methodology and methods, which were grounded in the constructivist paradigm. In Chapter 4, I present an analysis of the data and a discussion of the research findings. In Chapter 5, I summarize the dissertation, delineating conclusions and recommendations for further research. The bibliography and appendices can be found at the end of this report.

Chapter 2 - Literature Review

This study sought to explore how parents learn from experiences within the context of caregiving. Chapter 2 - presents a thematic review of the literature, highlighting the gaps this study seeks to address. Ronson and Rootman (2017) posited that "health literacy arises from the interaction of the individual and the health context" (p. 109). As such this chapter is organized

into three sections: health literacy, ecological systems of caregiving, and learning from the caregiving experience. The ecological systems of caregiving section presents the characteristics of parents and the diverse contexts associated with caring for children with significant disabilities and introduces Bronfenbrenner's (1977) ecological systems model for organizing these complex, interrelated systems. The learning from the caregiving experience section situates parents as adult learners and presents experiential learning theory (Jarvis, 2011) as a framework for understanding how these learners make meaning from their varied experiences in the context of caregiving. Throughout the chapter, the multi-theoretical framework and study are grounded in current and historical literature.

Health Literacy

The emergence of the health literacy construct represents the convergence of multiple, overlapping perspectives, including public health, school education, adult education, and clinical medicine (Huber et al., 2012; Okan, 2019). In the 1940s, for example, the federal government recognized the need for generally understandable health-related materials for soldiers returning from World War II (Huber et al., 2012). At this time, health care was largely paternalistic in that expert providers made all the decisions, and patients passively received care and information (Pomey et al., 2015). This approach reflects the ontological model, where disease is thought to be an "entity located in the body and conceptually separable from the sick person" (Stewart et al., 2024, p. 28). Just as Dewey (1938) criticized education that presented static knowledge, this model of health care conceptualizes diagnoses and treatments as objective truths with little regard for the patient's subjective experiences.

Beginning in the 1970s, health literacy discussions shifted from individual-level interventions (e.g., understandable materials) to policy-driven social change, first involving the

health care sector, education system, and entertainment industry (Okan, 2019). During this time, patients were becoming more involved in their care, making health literacy a competency in need of measurement (Huber et al., 2012). Simonds (1974) coined the term health literacy to reference the outcome of health education in public schools (i.e., a health-literate person), although schools were slow to adapt health education standards (Okan, 2019). By the 1990s, the government, informed by concerning national literacy levels, recognized health literacy as a commodity for advancing the nation, making it worthy of federal investment (Huber et al., 2012). Adult educators recognized health literacy as a source of empowerment (Diehl, 2011). These professionals have been said to incorporate health literacy concepts into numeracy and literacy instruction long before the term was published in the literature (Okan, 2019). Results from the Test of Functional Health Literacy for Adults (TOFHLA) spurred increased attention from health care professionals, who identified health literacy as a means to improve treatment adherence and reduce costs (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association [AMA], 1999).

Historically, literature on communicating health information and assessing health literacy has largely focused on fixed, decontextualized information, reflecting the banking concept Freire (1970) described. In the banking concept of education, educators deposit their knowledge into passive learners, responsible for receipt, memorization, and repetition. This linear model remains evident in health care literature in that clear instructions are thought to lead to patient understanding and ultimately treatment adherence (Glick et al., 2024). In the context of personal health care management, the Centers for Disease Control and Prevention ([CDC], 2024) suggests using plain or simplified language when discussing complex health information as a best practice. The AHRQ Health Literacy Universal Precautions Toolkit further advises providers to

“limit information to one to three ‘need-to-know’ or ‘need-to-do’ points, and emphasize them more than once” (Brach, 2024). These strategies may represent important scaffolding techniques, but they may also result in gaps between the provider’s education and the parent’s learning needs.

Normed health literacy measures, which often assess individuals’ comprehension and pronunciation of common health-related terms (Agency for Healthcare Research and Quality [AHRQ], 2022), also exemplify a focus on fixed information. These measures, including TOFHLA and the Short Test of Functional Health Literacy for Adults (STOFHLA; Nurss et al., 1995), two of the more than 200 health literacy measures in use today (Okan, 2019; Tufts Medicine Center for Health Literacy Research and Practice, n.d.), frame health literacy as an individual competency. The TOFHLA and the STOFHLA rely at least partially on the cloze technique in attempt to subjectively measure comprehension (Baker et al., 1999; Williams et al., 1995). This method assesses a patient’s ability to select the correct word for blanks placed every 5-7 words in what the authors describe as common health-related texts (Baker et al., 1999). The following represents an example question from STOFHLA: “After (a. minute, b. midnight, c. during, d. before), you must not (a. easy, b. eat, c. drank, d. eat) anything at (a. ill, b. all, c. each, d. any) until after you have (a. are, b. has, c. had, d. was) the X-ray” (Nurss et al., 1995, p.7). Patients’ inability to correctly complete these sentences has been equated to numerous claims, such as “between 10.8% (Los Angeles, English) and 33.0% (Los Angeles, Spanish) of patients could not read well enough to understand standard preparation instructions for an upper gastrointestinal tract radiographic procedure” (Williams et al., 1995, p. 1675).

Critics of the cloze method posit that this type of assessment fails to measure a person’s ability to integrate and understand the broader purpose or implications of a text (Kleijn et al.,

2019; Shanahan et al., 1982), which is particularly important when considering a parent's understanding of health-related materials. Likewise, the AMA's Council on Scientific Affairs, notably lacking patient representation, explained:

An individual's functional health literacy—the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient—may be significantly worse than their general literacy, because functional literacy is context specific. That is, an individual may be able to read and understand materials with familiar content but struggles to comprehend materials written at the same level of complexity if that material contains unfamiliar vocabulary and concepts. (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, AMA, 1999)

To the ad hoc committee's point, TOFHLA and STOFHLA assess patients' abilities to interpret health care information related to procedures, medications, results, and services which may not have been representative of their lived experiences, such that they require patient education. Modifying the example question to electrical safety or car maintenance further illustrates this point.

- a. If the wires are still (a. current, b. on, c. hot, d. shock), do not (a. see, b. tie, c. touch, d., glue).
- b. If your engine oil is (a. dirty, b. fast, c. slow, d. empty), you should (a. drive, b. change, c. call, d. fill) it.

A person unfamiliar with basic electrical safety or car maintenance may or may not be able to recognize the correct word. Either way, this type of assessment does not capture an individual's ability to act on the information (e.g., turn off the circuit before touching the wires or changing

engine oil if it is dirty). In each of these contexts, we readily accept that consumers may need to hire an electrician or mechanic. In contrast, health literacy has historically been framed as an individual deficit in need of remediation.

Conventional approaches position patients as individually responsible for their ability to engage within these complex systems. However, health literacy has increasingly been recognized “as a two-sided concept in which individual abilities and system demands and complexities must meet to promote health literacy and sustain effective health practices” (Okan, 2019, p. 27), and recent decades have seen efforts to adjust system structures to meet the needs of patient populations (Altin et al, 2014). Calls for a standardized measurement tool led to many theoretical frameworks, definitions, and assessments of health literacy. These assessments, which may include a combination of direct testing and self-report instruments, attempt to measure multiple dimensions of health literacy (e.g., print literacy, oral literacy, numeracy; Altin et al., 2014). For example, the Health Literacy Management Scale (HeLMS) aims to assess the following individual abilities: knowledge of where to access health information, verbal communication, being proactive, literacy skills, capacity to retain and process information, and application skills to manage health (Jordan et al., 2013). While HeLMS incorporates domains such as attitudes, communication, and social support, it continues to frame health literacy as a skillset or capacity owned by an individual patient without consideration of the learning process.

The recognition of health literacy as arising from interactions between the system and individuals and efforts to engage patients in their care and those of others align with Dewey’s (1916) and Freire’s (1970) views on education, empowerment, and democratic participation. Creating space for patient engagement represents a major paradigm shift, and achieving this ideal will involve an ongoing search for common ground (Stewart et al., 2024):

The search for common ground should be an exchange and synthesis of meanings. The physician interprets the patient's illness in terms of physical pathology, the name of the disease, causal inferences, and therapeutic choices. The patient interprets it in terms of experience: what it is like for them to suffer from the illness, beliefs about its nature, and expectations of therapy. Ideally, the exchange results in a synthesis of perspectives: they are, after all, different perspectives – concrete or abstract – of the same reality.” (p. 32)

Similarly, Freire (1970) described co-intentional education. When applied to pediatric health care, providers and parents, “content on reality, are both Subjects, not only in the task of unveiling that reality, and thereby coming to know it critically, but in the task of re-creating that knowledge” (p. 69). Likewise, Dewey (1916) emphasized education as an opportunity for collaborative inquiry, writing, “Communication is a process of sharing experience till it becomes a common possession. It modifies the disposition of both the parties who partake in it” (p. 12). Drawing on these insights, English (2017) conceptualized adult health learning, stressing “the need to focus on adults as participants, critical thinkers, and agents of change” (p. 13).

With the expansion of health literacy definitions, Healthy People 2030, the United States decennial public health agenda, attempted to balance health literacy as an individual, measurable skill while acknowledging it as a dynamic, contextual, and social process (Office of Disease Prevention and Health Promotion, n.d.). Healthy People 2030 also emphasized organizations' efforts “to address the skills that help people move from understanding to action and from a focus on their own health to a focus on the health of their communities” (Office of Disease Prevention and Health Promotion, n.d., para 3). This framework encourages collaboration across disciplines in responding to pressing public health concerns and new ways of researching health

literacy (Office of Disease Prevention and Health Promotion, n.d.), considerations in the present dissertation.

The complex, overlapping layers of health literacy begin to illustrate the context within which parents of children with significant disabilities must engage.

Studies

Health literacy has garnered a significant amount of attention across the globe—a search for the term on PubMed returned more than 37,000 results. Mackert et al. (2015) described four primary directions of health literacy research: condition-specific (e.g., diabetes, mental health), population-specific (e.g., age, role), channel or context-specific (e.g., how patients receive information such as media, internet, etc.), and language-specific studies. The present study seeks to understand the learning experiences (i.e., contexts) that have contributed to the perceived health literacy of English-speaking (i.e., language; resource limitation) parents (i.e., population) of children with significant disabilities (i.e., conditions), recognizing that “health literacy arises from the interaction of the individual and the health context” (Ronson & Rootman, 2017, p. 109). In a meta-narrative review of studies examining health literacy in relation to social context, Pitt et al. (2019) identified six primary traditions of study at the intersection of health literacy and the social context, including studies examining: (1) the relationship between functional health literacy scores and social resources, (2) support received from others, (3) collective health literacy, (4) social connections as an element of health literacy, (5) aggregates of individual health literacy across a dyad or community, and (6) health literacy as the ability to negotiate multiple knowledges. Like many of the studies, results from the present study may blur these lines (Pitt et al., 2019), but they will primarily fit within the knowledge related tradition, where minimal research has been conducted.

Efforts examining health literacy in the United States have been largely top-down, with limited engagement of patients, families, and communities (Huber et al., 2012) beyond data collection, which seemingly frames health literacy as something to be ‘diagnosed.’ For example, Glick et al. (2024) interviewed pediatricians caring for children with medical complexity to better understand the barriers and facilitators to parent comprehension and adherence to discharge instructions, exemplifying an ontological perspective in the context of parent health literacy (Stewart et al., 2024). Unsurprisingly, the findings represent pediatricians' perspectives rather than those of the parent learners. This study highlighted the “need for a family-centered and health-literacy informed approach”; however, recommendations focused on parents’ immediate understanding of what is being said (e.g., need for interpreters, stress as a barrier to understanding, and the use of plain language or teach back technique; Glick et al., 2024, p. 284). Although important factors, this emphasis does not demonstrate an interest by providers in developing parents as active participants over time, especially important for parents supporting their child’s chronic illness management. Although experienced parents have been described as experts in their child’s care (e.g., Glick et al., 2024; Ainbinder et al., 1998), no domestic studies were identified to have asked parents to articulate how experiences contributed to their learning.

Researchers in Australia, Canada, and several European countries (e.g., Ireland, the Netherlands, Norway) have demonstrated interest in broader approaches to examining the complex construct of health literacy. For example, Nutbeam (2008) expanded the deficit-based view that health literacy poses clinical risk, describing health literacy as also representing a personal asset developed through interactions with the health care context over time. Nutbeam’s (2000) previous work, in which he defined three levels of health literacy: (1) basic/functional health literacy (i.e., basic reading and writing skills for negotiating health-related texts), (2)

communicative/interactive (i.e., more advanced skills necessary for engaging with health information and participating in decision-making), and (3) critical literacy (i.e., advanced cognitive skills needed for critical analysis of health information and personal control) can be compared to Bloom's (1956) taxonomy of educational objectives such that he described health literacy as a progression of cognitive and skill development. This model, while underscoring health professionals' role in supporting parents' health literacy development and subsequently equitable participation, represents learning as a linear, hierarchical process which may not be indicative of learning in this dynamic context. A tension appears to exist such that parents need a certain level of health knowledge to meaningfully participate in the development and implementation of their children's care, yet they develop health knowledge through active participation (Nielsen-Bohlman et al., 2004). Balling and McCubbin (2001) explain, "If health care professionals fail to provide parents with opportunities to learn and to participate in the child's care, there is a risk that parents may be unable to make informed decisions and evaluate options that may improve the child's care" (p. 111-112).

Building from Nutbeam's work, Tschamper et al. (2023) explored parents' experiences caring for their children with epilepsy as part of a larger project aimed at co-creating a health literacy intervention. This study's results showcased the knowledge gained by the 10 parents through their experiences in the caregiving role, emphasizing that their development of health literacy was a "continuous emotional, cognitive, and social process" (Tschamper et al., 2023, p. 5). In their publication, referenced in Pitt et al.'s (2019) knowledge tradition, Lloyd et al. (2014) introduced the sociological and embodied aspects of what they called health information practice. Informed by interviews with 10 people with chronic kidney disease and 8 people with HIV, the researchers argued that health literacy in the context of chronic illness represents a

whole person experience such that people construct an ‘information landscape’ through interactions with others (e.g., peers, providers, social networks) and their body (e.g., living with and managing their illness). The authors highlighted health literacy as being constructed across multiple levels, beginning with information about the patient’s illness and moving to information about structure and ways of thinking in various environments (Lloyd et al., 2014).

The current study leverages “the applied learning focus of adult education” (Coady, 2013, p. 322), by employing a theoretical framework supporting the analysis of parents’ interactions within the complex context of caregiving (the “what”) in the United States as part of their ongoing personal biography development (the “how”) as introduced in Figure 1.1. This framework, discussed in the following sections, allows for examination of the social context of adult learning (i.e., societal influences), learning environments (i.e., where learning occurs), and adult learners (Conceição et al., 2011).

Ecological Systems of Caregiving

Parent Characteristics

Parents of children with significant disabilities represent a growing, heterogeneous population. Advancements in technology, health care, and nutritional support have increased the survival of medically fragile infants and children affected by conditions such as premature birth, cerebral palsy, congenital anomalies, and traumatic brain injury (Burns, 2010). Estimates suggest that more than 15 million American youth ages birth to 17 live with a chronic condition (i.e., lasting 12 months or more) or functional limitation (Child and Adolescent Health Measurement Initiative, n.d.), including an estimated 4.2 million children with significant disabilities—conditions that limit a child’s ability to do most age-appropriate activities or greatly affect daily life—and approximately 1 million children with medical complexity—conditions requiring

intensive health care services and frequent utilization of system resources (Yu et al, 2022). While these children may experience hospital stays lasting months or even years (Davies et al., 2014), and systematic health problems may lead to recurring hospitalization during childhood (Burns, 2010), most children with significant disabilities, including those with medical complexity, live at home and rely at least partially on family members for care and support (Yu et al., 2022; Sterni et al., 2016).

These children and their parents come from diverse racial and ethnic backgrounds, family structures and sizes, and economic conditions (Child and Adolescent Health Measurement Initiative, n.d.; Yu et al., 2022). The caregiving role has been linked to economic challenges (e.g., employment reduction or loss; Mandic et al., 2017; Keim-Malpass et al., 2024) and poor mental health (McLachlan et al., 2024; Cousino & Hazen, 2013; Bayer et al., 2021), each with the potential to influence a parent's ability to manage their child's health condition. Parents also have varied educational backgrounds (Child and Adolescent Health Measurement Initiative, n.d.). Data from the 2023 National Survey of Children's Health claim that more than 25% of CSHCN lived in households where the highest level of educational attainment was a high school diploma or less, which may influence understanding of health-related information (Child and Adolescent Health Measurement Initiative, n.d.). Estimates suggest that one in four parents in the United States has low health literacy, which can have far-reaching effects on pediatric health outcomes (Morrison et al., 2019).

Caregiving Contexts

This diversity in demographics is reflected in children's varied health care experiences and parents' changing needs over time. Because of the wide range of medical conditions and developmental disabilities, and the unique ways each presents in individual children, this section

presents only a glimpse into parents' roles and responsibilities as lay health workers (Lewin et al., 2010), specific to supporting children with ventilator dependence, autism spectrum disorder (ASD), spinal cord injuries, and communication disorders. This section also introduces the parent education described in the literature related to supporting children with these conditions; however, the education described may not represent the experiences of all parents.

Ventilator Dependence

At what has been described as an extreme level of medical complexity (Sterni et al., 2016), approximately 8,000 children in the United States receive long-term mechanical ventilation at home, the highest level of respiratory support delivered through an artificial airway or tracheostomy tube (Boroughs & Dougherty, 2012). Due to the risk of morbidity and mortality, parents and home nurses must collaborate to provide continuous monitoring and care (Sterni et al., 2016). Parents must be equipped to deliver routine care (e.g., monitor vital signs, tracheostomy tube replacement and cleaning, airway clearance procedures, and medication administration), recognize and respond to potential problems (e.g., medical equipment failure, unexpected vital signs, and gaps in nursing coverage), and provide lifesaving care in the event of a medical emergency (e.g., accidental decannulation, airway obstruction, and respiratory distress; Sterni et al., 2016). Children who rely on long-term mechanical ventilation often experience co-occurring medical or developmental conditions, each requiring separate health care visits and unique interventions that parents may coordinate or administer (Sterni et al., 2016). For example, children relying on ventilator support are often unable to consume all their nutrition orally and instead intake liquid feedings through a gastrostomy or gastrojejunal feeding tube (Sterni et al., 2016).

Training a parent to support a child who requires long-term mechanical ventilation necessitates an intentional educational program beginning before the tracheostomy tube placement and spanning the admission (Sterni et al., 2016). At Baylor University Medical Center, training for parents included topics such as routine tracheostomy care, tracheostomy tube changes, tracheostomy-specific cardiopulmonary resuscitation (CPR), and home equipment use, including the ventilator (Graf et al., 2008). After this estimated 3-week training period, parents were ‘tested’ by way of a 24-hour room-in experience where they provided all the child’s care independently before taking the child home. At Alfred I duPont Hospital for Children, the training program began with the placement of the tracheostomy tube and spanned 10 weeks, unless the family demonstrated and was “signed off” on each competency sooner (Tearl et al., 2007). Objectives for 13 key topics (e.g., airway management, tracheostomy care, manual ventilation, CPR, suctioning) included “Demonstrate knowledge of indications and precautions for [insert topic]” among others. These trainings demonstrate the variance in parent education from one hospital to another. Furthermore, results from a 25-question, true/false survey of parents followed by a third hospital, Children’s Hospital of Los Angeles, suggested significant gaps in knowledge related to ventilator alarms, mucous plugging, and decannulation (Kun et al., 2010). Like providers at Baylor, Tearl et al. (2007) did not investigate parents’ perception of the educational experience or their perceptions related to preparedness for caring for the child. These studies highlight the need for more research on parents’ learning experiences to support further development of educational strategies (Graf et al., 2008).

The advancement of technology has resulted in the incorporation of simulation-based training (SBT), one such strategy, which studies suggest improves parents’ knowledge and confidence related to tracheostomy-related emergencies (Truitt et al., 2025). At Children’s

Hospital of Atlanta, parents completed standard tracheostomy-related emergency training, which includes one-on-one teaching, audio-visuals, and low-fidelity simulations, and skills demonstration. In 2016, the hospital added a two-hour, high-fidelity simulation-based training, using a programmable mannequin in a simulation lab or education classroom to further prepare parents for responding to tracheostomy-related emergencies. Results from a cross-sectional questionnaire study showed no statistically significant difference in knowledge of tracheostomy-related emergencies between parents who had completed the high-fidelity simulation and those who had not. This finding was particularly interesting as parents who had received the high-fidelity simulation-based training were trained on the same three scenarios described in the survey. While nearly 80% of participants had reported experiencing a tracheostomy-related emergency in the last year, less than half answered all three multiple-choice, scenario-based questions correctly, demonstrating the difference between knowing about and being able to do that Jarvis (2009) described. These parents reported bearing responsibility for 63% of the tracheostomy-related emergencies without a home health care nurse being present. Because these emergencies can result in the death of the child, further study of parents' learning experiences and needs may be warranted.

Autism Spectrum Disorder

Like children with chronic health conditions, some children with disabilities require intensive support to participate in society, although their needs may be more developmental than medically-based. For example, children with autism spectrum disorder (ASD), a neurodevelopmental disorder, frequently experience unique sensory, social, and communication needs (Althoff et al., 2019), such that approximately 25-30% of children with ASD may not be able to rely on speech alone to communicate (Brignell et al., 2018). For some children with ASD,

communication delays can present as challenging behaviors (Brignell et al., 2018). Children with ASD may also experience varied delays in performing self-care skills, such as toileting, dressing, and eating, leading some parents to seek a range of therapeutic services (e.g., behavior therapy, speech therapy, physical therapy, or occupational therapy; Althoff et al., 2019). In addition to coordinating these services, parents are often tasked with mediating therapeutic interventions under the guidance of these therapists (Althoff et al., 2019). Children with ASD may also experience one or more co-occurring conditions, such as insomnia, attention-deficit/hyperactivity disorder (ADHD), intellectual disability, anxiety, or depression (American Psychiatric Association, 2024).

Parents of children who experience ASD may receive “parent training,” a term connected to a range of interventions related to communication, imitation play, adaptive skills, and disruptive behavior (Bearss et al., 2015). In an attempt to provide clarity for practitioners, academics, and parents alike, Bearss et al. (2015) distinguished between *parent support*, during which parents are educated about the child’s diagnosis, and *parent implementation*, which aims to involve parents in supporting skill acquisition or behavior change in their child.

Psychoeducation has a long history of use with families supporting individuals with psychiatric conditions, such as schizophrenia (Smith et al., 2015). For parents of children with ASD, psychoeducation can be self-directed or provider-mediated and may involve providing information about ASD and supporting expectation-setting, services-related advocacy, and treatment evaluation (Bearss et al., 2015). *Transitioning Together*, one psychoeducation program designed to prepare families for their adolescent’s transition out of secondary education, involves a total of 10 sessions, eight of which are group sessions with other families (Smith et al., 2015). Each one and a half-hour session reserves 15 minutes for socializing, 30 minutes for a didactic

session, and 45 minutes for co-constructed problem solving and updates. Out of the ten families that participated in this pilot study, one was highlighted as a case study, with themes relating to reduced feelings of isolation and improvements in the parent-child relationship (Smith et al., 2015).

Parent-mediated interventions prepare parents to either: (1) be the primary agent of skill acquisition or behavior change or (2) support the generalization of skills to the parent or home setting (Bearss et al., 2015). This type of programming can vary greatly in duration and length and can be delivered by a range of providers, including Board Certified Behavior Analysts (BCBAs), special education teachers, and speech-language pathologists (SLPs). Kasari et al. (2010) employed a randomized wait-list control design to evaluate a parent-mediated joint attention intervention. This high-intensity intervention involved three, 45-minute sessions per week for eight weeks where the parent-child dyad received direct instruction, modeling, guided practice, and feedback. Assessment data collected immediately following the intervention and again one year later suggest the intervention contributed to increased joint attention and diversity in functional play. However, the study did not control for natural development or other variables, meaning maintenance or continued growth may have also been influenced by factors other than the intervention (Kasari et al., 2010). Furthermore, no qualitative results were reported to disclose parents' experiences with the intervention.

Spinal Cord Injuries

In addition to changes in mobility and functional abilities, children with spinal cord injuries (SCI) may experience a range of medical conditions (Vogel & Zebracki, 2015). Parents often provide care related to these complex health and daily living needs (Ryerson et al., 2017), which can include tasks like intermittent catheterization to empty the bladder, implementing a

bowel program, and providing essential skin care to reduce the occurrence of pressure ulcers.

Parents are often also involved in their children's use of assistive technology (e.g., power wheelchairs, braces and other orthopedic supports, and aids for bathing and toileting), which supports the child's social participation and participation in activities of daily living.

Additionally, parents provide ongoing support for their child as they navigate the physical and psychological implications of SCI (Ryerson et al., 2017).

Because few studies have explored the experiences of parents of children with spinal cord injuries, Rivelli et al. (2019) grounded the development of their intervention, *Parent Forum*, in the literature on other chronic illnesses and disabilities. The researchers also asked parents how the hospital could support them in caring for their child as part of another study, and informal conversations with parents suggested they would benefit from education, problem-solving training, and peer support. The program's curriculum was developed and delivered by clinical providers across a range of related disciplines, such as pediatric medicine, nursing, recreational therapy, and social work. An advisory board, which included two parents of children with SCI, provided feedback on the design. The program consisted of two half-day sessions with structured PowerPoint presentations focusing on parent mental and physical health, advocacy and problem-solving, treatment evaluation, and unstructured time scheduled to foster further connection among parents. Although feedback from this session suggested high satisfaction, parents desired a greater focus on supporting their children rather than managing their own health and shorter, discussion-based interactions with professionals. Themes from a focus group conducted following the second round of the Parent Forum suggested that parents benefited from the quality of information shared, the opportunity to learn with other parents, and time away from their

regular routines (Rivelli et al., 2019), demonstrating the value of mutual learning among expert providers and expert parents.

Children Who Use Augmentative and Alternative Communication Systems

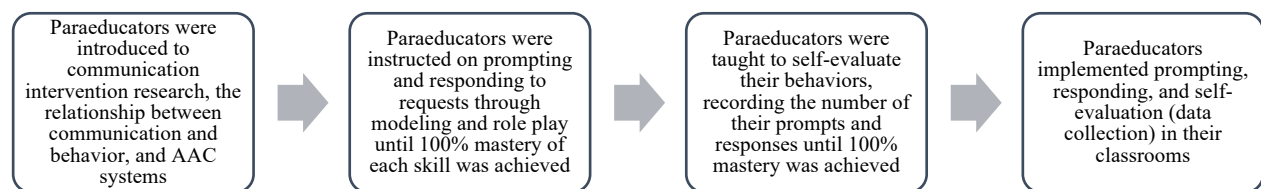
Children with some spinal cord injuries, ASD-related, and other communication disorders may benefit from the use of augmentative and alternative communication systems (AAC; Fager & Spellman, 2010; Light & McNaughton, 2015). AAC systems include any method of communication used in place of or in addition to speech, such as hand gestures, picture cards, or speech generating devices (Holyfield et al., 2023), and can support children's participation in social activities, education, and future employment (Fager & Spellman, 2010). To support participation, parents may need to learn how to use low-tech or high-tech tools and coordinate their use across communicative contexts (Light, 1997). In this way, parents may take on the role of "language intervention agents," functioning as therapists in home and community-based settings (Nunes & Hanline, 2007).

The literature suggests SLPs rely on the guided instruction method, typically implementing one of three general approaches for communication partner interventions: teaching individual or multiple skills in isolation, providing instruction as a group without a clear implementation sequence, or utilizing strategy instruction (Kent-Walsh et al., 2015). Strategies for communication partner interventions might include a checklist to support memorization of the steps in choice-making (Gormley et al., 2023) or instruction on prompting using role play (Bingham et al., 2007).

Individual communication skill training involves the instruction of a single skill, such as manding (i.e., requesting; Ben Chaabane et al., 2009), or multiple skills, such as the components of behavior, communication, prompting, and self-evaluation (Bingham et al., 2007). Ben

Chaabane et al. (2009) trained mothers on baseline and training procedures expecting each mother to implement them with 90% accuracy across sessions or be retrained. Across a series of multi-hour sessions with paraeducators, Bingham et al. (2007) summarized research on communication interventions, highlighted the relationship between behavior and communication, introduced AAC systems, instructed on prompting and responding to requests through role play and modeling, and taught self-evaluation by having learners assess videos of their baseline skills. Paraeducators were provided feedback and retraining until they achieved 100% mastery of each component. The paraeducators were then asked to implement their learning in their classrooms for assessment (Bingham et al., 2007) as illustrated in Figure 2.1.

Figure 2.1. Multiple Skills Training



Note. Based on Bingham et al. (2007)

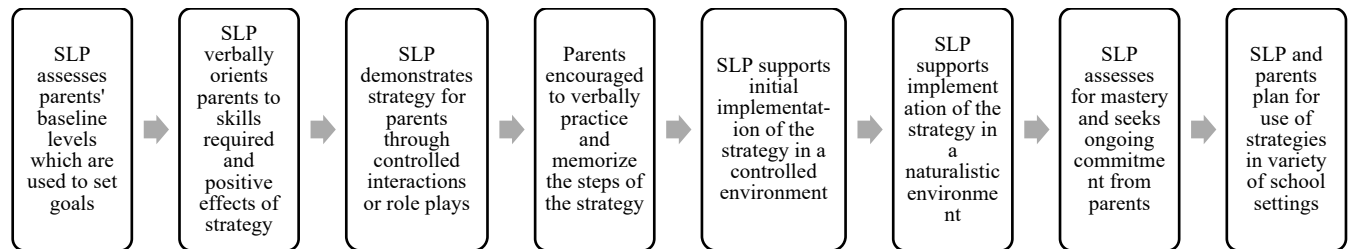
Strategy instruction, another method for implementing communication partner training, is a “method for teaching individuals to apply a series of multi-step procedures to address a specified challenge” (Kent-Walsh & McNaughton, 2005, p.197). The authors grounded their 8-stage process in Ellis et al.’s (1991) method for teaching learning strategies to struggling students. The goal of strategy instruction, which is also referred to as intensive-explicit (IE) instruction, is “to teach so effectively that every student masters and generalizes the content being covered” (Knight, 2002, p. 6). This procedural approach to communication partner training includes the following steps: (1) evaluation of baseline skills and establishing commitment from participants (e.g., learning contract), (2) description of strategy skills and their benefits (e.g.,

lecture), (3) instructor-provided demonstration, (4) rote memorization of strategy steps, (5) participant implementation in a controlled environment, (6) transition to participant implementation in a natural environment,; (7) assessment of mastery and establishing ongoing commitment, and (8) generalization across settings (Kent-Walsh & McNaughton, 2005).

Using strategy instruction with parents, as illustrated by Figure 2.1, the SLP might document each parent's pre-intervention skill level, develop training goals based on these baselines, and seek their commitment to the training processes. Next, the SLP might describe the necessary skills for implementing the strategy (e.g., prompting, modeling, etc.) and the benefits of using the strategy, encouraging parents to compare their baseline behavior to that using the strategy. The SLP might also encourage parents to make connections between the strategy and their unique contexts (e.g., home, school drop-off, park). Following this discussion, the SLP might demonstrate the strategy to the parents with the child or while role playing with communication partners, modeling the process and articulating their actions and decision-making processes aloud. Next, the parents might be encouraged to verbally practice and memorize the steps of the targeted strategy to support recall. The parents' initial opportunities to implement the strategies would most likely occur in a controlled space, such as a treatment room with only the SLP, child, and parent present. This practice would then transition to the naturalistic environment (e.g., home) with the support of the SLP. After fading support, data might be collected to document the parents' mastery of the strategy. Finally, parents might be encouraged to use the strategy across settings to support the generalization of their learning (Kent-Walsh & McNaughton, 2005).

Training programs incorporating strategy instruction often range from 2.5 to 3.5 hours across multiple sessions to master one strategy (i.e., communication turns; Kent-Walsh et al., 2004) to 12 weeks or more (McConachie & Pennington, 1997).

Figure 2.2. Strategy Instruction Applied to a Public School Setting



Note. Based on Kent-Walsh & McNaughton (2005).

Circling back to parent experiences, care provision and coordination for any one of these conditions (i.e., ventilator dependence, ASD, SCI, or communication disorders) may require an understanding of medical terminology as well as the ability to evaluate and implement treatment plans, communicate with health care team members, and problem-solve a range of related obstacles (e.g., equipment failure, access barriers, provider changes; Sterni et al, 2016; Mirza et al., 2018). In response to the 2023 National Survey of Child Health, 30% of parents reported spending five or more hours delivering care, and 10% reported spending five or more hours coordinating care (Child and Adolescent Health Measurement Initiative, n.d.). While discussing the caregiving demands represents an important part of conceptualizing the knowledge and skills parents acquire and the valuable insights they can provide, it is critical to approach this topic without portraying disability as inherently tragic (Swain & French, 2000). Instead, aligning with the constructivist paradigm, this study encouraged parents to share the meaning they have made from their experiences and how these experiences have contributed to their learning.

Ecological Systems Theory

The care needs and approaches to educating parents highlighted above further demonstrate the contextual nature of health literacy, but these snippets do not paint a comprehensive picture. As presented in the introductory chapter, the health care landscape is comprised of multifaceted, interconnected systems spanning personal interactions (e.g., child, siblings, health care providers, educators) and environments (e.g., home, clinic, hospital, school, medical daycare, community), organizational practices (e.g., protocols, scheduling, electronic health record, insurance policies), community resources (e.g., home-away-from-home housing, community foundation, free clinics), state and national policies (e.g., laws such as the Affordable Care Act, Medicaid eligibility criteria, Family Medical Leave Act, free and reduced lunch program), and societal expectations (e.g., values related to participation, stigma related to certain conditions, access to care; Carman et al., 2013). Exploring issues within this complex context requires a framework that supports the consideration of these intersecting influences.

Deeply influenced by Lewin's work in applied psychology, Bronfenbrenner (1977) posited that a child's interactions across various systems within their changing environments influenced them over time, highlighting parents' role in their development:

Whether parents can perform effectively in their child-rearing roles within the family depends on the role demands, stresses and supports emanating from other settings ... Parents' evaluations of their own capacity to function, as well as their view of their children, are related to such external factors as flexibility of job schedules, adequacy of child care arrangements, the presence of friends and neighbours who can help out in large and small emergencies, the quality of health and social services and neighbourhood safety. (Bronfenbrenner, 1979, p. 7)

Bronfenbrenner's framework "facilitates organizing information about people and their environment in order to understand their interconnectedness" (Algood et al., 2013, p. 128) and has been adopted for numerous research studies related to health care, caregiving, education, and more. Before discussing the current literature base, the following section introduces the framework's nested systems, including microsystem, mesosystem, exosystem, macrosystem, and chronosystem. Discussion of this naming structure, which Bronfenbrenner (1977) adapted from Brin (1975), will further illustrate parents' knowledge and skill needs. Because this study explores the ongoing learning and development of parents, they will be centered in the model.

Microsystem

The microsystem includes relationships, activities, and social roles an individual experiences in their direct environments or specific settings in which they are present (Bronfenbrenner, 1977). For example, a parent may interact with their child, spouse, and an array of professionals (e.g., primary care physicians, specialists, nurses, allied health professionals, social workers, educators, support staff, daycare provider, social services case managers) across numerous settings (e.g., school, clinic, hospital, daycare, home). For some children, this can involve the presence of home health nurses or behavior therapists in the family residence for service delivery (Leaf et al., 2018; Sterni et al, 2016). In addition to supporting care delivery, parents may engage in activities such as care and service planning and coordination, shared decision-making, and the administration of medical procedures, embodying roles such as care coordinator, educator, and advocate.

Mesosystem

A mesosystem represents interactions between microsystems (Bronfenbrenner, 1977). In the context of CSHCN, microsystems can be significantly interrelated. For example, parents may

collaborate with school and health care personnel on diagnostic assessments as well as individual education plan (IEP) and medical plan development. Parents may mediate care plans between the child's primary health care team and home health providers. They often also bear responsibility for initiating information sharing between health care organizations, schools, and other social services systems (e.g., to facilitate access to services including Social Security, Medicaid, SNAP, and Women, Infants, and Children) and identifying and mitigating barriers to their children's access to and participation in services (Kramer et al., 2018).

Parent engagement across health and related systems can also be considered part of the mesosystem. In participating in care experience surveys, serving on advisory councils, or contributing to academic research, parents link their family's and community's experiences across related systems to the tasks at hand. Participation in community-engaged research, for example, can lead to varied involvement across the scope of a research project depending on the parents' skills and expertise (Friedman Ross et al., 2010).

Exosystem

An exosystem refers to social structures influencing the mesosystem and what transpires in those environments (Bronfenbrenner, 1977). For example, state and national governance, medical schools, health care organizations, school districts, community resources, and informal social networks (e.g., social media) may influence what happens within the mesosystem. Shifting federal priorities and changes to funding models, as well as state-determined income eligibility guidelines, reimbursement rates, and administrative rules, can significantly impact access to coverage from Medicaid and the Children's Health Insurance Program and subsequently access to care (Currie & Chorniy, 2021). On a more local level, a school district's policy on community collaboration may influence how involved a child's external care providers can support them

while at school. Parents assuming an advocate role may pay careful attention to proposed policy changes that can affect their child, family, or community's access to services.

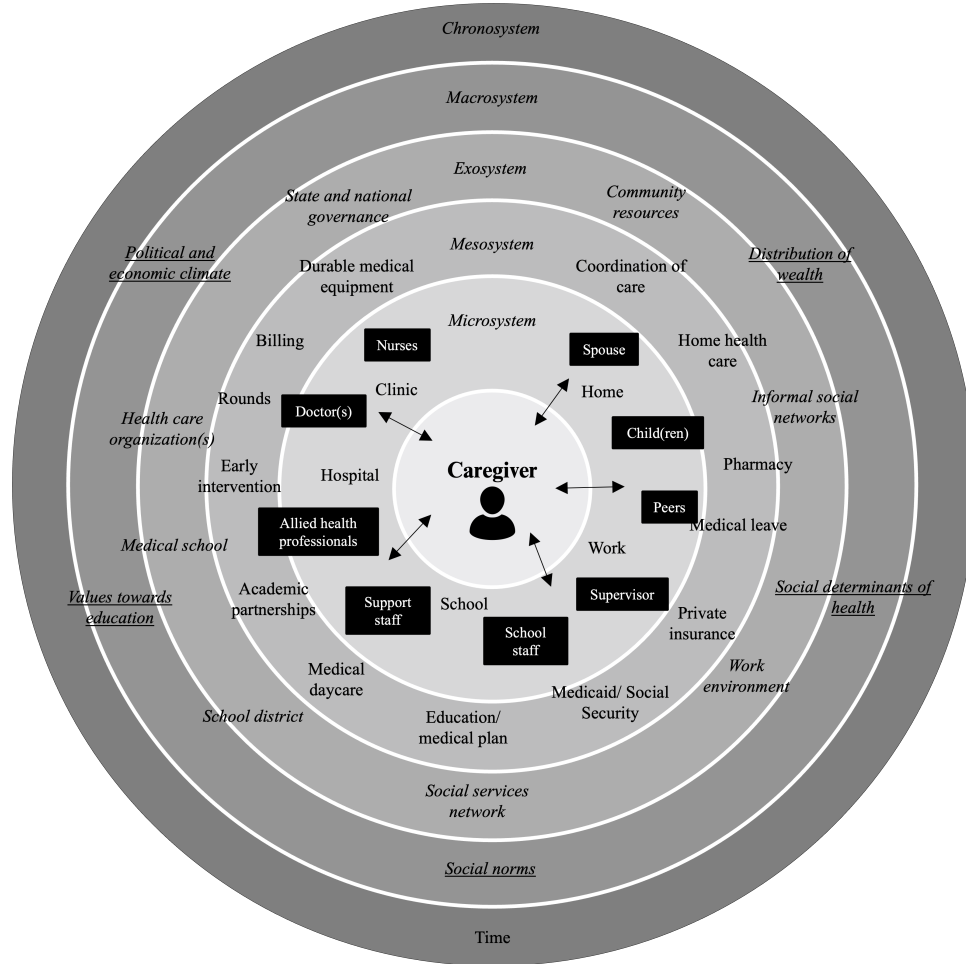
Macrosystem

A macrosystem refers to broader, “overarching institutional patterns of the culture or subculture, such as the economic, social, educational, legal, and political systems, of which micro-, meso-, and exosystems are the concrete manifestations” (Bronfenbrenner, 1977, p. 515). This can include social norms and values, social determinants of health, the political and economic climate, and the distribution of wealth, which influence the experiences of parents of children with significant disabilities. Returning to the health literacy discussion introduced at the beginning of this chapter, this structure requires parental involvement in care decisions but only to the extent allowed by society (Huber et al, 2012). While the present study will primarily focus on micro- and mesosystems, with results potentially of interest to organizations within related exosystems, the influence of exosystems and macrosystems will also be considered to provide a holistic discussion of parents' learning experiences.

Chronosystem

The chronosystem, identified in Bronfenbrenner's (1994) later models, accounts for the changing world over time, encompassing an individual's personal timeline (e.g., events at specific ages), the recurrence of interactions across time, and broader societal shifts. For parents of children with significant disabilities, this might include personal milestones (e.g., going back to school, starting a new job), changes in family structure (e.g., marriage or divorce, birth of another child), and cultural changes (e.g., shifts in attitudes towards disability).

Figure 2.3. Ecological Systems of Parents of Children with Significant Disabilities



Note. Figure developed by the author based on existing literature. The specific systems parents encounter will likely vary.

Studies

Rooted in child development, ecological systems theory has been applied to many studies in the primary and secondary education context (Edwards, 2019). For example, Dunst et al. (1988) tested their hypothesis that family resources correlated with well-being and adherence to recommended regimens within early intervention (EI) programs. EI represents the individualized special education services provided to qualifying children with disabilities, ages birth to three (Sheppard & Moran, 2022). While their study supports the notion of family resources as a

supportive factor for well-being and a commitment to recommended interventions, this study's focus was limited to school systems (Dunst et al., 1988). Furthermore, the researchers did not consider parents as collaborators in negotiating interventions, nor did they seek to understand parents' learning experiences or needs (Dunst et al., 1988). Sheppard and Moran's (2022) study expanded the focus to include the actions and interactions of early care providers (i.e., adults providing out-of-home childcare) with young children with disabilities and their families. The study's results suggested early care providers may be a valuable resource to parents related to communicating concerns identified through routine screenings or observations, service coordination, and advocacy for services (Sheppard & Moran, 2022).

In another study, Edwards (2019) applied the ecological systems model to conduct a dual study examining EI providers' communication of recommended strategies, perceived use among parents, and the methods for promoting carryover within the family's support network as well as parents' satisfaction with service delivery, perceived support from their support network, the extent they report sharing recommended strategies with others in their support network, and their perceptions of how consistently those individuals implement the strategies. Most EI providers reported using a similar approach with parents that involved modeling or 'adult practicing,' a term not defined by the researchers, with providers sitting next to them or nearby. However, a portion of EI providers reported that parents were not able to observe the whole session. Despite most providers feeling highly confident that parents were aware of the recommendations, most reported feeling only somewhat confident that the strategies were used outside of sessions (Edwards, 2019).

While Edwards (2019) did not describe their approach to coding open-ended responses from parents, the researchers report that half of the parents (n=97) "expressed comfort with

providers' validating concerns or brainstorming solutions," sharing examples like "talk to me in a way that I can understand and then follow through" (p. 215). Nearly 40% focused on the providers' instructional strategies, with comments relating to using toys present in the home and providing feedback. Interestingly, approximately 93% of respondents self-reported being at least likely to implement the strategies outside of sessions, and 86% reported asking one or more individuals from their network to implement the strategies. However, parents reported being unsure about their actual implementation (Edwards, 2019). The study helps to illustrate that parents may also assume the role of trainer and helps frame a discussion on the difference between knowing how and being able to (Jarvis, 2009), which we will return to later in this chapter.

In addition to the educational context, the ecological systems framework has been adapted to examine numerous related topics related to child-rearing (Zhang et al., 2025), such as factors associated with parenting success specific to raising children with disabilities (Algood et al., 2013), perceived effects of mesosystem interactions on parents of children with tracheostomies (Sherman et al., 2024), and parents' perceptions of their child's weight-related behavior considering both a developmental disability diagnosis and provider-mediated support (Polfuss et al., 2019). In Zhang et al.'s (2025) qualitative exploration of the experiences of rural Chinese parents (i.e., family members providing childcare for children ages 0-3 for at least 6 hours daily), many parents reported learning about childcare through medical professionals, family members, online sources, and hands-on experiences. Most asserted an understanding of childcare, including mention of Traditional Chinese Medicine practices by more than 25% of participants. Some dismissed the value of reference materials, such as developmental milestones,

in favor of their personal beliefs (Zhang et al., 2025), illustrating the importance of examining health literacy and learning from a holistic perspective.

Also concerning health literacy, Kramer et al. (2018) measured the number of environmental barriers that parents of children with developmental disabilities could identify with and without a ‘health literacy informed, environment-focused problem-identification approach,’ which included a socio-ecological visual aid depicting the environmental context and intentional prompting from a trained professional. While parents identified more barriers within the standardized stories with the intervention, these stories may not be universally significant, which could potentially result in varied levels of engagement and depth of responses. Furthermore, the study sought to explore the feasibility of a provider-mediated approach (Kramer et al., 2018) rather than seeking to understand parents’ learning experiences across these systems more broadly.

Learning From the Caregiving Experience

Parents as Adult Learners

Parents taking on the role of the caregiver to a child with significant disabilities is a relatively contemporary phenomenon (Sterni et al., 2016). Once deemed “unfit” and or in need of fixing, doctors often encouraged parents of children with disabilities to place them in overcrowded and understaffed institutions (Nielsen, 2012). Advancements in technology, which allowed for shifting the care of ventilator-dependent children from hospitals to homes (Sterni et al., 2016), and large-scale parent advocacy led to a shift in attitudes towards children with disabilities and eventually the deinstitutionalization movement (Nielsen, 2012). The 1987 U.S. Surgeon General’s Report proclaimed the federal government’s commitment to home and community-based care for CSHCN (Sterni et al., 2016). Program underfunding, workforce

shortages, and high service requirements have contributed to many parents assuming unpaid caregiver roles supporting their children's health and developmental needs (Foster et al., 2021; Sterni et al., 2016) in addition to other roles they may assume within their family units.

Accompanying this shift has been the endorsement of patient- and family-centered care by government health care agencies, including the Institute of Medicine and the American Academy of Pediatrics. In contrast to the paternalistic model of health care previously introduced, patient- and family-centered care represents a “partnership approach to decision-making between health professionals and the [patient and] family in all aspects of care” (p. e19). In the context of pediatric health care, recognizing parents as partners—“as bona fide members of the care team—encourages the development of their competency in care...” (Karazivan et al., 2015), a notion that aligns with Healthy People 2030's acknowledgement “that personal health literacy is contextual and that producers of health information and services have a role in improving health literacy” (Office of Disease Prevention and Health Promotion, n.d., Organizational health literacy section, para. 1).

Evolving caregiver roles, shifts in care models, and the expanded health literacy definitions further illuminate philosophical tensions present in this study. These developments highlight the need for a nuanced understanding of parent experiences. Recognizing the complexity of humanity and the changing world, this study is grounded in the constructivist worldview, which acknowledges that knowledge is constructed through experience and shaped by context and culture (Elias & Merriam, 2005). It values diverse philosophical perspectives and recognizes that each offers valuable insights (Elias & Merriam, 2005). This perspective, like the expanded definition of health literacy, aligns with Jarvis (2009) understanding of learning, which he defined as:

the combination of processes throughout a lifetime whereby the whole person – body (genetic, physical and biological) and mind (knowledge, skills, attitudes, values, emotions, beliefs and senses) – experiences social situations, the perceived content of which is then transformed cognitively, emotively or practically (or through any combination) and integrated into the individual person's biography, resulting in a continually changing and more experienced person. (Jarvis, 2009, p. 25)

Using this definition, parents can be understood as learners making sense of a dynamic, contextual, and social process consisting of primary experiences (e.g., new sights, sounds, smells) and secondary information (e.g., organization- and provider-mediated education, self-directed learning) through the lens of their individually constructed lifeworlds (Jarvis, 2009). As parents take on roles associated with adulthood (Knowles, 2005), they are considered adult learners for this study.

Returning to the field of adult education for a moment, efforts have been made by multiple scholars to differentiate between educating children and adults. For example, Lindemann (1926) attempted to define specific characteristics of adult learners, and Knowles (1970), expanding on work from Europe, sought to differentiate the art and science of teaching adults from that of teaching children. More recently, Jarvis (2011) sought to move towards an existential or ontological theory of learning, working to overcome criticisms that prior models were grounded in Western ideals. He posited that:

Our perception of the situation in which we are will affect our understanding of the event or its contents. In other words, we will see things culturally and individually as a result of our previous learning experiences, the memories which are stored in our biographical history, and our biographical history, which expands with age. (Jarvis, 2009, p. 51)

Parents' journeys begin in different ways (e.g., congenital, developmental, or acquired; Moyes et al., 2022) and proceed along different paths (e.g., course of illness or disability); however, they often acquire specialized knowledge in their child's conditions, perform related treatments and therapeutic interventions, and engage within complex systems (Jonas et al., 2022). As such instead of making assumptions about parents as learners, the characteristics of adult learners introduced by Rogers (1986) were reframed as questions, as advised by St Clair (2015):

1. What level of self-direction has the parent demonstrated?
2. What experiences are parents moving through?
3. What is the parent's history with health care systems, their child's condition, the health care team, etc.?
4. What values related to health care and learning are salient to the care experience?
5. What does the parent want/need to learn?
6. What expectations does the parent have related to learning in the health care experience?
7. What roles, responsibilities, and priorities are competing for the parents' time and attention?
8. How does the parent prefer to approach something new? What learning strategies does the parent prefer (St. Clair, 2015)?

Many of the topics represented here have contributed to the literature base on caring for a child with significant disabilities, but for those outside of the field of adult education, these questions may support the consideration of parents as adult learners navigating complex systems in the context of caregiving.

Experiential Learning Theory

As was presented above, Bronfenbrenner's (1977) model provides a tool for organizing parents' experiences and considering broader environmental influences, but it fails to consider the internal processes of learning. Layering experiential learning theory provides a framework for exploring the processes of interpreting and learning from these experiences. Recent literature on health literacy originating from the adult education field has focused on self-directed learning (e.g., Baumgartner, 2011, Conceição et al., 2011; Rager, 2003) transformative learning (e.g., Baumgartner, 2011; Coady, 2013), problem-based learning (e.g., Baumgartner, 2011), lifelong learning (e.g., Jackson, 2006; Merriam & Kee, 2014); interprofessional curriculum development (e.g., Conceição et al., 2011), community education, program and intervention development (e.g., Mayfield-Johnson, 2011), health equity (e.g., Hill, 2011; Ziegahn & Ton, 2012), adult basic education (e.g., Diehl, 2011) literacy levels (Feinberg et al., 2018), artistic expression as a coping mechanism (Stuckey et al., 2009) and roles for adult educators (e.g., Hill, 2011; Wright & Grabowski, 2011). However, no studies were identified to examine experiential learning in this context.

Drawing on Lewin's focus on immediate experience and feedback processes, Dewey's emphasis on the developmental nature of learning, and Piaget's work on cognitive development and knowledge construction, Kolb's (1984) experiential learning cycle linked experience, perception, cognition, and behavior. Kolb posited that

[Learners] must be able to involve themselves fully, openly, and without bias in new experiences (CE). They must be able to reflect on and observe their experiences from many perspectives (RO). They must be able to create concepts that integrate their

observations into logically sound theories (AC), and they must be able to use these theories to make decisions and solve problems (AE). (Kolb, 1984, p. 30)

Building from Kolb's (1984) work, Jarvis (2009) suggested that learning is a lifelong, holistic process occurring through primary experiences (i.e., mediated through a learner's senses) and secondary experiences (i.e., mediated by others). Like Dewey (1938), Jarvis (2009) recognized that experiences may not be equally educative. Jarvis also acknowledged that learning processes can be non-linear or incomplete, a key differentiator between his model and Kolb's work.

Drawing on Csikszentmihalyi, Jarvis (2011) suggested "flow" (i.e., one's ability to take their lifeworld or patterned existence for granted) as both the starting point and anticipated end point of learning. A person's experiences can reinforce their understanding of the world or lead to disjuncture, which Jarvis described as disharmony between the world as one knows it and the world they are facing. It is within periods of disjuncture when people become aware of a gap between their prior learning and their current situation. Depending on the experience and the size of the gap, one might adjust their behavior without experiencing a shift in worldview, or they might be faced with a wider gap that requires significant learning. Resolving this disjuncture can involve a combination of reflection, emotion, or action to become part of the person's ever-developing biography, whereas the person learns about the context of the experience and/or about themselves (Jarvis, 2009).

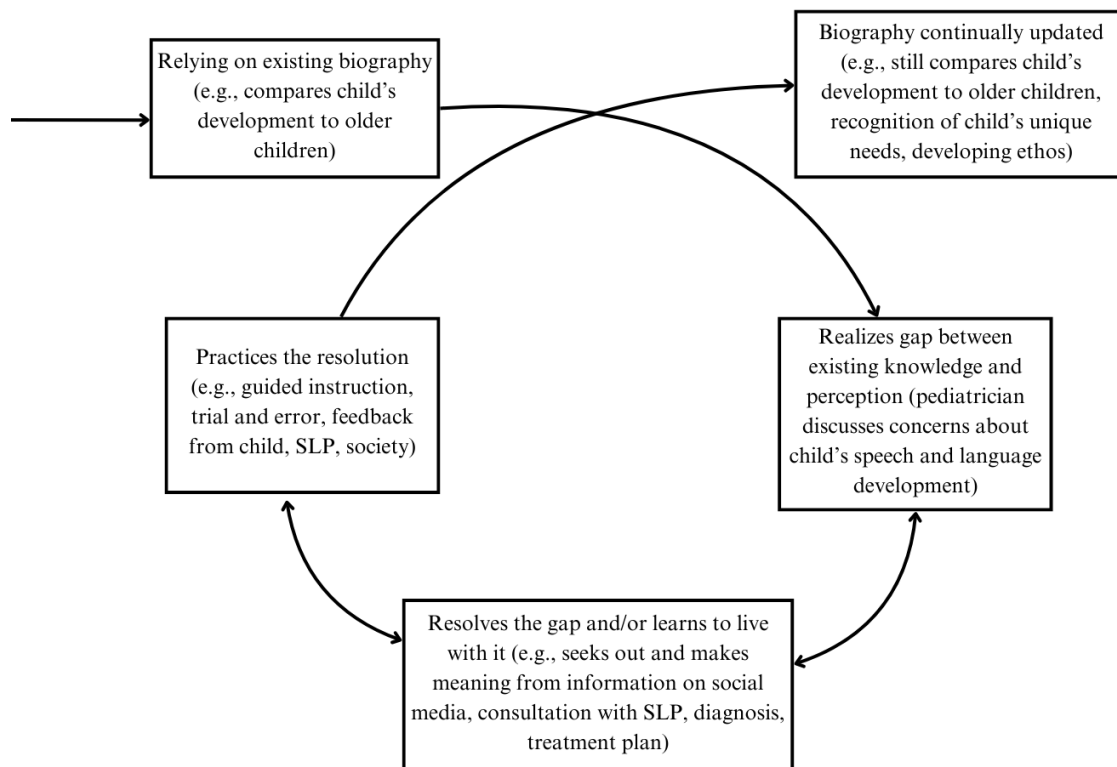
For some parents, learning about their child's diagnosis or specific care needs may create a period of disjuncture as depicted in Figure 2.4 below. Without access to academic medical education, parents may seek information from health care providers, family members, and online, each of which may involve largely learning from others' experiences. For example:

a parent may internalize condition- and intervention-specific terminology, replay discussions with providers, tune into their feelings of fear regarding the child's future, or experiment with the recommended intervention as they make meaning from the situation. Another parent may rely on insights from other parents on social media as they make meaning of the situation. (Fiala et al., 2024, p. 4)

However, assuming the role of caregiver often requires knowledge and skill beyond rote memorization of steps or techniques. For example, explaining the steps for a specific intervention such as completing routine tracheostomy cares represents what Jarvis (2009) described as “knowing how,” but “being able to” necessitates the actual implementation of the procedure (i.e., a primary experience), a process which may result in the development of parent-specific words or processes (Fiala et al., 2024). With practice, new responsibilities, like tracheostomy care, may become routine (Jarvis, 2009). As part of a previous studies, parents described learning to assess their child's condition, considering knowledge from previous experiences in making decisions about care needs (Rennick et al., 2019). Balling and McCubbin (2001) explained:

Normalization and normalcy have been redefined by the parent caregivers of children with chronic illness. Parents come to know the child's needs and how to care for the child by engagement and involvement in the child's care on a day-to-day basis. (Balling & McCubbin, 2001, p. 111)

Figure 2.4. Jarvis' (2011) Learning From Experience Model Applied to Caregiving Example



Note. Adapted from Jarvis (2011).

Insights regarding the meaning parents have made from primary and secondary learning experiences may be valuable to organizations seeking to design learning systems with these learners in mind (St. Clair, 2015).

Studies

Studies related to child rearing and caregiving have referenced Kolb's experiential learning model. For example, Ferreira and Midgette (2024) examined child rearing using the psychological processes for care framework. Their findings, particularly related to the influence of past child rearing experiences on current practices, aligned closely with Kolb's model. Other researchers have examined interventions for caregivers of dementia patients developed based on Kolb's experiential learning theory (e.g., Arakawa & Anme, 2020; Xu et al, 2025). For example,

Xu et al. (2025) measured caregiver burden following the completion of a four-week training based on Kolb's model. The intervention involved role plays and interactions with simulated dementia patients (i.e., concrete experience); shared reflection and discussion of caregiving challenges (i.e., reflective observation); discussions with the nursing researcher to foster a deeper understanding of their experiences (i.e., abstract conceptualization); and application of knowledge to patient care scenarios with ongoing support (i.e., active experimentation). Results from their study suggested the training intervention reduced caregiver burden (Xu et al., 2025); however, the researchers did not examine caregiver learning through an experiential learning theoretical lens as proposed by the present study.

Håkanson et al. (2012) grounded their qualitative study in Jarvis' experiential learning theory, acknowledging the biomedical focus of most irritable bowel syndrome (IBS) patient education and research. The researchers sought to understand patients' experiences completing an IBS patient education program. The five-day program consisted of traditional lectures, discussions, and practical exercises. Themes from the focus groups suggest participants felt comfortable sharing their lived experiences in community with other IBS patients and a mutual relationship with the nurse coordinating the sessions. Most participants also described listening to the experiences of others as helping them to make meaning from their own experiences. For some, participating in the program and paying attention to their body's responses to the practice exercises contributed to a reframing of their experience of illness as an inseparable part of being in the world. Håkanson et al. (2012) linked these findings to contributing to participants' readiness for self-care and improved well-being, writing:

The combination of reciprocal sharing of experience-based knowledge between the group members, and the provision of professional scientific knowledge brought about a growing

readiness based on new understandings of the body and illness as a whole and a new ability to make knowledge-based decisions about health and illness in everyday life.

(Håkanson et al., 2012, p. 744)

The researchers highlighted the potential for aligning the sessions more closely with participants' needs by collecting information before the program (Håkanson et al., 2012).

The present study also draws on Bjursell's (2020) application of Jarvis' work in experiential learning to the COVID-19 pandemic in seeking to inform potential organizational responses. Bjursell posited that shifts in the broader social environment (e.g., public health policy, digital learning, economic tensions) in response to the pandemic led to individual and widespread fear. She emphasized the need for reflective learning to avoid resistance to future change, isolationism, or closed-mindedness resulting from non-learning or non-reflective learning. Her claim corresponds to the few experiences of participants who felt like outsiders after the IBS education and support program (Håkanson et al., 2012). Without the opportunity to critically reflect on the experience, these individuals may feel more alone in their health care journey. Aligning with Healthy People 2030, Bjursell's work supports expanding health literacy beyond an isolated set of skills or capacities to socially embedded learning processes influenced by social structures. For parents of children with significant disabilities, who often experience feelings of fear, stress, and isolation, it emphasizes an urgent need for integrated learning systems that recognize caregiving as a learning experience that shapes the individual while also contributing to the public health knowledge base.

Chapter Summary

In this chapter, I introduced the emergence of the health literacy construct and presented this study's multi-theoretical framework. In the first section, I illustrated the ecological systems

of caregiving by introducing the characteristics of parents and the diverse contexts associated with caring for children with significant disabilities. Next, I presented Bronfenbrenner's (1977; 1994) ecological systems model for organizing the elements of these complex, interrelated systems. In the following section, learning from the caregiving experience, I positioned parents as adult learners and presented experiential learning theory (Jarvis, 2011) as a framework for understanding the processes through which parents make meaning from their varied experiences. I introduced related literature and tied it to the current study. In Chapter 3 - , I expand on the methodology and explore the philosophical tensions introduced here.

Chapter 3 - Methodology

This study sought to explore how parents of children with significant disabilities learn from experiences within the context of caregiving. After revisiting the research question, this chapter introduces my worldview and details the methodology guiding this study in addition to the proposed research methods and my approach to managing subjectivities.

Research Questions

This study aims to address the following research question:

- How do parents of children with significant disabilities describe learning from their experiences in the context of caregiving?

Researcher's Worldview

A research paradigm describes a researcher's foundational beliefs about reality (i.e., ontology), the creation of knowledge (i.e., epistemology), and the influence of values in research (i.e., axiology; Pretorius, 2024). A researcher's ontological position, their beliefs about existence, converges with their epistemological position, their beliefs about the basis of knowledge (Crotty, 1998). These philosophical leanings frame how researchers work, including what the researcher is looking at and how it is measured (Kuhn, 2012). For example, a researcher who believes that objective truths can be uncovered or measured with the right tools free from bias can be positioned within the positivist paradigm; whereas a researcher who believes reality is constructed by individuals based on their experiences in society and their values can be said to align with the constructivist paradigm (Pretorius, 2024). These worldviews directly influence research design, data collection, and representation of findings (Crotty, 1998), making the researcher's paradigm a critical factor in interpreting a study (Creswell & Creswell, 2023).

For this study, reality was thought to be shaped by individual experiences within the context of society (Pretorius, 2024). This assumption most closely aligns with constructivism (e.g., interpretivism), which rejects the notion of a singular truth (Constantino et al., 2008) in favor of multiplicity. As a researcher, I acknowledge the contributions that arise from diverse philosophical perspectives, as Elias and Merriam (2005) posited. Stemming from a constructivist ontological position, I believe truth “comes into existence in and out of our engagement with the realities in our world” (Crotty, 1998, p. 8). Extending this reasoning to research, knowledge is collaboratively constructed through the interaction between the researcher and participants in the context of society (Pretorius, 2024), although, the focus of my research remains on the individual participant’s meaning-making process (Crotty, 1998). Similarly, Healthy People 2030, the United States’ 10-year public health plan, attempted to balance health literacy as an individual, measurable skill while acknowledging it as a dynamic, contextual, and social process (Office of Disease Prevention and Health Promotion, n.d.) with the addition of a definition for organizational health literacy and the expanded personal health literacy definition. Historically, health literacy has been overwhelmingly examined through a positivist lens, relying on normed health literacy measures. However, the complex, contradictory, and unpredictable nature of human beings (MacLeod et al., 2023) supports the exploration of engagement within the complex systems of caregiving from a constructivist perspective.

Rooted in the constructivist paradigm, I conceptualize research as value-laden and never objective (Pretorius, 2024). Like one’s ontological and epistemological position, a researcher’s axiology can significantly influence their work. My experiences, values, and assumptions cannot be separated from me as a researcher, which highlights the importance of researcher reflexivity as part of producing trustworthy knowledge (Braun & Clarke, 2013). Reflexivity represents a

process “for maintaining integrity and transparency in research, as it highlights how personal and cultural values influence the research process, from the formulation of questions to the dissemination of results” (Pretorius, 2024, p. 2700). Charmaz (2006) explained:

Neither observer nor observed come to a scene untouched by the world. Researchers and research participants make assumptions about what is real, possess stocks of knowledge, occupy social statuses, and pursue purposes that influence their respective views and actions in the presence of each other. (p. 15)

My subjectivities and those of my participants are viewed as strengths of this qualitative study (Pretorius, 2024). As such they will be acknowledged throughout this dissertation to support transparency.

Research Design

Qualitative research, which is gaining popularity in health disciplines (O'Reilly et al., 2025), represents the most appropriate methodology for this study exploring parents' learning in the context of caregiving. A study's methodology describes the framework for conducting the research (Braun & Clarke, 2013). Qualitative research, the methodology of this dissertation, consists of diverse techniques for collecting and analyzing data that can vary by discipline and ontological and epistemological assumptions (Braun & Clarke, 2013; Prasad, 2018). Rooted in sociology and anthropology, the qualitative arm of research provides “an approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem” (Creswell & Creswell, 2023, p. 5). In contrast to researchers who seek to identify objective causation, constructivists “are interested in understanding how people interpret their experiences, how they construct their worlds, and what meaning they attribute to their experiences” (Merriam & Tisdell, 2015, p. 6). While Merriam & Tisdell (2015) specifically refer to qualitative research

here, I align with Crotty's (1998) position that qualitative versus quantitative research represents a methodological decision.

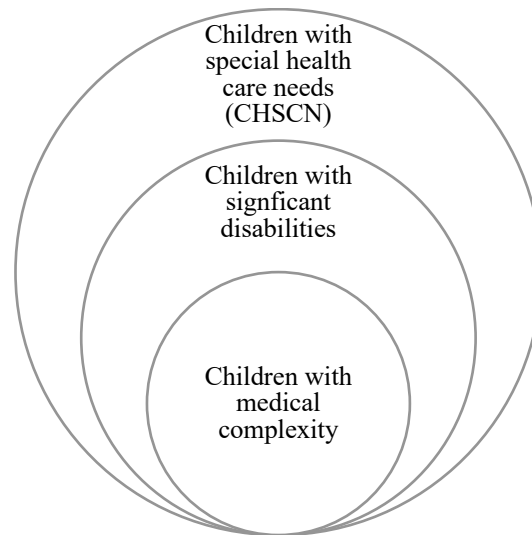
To best answer the research question, I selected a basic interpretive approach for this qualitative study. The basic interpretive qualitative study represents a commonly used approach in applied fields, such as health, education, social work, and business (Merriam & Tisdell, 2015). Specifically, a basic interpretive approach supports the inductive generation of knowledge that can be applied to diverse disciplines, including health care (Håkanson, 2012). This approach, centers participants' interpretation of experiences, meaning making from these experiences, and construction of their lifeworlds (Merriam & Tisdell, 2015), aligning with this study's aim. Furthermore, this approach supports the in-depth analysis of diverse data sources, including interviews, observations, and documentation (Merriam & Tisdell, 2015).

Study Participants and Sampling

Conducting research involves identifying a data sample that is both appropriate for the research question and sufficient for a comprehensive analysis of the topic of interest (Braun & Clarke, 2013). I selected purposive sampling, or intentional sampling (Terrell, 2022), as the most appropriate sampling method for this study. Purposive sampling allowed me to ensure that all participants are parents or guardians with experience providing care and support to a child with significant disabilities and/or medical complexity. Characterization for this study followed Yu et al.'s (2022) nested classification strategy which is depicted in Figure 3.1. The authors conceptualized the population of children with significant disabilities (i.e., children with health conditions lasting 12 months or longer who cannot do things most children of the same age can do, and/or their daily activities are substantially affected by a chronic health condition) as a small subset of the larger population of children with special health care needs (CSHCN). Children

with medical complexity (i.e., multiple severe conditions, extensive service needs, and high care utilization, in addition to functional limitations) including those dependent on technology for survival, are recognized as a subset of children with significant disabilities (Yu et al., 2022), and their parent caregivers are eligible for participation in this study.

Figure 3.1. Nested classification of CSHCN



Note: Adapted from Yu et al. (2022).

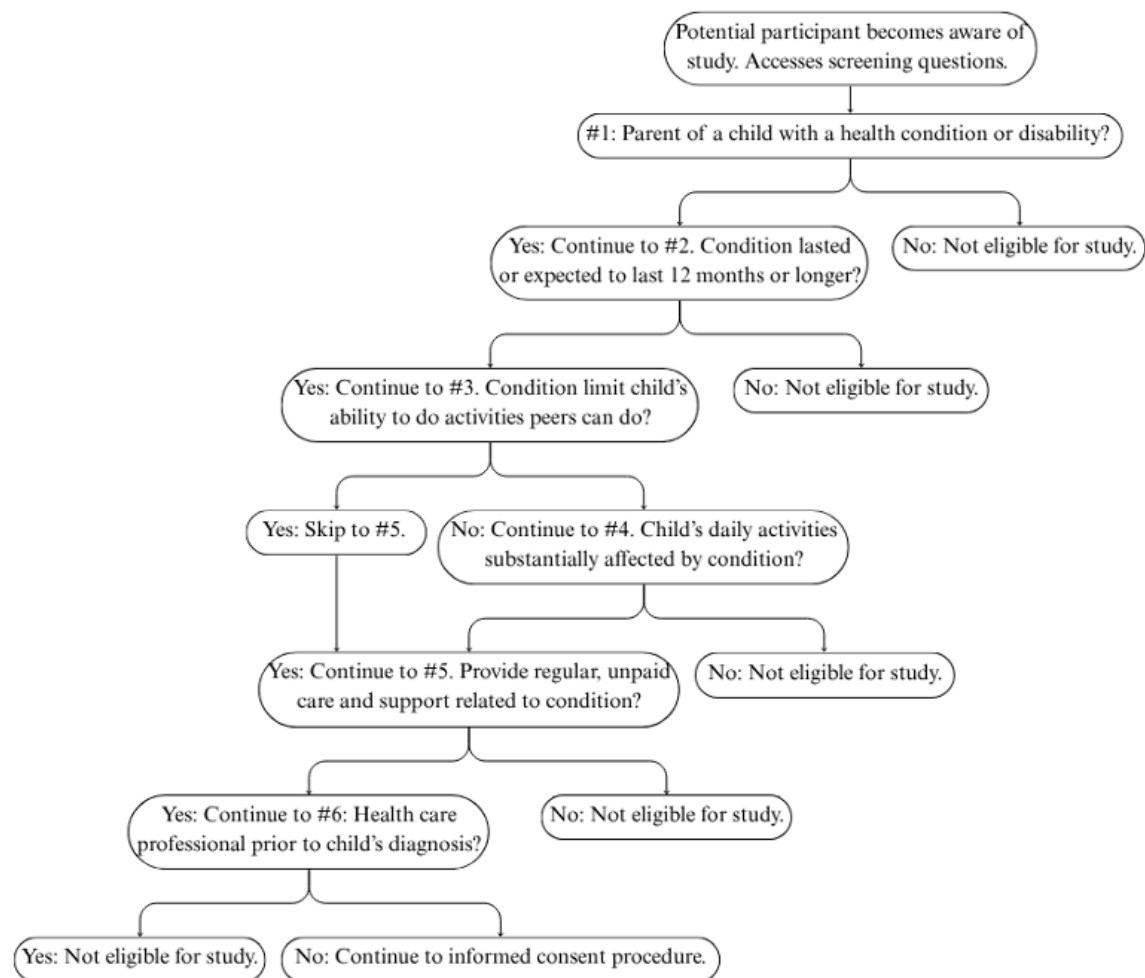
Exclusionary criteria were identified based on the study's purpose and the resources available for the study. Based on the experiential nature of this study (Braun & Clarke, 2013), individuals who are not the parent or guardian of a child (i.e., 18 years of age or younger) with significant disabilities were excluded. Parents who worked as health care professionals (e.g., doctor, nurse, speech-language pathologist) prior to their child's birth or diagnoses were also excluded from participation, ensuring that the study captured the experiences of parent caregivers who had not received prior clinical training. As a result of limited resources for hiring professional interpreters, parents who do not speak English were excluded from this study.

Participant Recruitment, Screening, and Consent

Parents were recruited for participation through my professional and social networks. An advertisement (Appendix A -) documenting the basic premise of the study, the link to the screening and consent form (Appendix B -), and my contact information was shared with members of my professional network, with the request that they consider sharing it with families in their networks. I also posted the advertisement to social media, including Facebook and LinkedIn, and virtual boards for communicating patient engagement opportunities (e.g., PFANetwork's Engagement Opportunities forum). On Facebook, I posted the advertisement within virtual communities for parents of children who may experience significant disabilities (e.g., Premie/NICU Moms, Autism Family Support, Trach Mommies, Trach Babies, Trach Buddies, Special Education Community) in accordance with community guidelines. This dissemination approach encouraged parents of children with significant disabilities to self-identify and initiate participation in the study.

Microsoft Forms was used to introduce the study, screen participants, and collect informed consent. I selected Microsoft Forms to conduct the combined screening and consent procedure with prospective participants in mind. All data collected via Microsoft Forms is stored on Kansas State University's password protected and encrypted systems, supporting maximum protection of personal information. Moreover, potential participants reviewed a short video or narrative introducing the study and responded to screening questions at their convenience. Microsoft Forms' functionality allowed for immediate communication regarding eligibility for participation in the study and documentation of informed consent, as depicted in Figure 3.2.

Figure 3.2. Screening protocol



Note: All participants were thanked for their interest at the beginning of the screening form and upon notification of their eligibility.

Individuals who were determined to be eligible for participation in the study could download and review the consent form (Appendix C -) and watch a recorded video of me reviewing the consent form, including participants' rights, before providing contact information and responding to the consent-related questions. At this point, the participant's name and preferred contact method were collected. As part of the consent process, participants were notified of the stipend being offered for participating in the study. To acknowledge the expertise parents brought to this study, participants received a \$20 stipend for completion of the

information checklist and initial interview, \$20 for participation in the second interview, and \$10 for validating interpretations during the member checking process. Stipends were paid by electronic gift card to support detailed recordkeeping. No participants requested an alternative process for completing the screening questions or consent process, although they had the opportunity to request that as part of the form. Participants with questions about the study were instructed to contact me at my Kansas State University email address.

Sample Size

Qualitative studies typically use smaller sample sizes than quantitative studies, a decision influenced by several factors including the research question, a study's purpose, and available time and resources (Patton, 2002). The present exploratory study sought to understand the learning experiences of parents in the context of caring for a child with significant disabilities, a rich topic, through multiple, in-depth interviews. Seeking to provide a deep analysis of parents' experiences through a novel lens (i.e., ecological systems and experiential learning) and to support future, larger scale qualitative and quantitative studies, I determined 18 participants to be the appropriate sample size for this study. The sample represented a range of backgrounds found in the broader population of parents of children with significant disabilities (Child and Adolescent Health Measurement Initiative, n.d.; Yu et al., 2022), varying in age, geographic location, family structure, educational attainment, and profession. Further, parents recalled varied lived experience with health care (beyond routine care and minor surgeries), disability, pregnancy, parenting, caregiving and social services systems. Parents described providing care for children of varying ages (i.e., 1-18), diagnoses (e.g., Down Syndrome, rare genetic conditions, traumatic brain injury, cerebral palsy, fetal alcohol syndrome, and multiple co-occurring conditions), and care needs (e.g., invasive or noninvasive respiratory

support, parenteral or enteral nutrition support, seizure management). Had the data collected from the interviews (N=36) not support the telling of “a rich story,” I would have recruited a larger sample size (Braun & Clarke, 2013, p. 27). However, that was not the case, and all 18 participants completed both the first and second interviews.

Data Collection

Following the screening procedure (Appendix A -) and collection of informed consent (Appendix B -), parents of children with significant disabilities were asked to complete the information checklist (Appendix C -). Like the screening and consent form, responses to the questions on the information checklist were collected via Microsoft Forms. The information checklist asked participants to share basic demographic information, such as marital status, number of children, employment status, and military experience, as of the present date and at the time of their child’s diagnosis. This information was used to prepare for the interviews with each participant. For example, knowing if the parent had prior parenting experience helped guide probing questions during the initial and second interviews. Likewise, knowing if the parent had prior military experience provided insights into their experience navigating complex systems.

As part of the information checklist, participants were also asked to create a timeline of their experiences within the complex systems of caregiving, specifically experiences they felt helped prepare them for providing care and support for their child with significant disabilities. Participants could choose to hand draw a timeline depicting noteworthy events, use a word processing or presentation software to create a digital timeline, or record a short video (3-4 minutes) describing their timeline, each of which were collected using the Form. I selected to provide digital storytelling as an option because it “allows people who are unused to expressing themselves in public [to] speak their mind on a given topic by making a short autobiographical

film... narrated in the first person” (Loignon et al., 2018, p. 4). I hoped to empower participants to participate in the way that aligned best with their unique situation. Previous research has explored care maps as a tool to support care coordination (e.g., Adams et al., 2017). The timeline technique described here was selected over care mapping because of my interest in the order of events.

Fourteen participants submitted a timeline through the Microsoft Form, and one participant sent a timeline to my University email. Three participants did not submit a timeline electing instead to share the order of events during the first interview. The length and depth of the timelines submitted varied greatly from participant to participant. For example, Susan shared:

[son’s name] was also born with [name of rare genetic condition] and several other major medical issues. He’s had three open heart surgeries (at birth, 4 months, and four years).

He’s also had a Ladds surgery, gtube surgery, and several emergency hospital stays.

Whereas Stephanie shared:

Age 0-17: I had a typical, healthy childhood. I was involved in school, and extra-curricular activities. I graduated high school with honors. I had very little experience even stepping inside a hospital other than to visit the occasional sick relative. I never had any medical conditions or issues that were significant. My mom would take me to my yearly physical with my pediatrician for vaccines and such, but otherwise did not go to the doctor often.

Age 18-21: I attended college. I continued to be healthy and have no health issues or complications. I got my wisdom teeth removed when I was 19, which was the only surgery I had ever had and my first time having anesthesia. Recovery was typical with no complications. I got engaged. I graduated college with my bachelor's and got married.

Age 22-26: My husband and I built our lives. We both worked full-time... We wanted kids in the future, but weren't ready yet. We enjoyed traveling and spending time with friends and family. We bought a house. Neither of us had any health issues or complications.

Age 26: My husband and I decided we were ready to start having kids. It took 10 months to conceive, but we finally did on our own. The pregnancy was normal. Every appointment and scan was normal. We did the 12-week gender and chromosome test and found out it was a girl and that everything observed through this test was normal. I did not have any complications or illnesses other than having Covid once during pregnancy. Baby was active in the womb and we had no reason to think our daughter would have any medical complications.

Age 27: Baby girl had not arrived and we were a few days past due, so I was scheduled to be induced on the evening of [date]. Our daughter, [name], was born on [date]. Labor and delivery was fairly normal; her heart rate started dropping during the pushing phase, so forceps were used, but once she was delivered, she was normal. During the first night at the hospital, my husband noticed that her breathing/sleeping was very loud. By the next day, nurses started noticing and paying more attention to her loud breathing and excessive secretions. Nurses were having to frequently use the suction and bulb syringes to clear out her mucus. By the next day, it was determined that she should be admitted to the NICU due to the concerns of her secretions constantly pooling in her mouth. Several doctors and nurses examined and gave thoughts, but there was no clear answer as to what was wrong. [daughter's name] was not breastfeeding successfully, so they put an NG tube in and gave her breastmilk via the NG tube. Doctors advised and coordinated

[daughter's name] to be transferred to the [hospital name] NICU. [daughter's name] stayed in the NICU for 2 weeks. Several tests were ran and several doctors from various departments examined her. It was found that her esophagus was not functioning correctly, even though it was structurally correct. We decided to have her get surgery for a G-Tube as she was not able to eat orally. We also completed genetic testing, which after a few weeks came back with results that she had an [specific gene] variant.

Age 27: We adjusted to life with [daughter's name], doing her GTube feeds via gravity bag which was challenging. I was pumping every 3 hours to provide breastmilk.

[daughter's name] started to have more and more issues with reflux, leading to a hospitalization on [date]. [daughter's name] was struggling to breath, her secretions and reflux was so severe that she was gasping and working so hard to breath, so we took her to the ER. Once admitted, this stay lasted about a week as doctors worked to adjust reflux meds, and change her to continuous feeds with a pump.

Age 27: [daughter's name] has a seizure at home. We called the hospital and talked to a doctor, and brought her in the next morning. The hospital ran EEGs and it was determined that she had Infantile Spasms. She was inpatient for about 10 days as we began... treatments.

Age 27: Insurance stopped covering... treatments, so Neuro advised [daughter's name] to be inpatient for two weeks while treatments completed. During this stay, a sleep study was conducted and found that [daughter's name] had sleep apnea and needed a CPAP for sleeping at night. Spasms were no longer present. [daughter's name] was no longer active (did not move legs and was not interested in anything) and mostly slept.

Age 27: Weaning [daughter's name] off [treatment], and EEGs showed improvement of her brain activity. However, spasm activity returned. [daughter's name] still lethargic and she then became very irritable, crying constantly if she was not asleep. We took her to doctor at the end of [month], and they advised it was a neuro issue and sent us to ER. [daughter's name] was inpatient for about 5 days as they ran tests, but found nothing new that would explain her constant crying.

Age 27: [Her daughter's name's] condition had improved, but she was still very lethargic. On [date], at home, [daughter's name] stopped breathing. We performed CPR and called 911. She began breathing again and was transported with me via ambulance to [hospital name]. Her stay lasted until [date], when her breathing and CO2 numbers finally improved enough without support. Her irritability was still increased during this time, as well as her seizures. New seizures meds were tried, including a Keto diet, which she did not tolerate. She was moved to a BiPAP instead of CPAP. Her oxygen level is now constantly monitored via oximeter.

Age 27-28: [daughter's name] wears her BiPAP at night with oxygen when needed. She requires frequent suctioning. Her oxygen is always monitored. We tried several different formulas to wean her off breastmilk; nothing was successful until we tried [specific formula] in [month/year]. [daughter's name] had one week-long hospital stay over [holiday] of [year] as she contracted [name of virus] and needed support with breathing and a high fever. She has tried many different med combos for seizures, all showing improvement at first, but then seizures return. Her neurologist switched her diagnosis to [rare syndrome]. She is currently on a combo of 3 meds, which has lessened her seizures

to a few a day. [daughter's name] is developmentally delayed and attends weekly physical therapy.

To complete the information checklist, participants identified their preferred channel for completing the interview (i.e., in-person if within 2 hours of Omaha, Nebraska or using web-conferencing software), they indicated their recording preferences (i.e., audio and video or audio only), and they self-scheduled their initial interview using my Microsoft Bookings page. A reminder email was sent to participants 24 hours in advance of each scheduled interview.

Data for this study, which sought to understand how parents learn in the context of caregiving, was collected through a series of semi-structured, in-depth interviews following review of the participant's information checklist. A research interview can be conceptualized as a conversation between the researcher and the participant related to the topic being studied (deMarrais, 2004). Interviews were the most appropriate data collection method for this study because of the type of data needed to answer the study's research question. Interviews allow researchers to explore things that cannot be directly observed, including "how people have organized the world and the meanings they attach to what goes on in the world" (Patton, 2014, p. 628). I elected to conduct multiple interviews with participants to support the development of rapport and the collection of rich narratives (deMarrais, 2004).

Aligning with the constructivist paradigm, I opted for dialogic methods that elicit rich descriptions of human experience. Freeman (2014) explained this dynamic relationship between the researcher and participant, writing:

The researcher makes the dialogue happen, but it is not necessary to separate what is researcher versus what is other as both are part of the fabric of humanity and have the potential to lead us astray or somewhere new. What is important to the research process is

attending to these threads, seeking ways to understand why these perspectives are being expressed in this way. (Freeman, 2014, p. 831)

As such I treated each interview as a human interaction responding to participants with empathy and compassion. I was careful to attend to emotional labor throughout the interview process (Hoffman, 2007), such that I monitored changes in affect, paused and allowed silence as appropriate, and acknowledged emotional disclosures (e.g., “thank you for sharing,” “that sounds very difficult). Throughout the study, I drew on reflexive field notes to consider the influence of my presence on participants’ accounts.

During the initial interview (Appendix F -) I explored participants’ developing biographies, specific to their experiences within context of caregiving. I asked open-ended questions to encourage in-depth responses and probing questions to invite further reflection (deMarrais, 2004). While some questions during the initial interview were framed from each participant’s timeline, I asked all participants to describe primary and secondary experiences related to the beginning of their child’s health care journey and how their understanding of their child’s diagnosis and support needs changed over time. Initial data analysis began immediately and helped inform the second interview (Merriam & Tisdell, 2015).

I conducted a second interview (Appendix G -) at the convenience of each participant most often within two weeks of the initial interview. After review of the initial transcript, I sought to understand each participant’s lifeworld before they took on the caregiving role. Looking through the lens of Jarvis’ (2009) model of experiential learning, this background knowledge represented important context for interpreting participants’ experiences in the caregiving role. Parents’ experiences included, but were not limited to, systems navigation on behalf of themselves or another person, their own health care journeys, or health care encounters

with a sibling or another child. Like the initial interview, I asked open-ended questions to elicit in-depth responses from participants, and probing questions were used to invite further reflection of parents' experiences, including their responses and reactions to each experience (deMarrais, 2004).

The information checklist and timeline, interview transcriptions, field notes, and analytical memos comprised the data corpus. Based on participants' preferences all interviews were completed and recorded using web-conferencing software. Sixteen participants consented to audio and video recording and two participants consented to audio only. These transcripts were initially transcribed using the web conferencing platform's digital transcription tool. Transcriptions were manually confirmed using intelligent verbatim transcription to support readability. Interview "recordings contain highly complex patterns of communication involving spoken utterances, embodied actions, and interactional features, and that researchers must package such phenomena into a spatially deprived document" (Jenks, 2018, p. 124), decisions potentially influenced by my subjectivities. As such I documented field notes from observing participants throughout the interview processes (Saldaña, 2021) and analytical memos, or researcher journal notes during the analysis stage. These notes challenged me to maintain focus on the research question and engage in ongoing reflexivity (Saldaña, 2021). Recordings and de-identified transcripts, each labeled with a pseudonym, are stored on Kansas State University's password protected and encrypted, cloud-based storage platform.

Data Analysis

Like the data collection method proposed for this study, data analysis occurred through an iterative process, supporting an in-depth exploration of the way people make sense of their lived experiences navigating the complex systems of caregiving. Qualitative data management

decisions, like the other elements of this study's design, were informed by my worldview, the study's multi-theoretical framework, and basic interpretive qualitative methodology (Bhattacharya, 2017). Saldaña (2021) described coding as "a cyclical act" that attempts to capture the essence of the essential components of the research project (p. 12). This process of synthesis required identifying patterns, concepts, and relationships within the data that answer the study's research question.

I engaged deeply and fluidly with the text of each transcript. To be immersed in each participant's lifeworld, I read each transcript and listened to the audio from the interview, making analytical memos regarding the data (Merriam & Tisdell, 2015). I used NVivo software to conduct two rounds of formal coding. NVivo was selected as it allows for an independent audit of the study and increased transparency.

I chose process coding for first cycle coding because of its focus on observable or conceptual actions enmeshed with time (Saldaña, 2021). This method of coding supported consideration of the participants' embodied and reflective actions in response to their primary and secondary experiences. For example, the following excerpt from Carol was coded across multiple codes.

Table 3.1. Example process codes from Carol's transcript

Excerpt	Initial Process Code(s)
And [her husband] was, like, sobbing, and... I was just sort of in a state of shock as well. And I... yeah, I... I don't know, and then we just had to sit there and kind of wait for the ambulance to come.	- Feeling shocked - Waiting for the ambulance
And I just remember holding my... my baby and just...	- Getting to be mom
Well, first, you know, they said that he has no anus, and we were like, what? You know, we didn't even know what that meant, so...	- Receiving a new diagnosis - Feeling confused - Not understanding what was said

Excerpt	Initial Process Code(s)
We did unwrap him, unswaddle him, because again, he had been handed to us swaddled, and his bottom is completely smooth. Oh, shit. No hole at all, no butt cheeks, just smooth.	- Seeing is believing - Trying to make sense of the situation
And we were just shocked, because we didn't even know that could be a condition. So yeah, once the doctor did leave, we were, like, googling it, and, you know, trying to find out...	- Feeling shocked - Not knowing what she didn't know - Seeking information online
she didn't even tell us the name, she just said he has no anus, and so we're googling no butthole, you know, like, trying to find out what was going on.	- Receiving information from health care providers - Identifying barriers to learning - Seeking information online - Trying to make sense of the situation
So yeah, it was a lot of, yeah, anxiety, and just to know that an ambulance is coming to take him, and we didn't know... and they're like, he's gonna need emergency surgery, so it was a lot of unknowns, and again, we're, like, super sleep-deprived. It's, you know, the middle of... he ended up, being taken away at 3 AM by ambulance, so...	- Feeling anxiety - Identifying barriers to learning
And we slept, like, a couple more hours, and then I asked to be discharged, like, at 7am to try to go over to be with him, and it was that moment I think I made the right decision, because I wouldn't have been able to hold him or anything, but I just...	- Assessing decisions - Justifying decisions
I was so traumatized by them taking him away from me in the night. But I had to stay with my husband because he was having a panic attack. And take care of him and try to get a few hours of sleep. And, you know, I co-slept with my son until just a few months ago, I think in part because he was taken from me in the night like that.	- Recalling traumatic experience - Justifying decisions - Supporting others and/or herself - Drawing conclusions between seemingly related events

Note. Excerpts from the data are paired with corresponding process codes to illustrate first cycle coding process.

After initial analysis of all transcripts, the process codes were consolidated into categories using pattern coding as depicted in Table 3.2 below. Some initial codes were promoted to category names (e.g., getting to be mom) whereas other codes were merged among

like codes into a newly named category (e.g., feeling shocked, feeling emotions, and feeling anxiety were merged into a category called coping with the diagnosis). As codes were merged into categories, I was able to continually analyze the data using NVivo and recode as needed. Initial codes that did not directly relate to the research question were omitted during second cycle coding. These categories stimulated the development of the extended phrases used for thematic analysis (Saldaña, 2021), which are presented in detail in Chapter 4 - .

Themes and subthemes were developed through consideration of both specific excerpts and the broader context of each transcript as well as other participants' transcripts. For example, Carol shared, "At the 20-week scan, we found out he only had 1 kidney, but [we] were assured he would be okay." After his birth, she explained, "They did the test, you know, they checked him," and she recalled, "eating pizza" with her mom and in-laws, experiences she interpreted as signs that "he's fine." Being informed of a new diagnosis, "a very obvious birth defect" that had not been previously identified, disrupted her expectations, albeit not immediately after birth. Other parents' accounts offered additional examples of this subtheme. Like Carol, Jessica initially interpreted findings from a viability scan of "excess fluid behind the...fetus's neck" as benign:

And they did not seem overly concerned about it. They just said, oh, there's extra fluid.

We're going to recheck it in a couple weeks, so come back in for another ultrasound.

So... I left being like, oh, cool, I get another ultrasound."

A repeat ultrasound revealed "there's still excess fluid. And that's kind of when it got more real for us." Jessica continued illustrating the subtheme that normalization delayed disruption, "I hadn't been concerned, like my husband didn't go with me or anything. This was our third child. Like I just thought I was getting another ultrasound."

Table 3.2. Organization of process codes from Carol's transcript into categories and themes/subthemes

Initial Process Code(s)	Pattern Code/Categories	Theme/Subtheme
- Receiving a new diagnosis - Waiting for the ambulance - Feeling shocked - Feeling anxiety - Experiencing a trauma - Supporting others and/or herself	- Experiencing a disruption - Coping with the diagnosis	- Experience disrupts expectations - o Normalization delays disruption
- Not understanding what was said - Feeling confused - Not knowing what she didn't know	- Identifying gaps in prior knowledge - Not knowing what she didn't know	- Limited prior knowledge and experience with significant disability - o Gaps in prior knowledge - o Not knowing what she didn't know
- Receiving information from health care providers - Identifying barriers to learning - Seeking information online - Seeing is believing - Trying to make sense of the situation - Assessing decisions - Justifying decisions - Drawing conclusions between seemingly related events	- Receiving information from health care providers - Seeking/receiving information from others - Experiencing through senses (e.g., sight, sound, smell)	- Making experiences intelligible - o Hypervigilant learning - o Learning with the care team - o Learning in community
- Getting to be mom	- Getting to be mom	- Learning a different version of motherhood - o A false equivalence

Note. Process codes are paired with pattern codes to illustrate second cycle coding

process. Pattern codes were used to develop phrases for thematic analysis.

Trustworthiness

To frame my research as systematic and structured, I implemented Tracy and Hinrichs' (2017) criteria for qualitative inquiry. Quality qualitative research is marked by the following characteristics: (1) worthy topic, (2) rich rigor, (3) sincerity, (4) credibility, (5) resonance, (6) significant contributions, (7) ethics, and (8) meaningful coherence. Tracy and Hinrichs described a worthy topic as relevant, timely, significant, and interesting. Changes in the conceptualization of health literacy in recent years and the potential impact of understanding parents' learning within the context of caregiving, as discussed in Chapter 1 - and Chapter 2 - , establish the worthiness and significance of this topic. Furthermore, this study employed a novel theoretical framework in attempt to contribute fresh insights and a deeper understanding to the knowledge base on health literacy, increasing the potential significance of the contributions. Next, methodological thoroughness and alignment of the research purpose, questions, and intended methods, backed by existing literature, supported the rigor and coherence of this study. Additionally, Chapter 3 - documented a detailed description of data collection and analysis procedures (i.e., transparency; Tracy & Hinrichs, 2017). The study's findings are discussed in light of existing literature to further establish academic rigor (Bhattacharya, 2017). Discussion of the findings in the context of previous research, alongside a detailed discussion of my background, demonstrate sincerity (Tracy & Hinrichs, 2017). Additionally, I regularly engaged in open dialogue with members of my dissertation committee regarding my values, assumptions, and beliefs (Bhattacharya, 2015). As part of managing my subjectivities, I was transparent with my interpretations, linking the data to its de-identified source (Costantino et al., 2008). Furthermore, this qualitative study presents a highly descriptive, detailed discussion of a phenomenon as described by Merriam and Tisdell (2015). I used thick descriptions in my

presentation of the findings to allow readers to develop their own conclusions from the data to demonstrate sincerity and resonance (i.e., the reader's ability to make connections to their contexts). Finally, I collected feedback from participants on the themes before presenting the study's findings to enhance credibility (Tracy & Hinrichs, 2017).

Ethics

Ethical research practices, including reflexivity, were maintained throughout the research study to minimize the risk of harm to participants and the researcher. Tracy and Hinrichs (2017) categorize ethical qualitative research in four ways: procedural ethics (i.e., established by the institutional review board [IRB]), situational ethics (i.e., ongoing attention to ethical decisions), relational ethics (i.e., treatment of others), and exiting ethics (i.e., wrapping up the study and sharing findings). Before participant recruitment or data collection, the protocols for this study were approved by Kansas State University's IRB. I shared the consent form (Appendix C -) with all research participants to support their understanding of their rights as research participants. This discussion included formal notification of the potential risks, such as loss of confidentiality and emotional reactions based on the potentially difficult nature of the topics being discussed. I shared my plan for protecting their confidentiality, including the storage of any identifiable data on Kansas State University's password-protected and encrypted information technology systems. I informed participants that deidentified data may be used as part of other, related studies, and that data will be deleted permanently after seven years. I also advised participants of the limited compensation being offered for this study, their right to request a copy of the completed report, and their right to withdraw from the study at any time. I solicited electronic and verbal consent from each participant before commencing the recorded interview. I worked to build rapport with each participant, allocating 60 minutes or more for each interview. However, the length of the

interviews varied out of respect for participants' competing responsibilities. Only deidentified data was shared with the dissertation committee as approved by the IRB, and I made every effort to reduce harm throughout the research process.

Role of the Researcher

The researcher's positionality affects every element of the research process, which underscores the need to acknowledge the social identities, preconceptions, and experiences I bring into this work (Coghlan & Brydon-Miller, 2014). Critical considering positionality means reflecting on how one's social identities and upbringing influence their perspectives, behaviors, and relationships within and across contexts (Bell et al., 2023). I am a caregiver of a child who has experienced medical complexity and significant disabilities. My youngest son was born 17 weeks premature and spent more than 18 months hospitalized between two hospitals. Upon discharge, my husband and I, neither of whom had any formal medical education, worked with home care nurses and an outpatient medical team to provide continuous monitoring and care until our son's tracheostomy tube was permanently removed. This journey represented the inspiration for this study and my work in interprofessional health care education and collaborative practice. I completed a two-year traineeship sponsored by the local University Center for Excellence in Developmental Disabilities (UCEDD), a federally funded program to advance training and education related to developmental disabilities, and I have relied on my lived experience as a consumer and family programs specialist within the UCEDD program.

Chapter Summary

Chapter 3 - provided an overview of this basic interpretive qualitative interview study. It began with a review of the research questions, presented the researcher's worldview, including

ontological, epistemological, and axiological positions, and discussed the methods and procedures employed for this study. The findings are presented in Chapter 4 - .

Chapter 4 - Findings

This study sought to explore how parents of children with significant disabilities learn from experiences within the context of caregiving. Specifically, this study aimed to address the following research question:

- How do parents of children with significant disabilities describe learning from their experiences in the context of caregiving?

Chapter 4 - presents the findings from this study, including participants' demographic and social characteristics and the four themes identified through thematic analysis. The four themes that emerged during data analysis as answering the research question include limited prior knowledge and experience with significant disability, experiences disrupt expectations, making experiences intelligible, and learning a different version of motherhood. These themes and their associated subthemes are presented in detail following a description of participants' demographic and social characteristics.

Demographic and Social Characteristics

A diverse participant group was recruited for this exploratory study. Eighteen parents of children with significant disabilities participated in this study including seventeen females (94%) and one individual who identifies as non-binary (6%) living in thirteen states across all four major geographic regions of the United States (i.e., Midwest, Northeast, South, and West). Participants self-identified their race/ethnicity as Asian (6%), Black or African American (6%), Hispanic/Latino (6%), or White (83%). Participants reported varied levels of educational attainment including some college (11%), associate's degree (6%), bachelor's degree (28%), master's degree (44%), and doctorate or professional degree (e.g., Doctor of Philosophy, Doctor of Medicine, Juris Doctor; 11%). One participant (6%) shared having prior military experience,

and three participants' (18%) current or former spouses also served in the military. Of the 18 participants, four (22%) referenced growing their family through adoption, and at least two (11%) mentioned taking on the caregiver role for at least one of their adopted children.

Participants reported additional demographic and social characteristics for two time points: at the time of their child's diagnosis and at present. These characteristics are detailed in Table 4.1.

Table 4.1. Caregiver Demographic and Social Characteristics at Diagnosis and Time of Interview

Characteristic, n (%)	At Diagnosis (N=18)	Current (N=18)
Age (years)		
18-24	1 (6%)	0 (0%)
25-34	13 (72%)	5 (28%)
35-44	3 (17%)	8 (44%)
45-54	1 (6%)	4 (22%)
55-64	0 (0%)	1 (6%)
Marital status		
Divorced	0 (0%)	2 (11%)
Married	13 (72%)	12 (67%)
Not married but living with a partner	2 (11%)	1 (6%)
Single	3 (17%)	3 (17%)
U.S. Geographic region		
Midwest	6 (33%)	8 (44%)
Northeast	2 (11%)	2 (11%)
South	7 (39%)	6 (33%)
West	3 (17%)	2 (11%)
Employment status		
Employed full-time	11 (61%)	11 (61%)
Employed part-time	3 (17%)	6 (33%)
Not employed and not looking for work	3 (17%)	1 (6%)
Not employed but looking for work	1 (6%)	0 (0%)
Social supports usage (e.g., Medicaid, SSI, WIC)		
Yes	3 (17%)	18 (100%)
No	15 (83%)	0 (0%)

Note. Table summarizes demographic and social characteristics collected from participants.

Parents also described varied lived experience with health care (beyond routine care and minor surgeries), disability, pregnancy, parenting, caregiving and social services systems:

- three parents described lived experience with chronic medical conditions (i.e., connective tissue disorder, type I diabetes) or neurodivergence (i.e., ADHD).
- eleven parents identified having prior pregnancies or parenting experience.
- four parents discussed pregnancy loss, including one parent who described the associated health care encounter as prompting them to reconsider their role in such settings.
- one parent described growing up with a sibling who experienced significant disabilities (i.e., microcephaly, G-tube dependence).
- one parent described being born to disabled parents (i.e., deaf).
- two parents described supporting their mothers amid chronic health conditions (i.e., multiple sclerosis and breast cancer), and several others described exposure to health care, disability, and caregiving.

Parents reported providing care for children ($N=20$) with a range of diagnoses including Down Syndrome ($n=2$), hypoxic brain injury ($n=1$), traumatic brain injury ($n=1$), severe bronchopulmonary dysplasia ($n=1$), cerebral palsy ($n=1$), other genetic conditions ($n=8$), fetal alcohol syndrome ($n=1$), congenital kidney and heart defects leading to heart transplantation ($n=1$), other congenital anomalies ($n=3$), a neuropsychological condition ($n=1$), and numerous comorbid conditions. Of the eighteen parents interviewed for this study, two parents (11%) shared experiences caring for more than one child with significant disabilities. Sixteen parents (89%) reported managing technology-dependent care, including invasive ($n=3$) and noninvasive ($n=2$) respiratory support and enteral ($n=13$) and parenteral ($n=2$) nutrition support. Nine parents

(50%) reported that their children have a history of seizures. None of the participants worked in health care prior to their child's diagnosis.

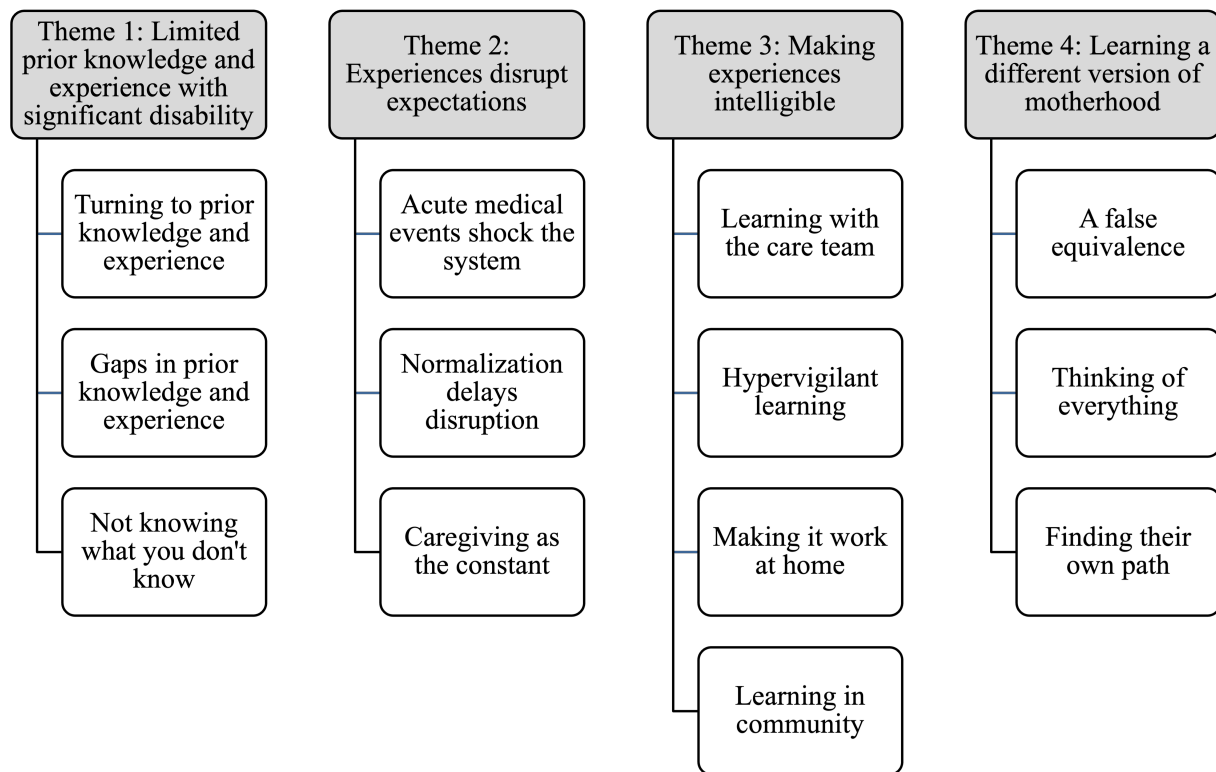
Themes

Informed by the multi-theoretical framework and a basic interpretive qualitative approach, data analysis focused on answering the research question, "How do parents of children with significant disabilities describe learning from their experiences in the context of caregiving?" Four themes and 13 subthemes (see Figure 4.1) were identified through coding and thematic analysis of participant interviews ($N=36$) and analytic memos. These themes include:

- Limited prior knowledge and experience with significant disability.
- Experiences disrupt expectations.
- Making experiences intelligible.
- Learning a different version of motherhood.

Each theme is presented in the following sections with representative evidence from the data.

Figure 4.1. Themes and Subthemes



Note. The graphic depicts the themes and subthemes identified through thematic analysis.

Limited Prior Knowledge and Experience with Significant Disability

Parents described approaching caregiving with full biographies but often limited prior knowledge and experience related to significant disability and medical complexity. This section is organized into the following subthemes: (a) turning to prior knowledge and experience, (b) gaps in prior knowledge and experience, and (c) not knowing what you don't know.

Turning to Prior Knowledge and Experience

Rather than approach caregiving as completely novel, parents recalled attempts to orient themselves by drawing on: (a) prior experience with health care, disability, and caregiving, (b) prior experience with pregnancy and parenting, and (c) their educational and professional backgrounds.

Prior Health Care, Disability, and Caregiving Experiences.

Most parents described limited personal experience with health care, disability, or caregiving prior to their child's diagnosis, aside from routine medical care. For example, Cassandra shared "I had LASIK done, I had my wisdom teeth out, my tonsils... It was very regular kind of stuff." However, Laura described drawing on her lived experience with a genetic connective tissue disorder when making sense of her son's condition. She shared, "I have [condition] and had many surgeries...because of that... Some of the lingo I knew just growing up, having medical complexities myself." She recalled, "I told my husband in the [operating room] that I thought he had it." Laura continued, "We were... initially told that he would be affected like me, and so we just didn't think that it was gonna be kind of an issue until... later in life..."

Felicia also compared her approach to learning in the context of caregiving to her own health care experiences and her experiences caring for her older son. She explained:

You learn things... because you have to. At least... that's been my way. So... I'm type 1 diabetic, and I was kind of just thrown into that, like, oh... you're diabetic, here's insulin... they didn't even make sure I could take a shot... I was deathly afraid of needles... that was a huge gamble... or, like, with my son, so he's adopted, I got him at 3. Well, he had all of these issues going on... and it's... you're just constantly having to fight and advocate for your kids.

Relatedly, Cassandra described drawing on their lived experience with neurodivergence to make sense of her caregiving experiences:

I was diagnosed ADHD when I was in 4th grade, I think... and my folks... treated that... as something to be fixed. They... threw all the tutors at me, study guides, and Ritalin and

Adderall... I do feel that by parenting [my children] in the way that I would have wanted to have been parented, I am re-parenting myself. There is some healing there. There is some... validation in... seeing my kids open up to me and thriving or being more confident and being able to speak up for themselves, where I remember being their age, and just being this shrinking violet, afraid to say anything, afraid to show any real emotion. No clue who I should reach out to, just kind of stumbling through... I think that it helps me to sort of heal myself and have some restoration.

Cassandra and other parents (e.g., Carol, Donna, Jessica, Susan) discussed experiencing one or more pregnancy losses; however, participants differed in how they discussed their loss in relation to their caregiving experiences. Some parents, like Carol, described prior loss as “contributing” to their attempts to make sense of subsequent pregnancies, which will be discussed in the next section. Cassandra described a shift in how they positioned themselves in health care following what they described as a “very difficult miscarriage” requiring “more than one procedure.” They recalled “pushing back and speaking up” during a particular encounter at a “freestanding birthing center” where they “[were] getting prenatal care.” They explained, “I really just sort of left it to [my parents], and... trusted the entire [health care] system. Because I had no reason not to. I had not [previously] had a poor experience or a reason to sort of advocate for myself... until my miscarriage.” Cassandra explained how her experience with miscarriage became a source of advocacy:

I never thought that something like that would happen to me. No one had ever talked to me about that. No one had discussed anything like that. But when I began... learning about it, it was like, one in every four women has had a miscarriage. It is tragically common. And so many women feel shame over it and feel like they have to hide it.... So

I would have been, like, 28. When I really started speaking up and speaking out... I experienced it in May. But then, I had issues through, like, August or September. And then October actually happens to be Remembrance Month for... miscarried or stillborn children and infant loss... And so... it became one of those things that I was like, you know what? I've experienced this and I'm still here, and I'm not broken, and I can still have kids, but this life, what was going to be, mattered, and it is still a loss that is worthy of being grieved... I became a very loud, outspoken person on that. And I had more than one person approach me after that and say, this was very comforting to me.

In addition to their own health care experiences, participants also recalled family members' or close family friends' encounters with the health care system. For example, Kara recalled her sister being born "11 weeks early at [hospital name] where [her son] was born... 14 weeks early." She explained:

I remember kind of going into autopilot, and just... falling back on the things that I kind of held onto and remembered from that time... there were a few things that I remembered, like... NEC [necrotizing enterocolitis], and ROP [retinopathy of prematurity], and just a few things like that, knowing that he was going to be susceptible to brain bleeds because of how early he was.

Carol also spoke to experiences with her sister who was born with microcephaly, including notifying her mother when her sister "would stop breathing" and "turn blue" as well as memories of her sister going "in and out of the ICU" in the weeks before she died. Carol recalled "learning sign language" to support communication, explaining, "I got very attuned to understanding her body language, her facial expressions." Carol described these experiences as fostering confidence in caring for a child with significant disabilities:

I wasn't upset about disability, I knew it was just a part of the variety of life. I knew that there were ways to just integrate people, to be inclusive... I think the hardest part is just figuring out diagnoses, figuring out care routines... Once you can kind of get that settled, you just kind of work through your routine, and so I felt kind of equipped, to do that.

She recalled, “We didn't really see a lot of other people with disabilities out and about, so we would get stared at, and... I'd get upset about that.” She also shared a “formative memory” of her sister’s day camp when “she and a couple other children in wheelchairs had to sit on the sideline and watch the other kids play.” She explained, “I was getting old enough to, like, really see that as a form of injustice, and to not want her to be left out.” She described reading about inclusive playgrounds in a Scholastic News article and her family’s efforts to “fundraise and build, an accessible playground in her [sister’s] memory.”

Like Kara and Carol, Natasha described a close connection to disability and medical complexity. She explained:

So I was actually born to two deaf parents, so I feel like I've kind of been... around disability my whole life. I'm the oldest of... four, and my brother just under me, had [congenital condition], so he actually was in children's hospitals all the time, and had, like, 4 surgeries by the time he was 3, so... pretty familiar with... different medical things.

Natasha described how she drew on her experience, including time in the foster care system and being adopted by her grandmother, as an “independent student” and as an advocate for her son:

Being able to understand... where people are coming from... just because I kind of went through that, even if it was a little bit of a different, unique experience. But I guess that's the point. Everyone's got their own... unique experience. And then when I became an

independent student, a lot of it was just... because I had navigated a lot of different systems, and... come across a lot of different people in different facets of life, like, I was just able to kind of figure things out. And I think that that really helped me with [son's name], which was, like, asking the right questions, trying to find the right things to... get me from A to B, but, like, having to advocate for myself in a lot of different situations, I could apply that to [son's name], because... I had to get over being scared of that for myself, otherwise I wouldn't have got stuff done.

Diana, Zoey, and Felicia described prior experience with or adjacent to caregiving. At nine years old, Diana began supporting her mother with “activities of daily living” (e.g., bathing, dressing) and “keeping [their] household running” after her mother’s multiple sclerosis (MS) diagnosis. Several parallels were evident in the way Diana spoke to these efforts and her caregiver role (e.g., many responsibilities, invisible illness, being scared in the hospital). She shared:

My mom lost her sight, and it was through that hospital admission and testing that they diagnosed her with MS. And so, I guess you could say that... I've been a caregiver since then. It was... difficult because, again, MS is more kind of an invisible illness. Much the same with... [my son's] diagnoses, for the most part. And so, I did feel that... some people maybe didn't acknowledge or understand our situation, because they couldn't see a disability... yet my mom was very disabled.

Like Diana, Zoey described a series of experiences during childhood and early adulthood that she drew on early in her caregiving journey:

[My mother] had a... gallbladder attack that was so severe, everyone thought she was dying, so we had to reroute [the flight,] the pilot called ahead, and an ambulance met us

on the tarmac... We spent a lot of time... maybe a week or two... at the [western university] hospital. And so, I just remember spending a lot of time... sitting in her hospital room and watching my sister advocate for her... and that level of familiarity allowed me to be an advocate for her later in life when she had breast cancer, and it gave me a sort of familiarity and confidence being in that setting, which I don't think a lot of parents have had.

Felicia connected memories of her siblings' health care experiences (i.e., autism spectrum disorder and bipolar disorder) to her understanding of caregiving. "I was the oldest, so... the caregiver aspect was kind of instilled in me," she explained. She described these experiences as informing her recognition of autism spectrum disorder indicators and to her self-reliance: "No one was coming to save me." Felicia explained:

A lot of stuff with my brother, the one that... has autism, helped me recognize things with my daughter, and so, I brought it to the neurologist's attention when she was 18 months old. I'm like, hey... I'm seeing these signs, which to me would indicate autism because of my brother. I also have a cousin that has autism, and two nephews. And a niece... Now, granted, not everybody's... autism manifests the same way, but it was similar things, and I'm like, at what point... do we start looking at, hey, she might have autism?

Other participants, including Donna and Raven, identified caregiving as part of their biography at a young age. Donna explained how she took on significant responsibility caring for her younger brother after her parents divorced. Likewise, Raven shared that she "grew up quick," to support her mother and sister. Relatedly, both Selina and Gwen described exposure to significant disability:

So my first cousin is paralyzed, from the waist down, and... and that was a... a learning experience, too... We think something happened at birth, but... seeing... how my aunt and uncle, and cousins... interacted with and how we interacted with her. It was... we just have to learn how to do things differently. So that was before [son's name], and then I can say... as he has grown up, my exposure and interaction with other families have definitely shaped how I... how I make decisions. (Selina)

Gwen discussed growing up in an integrated high school and volunteering “at a summer camp for adults with developmental disabilities.” She recalled, “I had witnessed a seizure... I had witnessed... all sorts of... mobility aids, and... I knew how... life could be hard. I also... attended funerals of some of our campers that... passed away...”

Prior Pregnancy, Birth, and Parenting Experiences.

Parents also described drawing on prior pregnancy, birth, and parenting experiences. Eleven participants acknowledged having prior parenting experience, yet not all parents discussed their pregnancies. Because of the richness of her description, Jessica's narrative introduces this subtheme and serves as an entry-point for discussion of the broader dataset.

Jessica began her second pregnancy expecting a familiar journey. She explained, [First child's name] was healthy, she nursed easily and well. I exclusively breastfed and pumped for her for the first year... Everything just kind of fell into place very easily... Where, between [first child's name] and [second child's name], we did have a miscarriage, and that's kind of when we were like, oh... everything for [first child's name] came so easily that it kind of... surprised us. Like, this happens? Like, after you've already had a healthy pregnancy? Like, just being young and naive, I was 23... when we had [first child's name]. And so... not knowing how to handle that, like, do we call a

doctor? ...because... we were, like, 6 weeks along... it was very, very early in the pregnancy. We were like, what do we do?

Jessica's account depicts a gap (i.e., "What do we do?") between her accumulated knowledge at the time and the unexpected miscarriage.

Jessica described drawing on experience with her first child throughout her third pregnancy and early days parenting her second "typically developing" child, comparing several characteristics of the experiences (e.g., choosing a physician in a new location, difficulties nursing):

I knew I was gonna have or intended to have a second C-section. So I was like...let's go with somebody who is known for surgeries... Again, everything was just very easy and smooth... no hiccups or blimps along the way... He was harder to nurse. He was more stubborn. But, because I had had the experience of, like, it is possible, and it gets easier because I did it already for a year with another, I was able to push through. But...I remember saying, if I didn't have such a great experience nursing my first, I probably would not have been successful nursing [second child's name], because... the first week was, like, a week of hell... he wasn't latching, and... the position was wrong, and I remember... the bleeding... I remember they said it might bleed with [first child's name], and... that never [happened] ...it was just a whole different nursing experience. But we were in the larger city, so... a breastfeeding consultant was able to come to the house and assist. I went to a breastfeeding support group every Wednesday morning, and they... weight-checked him, and they were able to answer... any questions. So it was really nice that the struggles I had, there were services and groups available to assist with that. Plus, my past experience, I was like, this is gonna work... I know it can work.

In this account, Jessica's refers explicitly to her "past experiences" as she made sense of nursing her second child (i.e., "I know it can work"). She recalled being told with her first child that she might bleed, information that only became relevant to her experience with her second child. Jessica also described seeking community support in response to the "struggles," adding to the accumulated knowledge and experience she continued to draw on when trying to make sense of her fourth pregnancy.

Jessica's account of the early weeks of her fourth pregnancy depicts a familiarity with clinical routines, including the viability ultrasound, sharing "not that you get to see anything when they're like the size of a bean... or a pea or whatever." She continued:

So initially it was our like viability ultrasound. So very, very early, they noticed that there was excess fluid behind... the fetus's neck. And they did not seem overly concerned about it. They just said, oh, there's extra fluid. We're going to recheck it in a couple weeks, so come back in for another ultrasound. So... I left being like, oh, cool, I get another ultrasound... I didn't really understand at that point what the concern potentially could be.

At a follow-up ultrasound, Jessica recalled being informed that "there's excess fluid" which "could be nothing... could be something like a chromosomal difference, or it could be incompatible with life." She explained how she made sense of this news and their recommendation to have "the genetic blood work done." Jessica continued by sharing:

I hadn't been concerned, like my husband didn't go with me or anything. This was our third child. Like I just thought I was getting another ultrasound... I was only, not only, but I was 31 years old at the time. And so, I was not in that age range that it would have necessarily been recommended.

Jessica's account includes explicit references to this being their "third child" and her identification of a mismatch between her physician's recommendation and routine pregnancy guidelines. When the lab results came in, she learned that she was expecting "a boy," and "it's very likely he has Down syndrome," news to which she responded, "I don't even know what to ask."

Jessica described attempts to make sense of the uncertainty that came with her son's diagnosis as involving interconnected emotional, spiritual, and informational processes:

...it was very emotionally trying. I remember crying a lot just thinking like, why? Why us? I mean, that's still even a question I asked eight years later. You know, why? Why is this the deck of cards that we've been dealt? And even though we are a faithful people and... never imagined ourselves being in a position where a termination or an abortion would even be a consideration... I really struggled even with my faith early on in... the pregnancy, being upset that I even had a choice, but then realizing like, I don't have a choice... it was very, very confusing. I think I did start looking information up just because I was not very experienced with individuals with Down syndrome... I've known a few, like in passing at church or in passing in the community. Like I knew very limited information about the disability. And so, I tried to learn a little bit more about it. Like, is this something that we can handle, but you really don't know what you can handle until you're doing it, you know?

Jessica's description of processing "her son's Down syndrome diagnosis illustrates a gap between her prior experience and knowledge and her situation at that time (i.e., "I knew very little information about disability) and her efforts to reconcile this gap using online resources (i.e., "trying to figure out what do we ask") and information from the geneticist. She recalled, "I

remember one of the questions we asked was... How will his disability affect him? Or how will we know like what his disability will...look like,” an initial worry voiced by several parents (e.g., Stephanie, Natasha, Doreen, Raven).

Jessica shared that she developed “preeclampsia and got admitted at 33 weeks after a relatively normal pregnancy.” Her son was born by c-section at 34 weeks. She had constructed a narrative based on what she had known: Her son had Down syndrome and a known heart defect. She recalled the subsequent echocardiogram and blood work as confirming these diagnoses and not overly disruptive even though an additional heart defect was identified. She described her son’s first week of life as “waiting to see if the second heart defect... would need to be surgically corrected” alongside a period of feeling “really frustrated” that she was unable to breastfeed like she had with her older two children.

Like Jessica’s experience, Carol’s son’s prenatal diagnosis occurred following a pregnancy loss. Carol described her experiences with pregnancy loss as “contributing” to how she made sense of her subsequent pregnancy and the news of her sons’ congenital kidney anomaly. She explained:

Dr. [name], was very kind and reassuring, and she... said things like... until they had more recent ultrasounds, people didn't even know they only had one kidney... That you just need to... think about hydration, think about healthy eating... and... she said... he'll be able to play... most sports. It'll be fine. But I think in my gut, the whole pregnancy, I just had this feeling something was wrong, and I was... worried about losing him the whole time... I'd just come off of two early-term miscarriages, as well as a failed adoption within the prior year, so I know that was contributing to it... I just had this...

feeling... that something was gonna go wrong. And so... so even though she was reassuring about it, I just... didn't feel good about it.

While Carol acknowledged the nephrologist's evidence-based explanation, she described canceling her own work-related travel plans after reading a memoir documenting the author's experience with infant loss after going into premature labor during an international trip. Carol expressed first finding a sense of relief when holding her son, explaining, "I did it, like, he's here, he's alive, he's fine," unknowing that his first hours and days of life would bring news of multiple congenital anomalies not previously identified via ultrasound.

Similarly, Susan and her husband had constructed their expectations around their son's prenatally diagnosed, congenital heart condition. She recalled her "advanced age" (i.e., 41) and life experiences, which included "raising two kids and having some losses," as enabling an attitude of "rolling with it" during pregnancy. Like Jessica and Carol, Susan described her sense of preparedness as disrupted by the discovery of several additional anomalies (e.g., malrotation, severe hearing loss) after her son was born.

Gwen also described drawing on experience from a prior pregnancy when making sense of her second pregnancy. She explained, "probably around... 13 or 14 weeks, I thought... my dates are wrong, or something... I am getting bigger by the second, something is... different." An ultrasound revealed she was expecting twins which led to an abrupt transfer of care.

And so that was... a really fast... terribly rude awakening to medical complexity that went from a place of... low intervention... midwifery model of care, birthing center, water birth... unmedicated... very opposite of... the American health care system... And so that was my reference point, right? And... breastfeeding for a long time, and... that was where I was coming from. So when I was pregnant with twins... my whole

pregnancy was definitely... a bit shocking, because it was so... intense and very medicalized when, I mean, there was never any indication that it necessarily needed to be...

In this account, Gwen explicitly described her first pregnancy and birth experience as serving as her “reference point.”

Some parents (e.g., Gwen, Jane, Donna) mentioned drawing on other experiences with their older children. For example, Jane attributed her knowledge of developmental milestones to parenting her daughter. Jean described differences between her first and second child, sharing:

Our other son was... like, if you were to... paint a picture of the easy baby... that's him... and of course, we had decided... that's because we're so good at this. Like, we are such great parents, this is why our baby's easy. No... he was just born that way. And we quickly realized with [second son's name] that we knew nothing. But what we knew for sure, even though these were two very different kids, is there is an amount that even a tiny baby is present in the world, and is engaged with the world around them.

Donna offered,

I think having had [my daughter] first helped with [expectation development], because it... kind of laid some of that, this is what a typically developing kid would do, and if we'd had him first, having never parented anybody ever, I think we would have been struggling with that a bit.

Likewise, Gwen shared, “I was able to already be so confident in... the mom that I was... Like, I'd already had 4 years of loving so fiercely, and... knowing... we were... in a... really... solid place of parenthood.”

Educational and Professional Backgrounds

Parents also described drawing on their educational and professional backgrounds to make sense of early caregiving experiences. Four participants (e.g., Felicia, Raven, Natasha, Kara) experiences were in or adjacent to law enforcement or the military. For example, Felicia described her training as a police officer as prompting her inquiry into her daughter's vision. She explained, "I had noticed... that she had... nystagmus... I'm a police officer, and that's the only reason I recognized it... because I'm trained with that for DWIs, and I'm like... I know she's premature. Is this normal... developmentally?" Felicia also described drawing on her work in this "highly stressful field" when they "were going through all this stuff [i.e., intestinal issues including colon rupture following premature birth] in NICU." She explained, "I know how to manage stress, and to compartmentalize things until I can deal with them later." Felicia described turning to this experience across contexts, including preparing for IEP meetings: "like I'm prepping for a trial, going to court. I have all of my evidence printed, you know, marked, my exhibits, so I'm like, hey. legally, you can't tell me this." Like Felicia, Raven described drawing on her experience working in law enforcement as a source of advocacy:

I know some parents, and especially moms, sometimes are... timid... my job... has definitely... hardened me to the point where... I'm not afraid to... speak up if I need to. I do go through these... phases where it's like, do I want to overstep and... come off as a crazy person... or do I want to... relax a little bit? I do struggle with that because [of the people I work with,] I have... this persona... But in the end, I think it has definitely helped me... be a better advocate for my child... especially with the insurance stuff...

Like Felicia and Raven, Natasha described drawing on her professional experience in a "male-dominated, military-like, veteran-dominated industry." She explained,

You really gotta fight for your spot, and kind of prove that you belong in those circles.... I'm allowed to ask questions even if I'm not an expert, because I'm putting in the time. And so, I would say definitely that... being able to navigate multiple stakeholders... like, when we were putting together solutions for our clients, a lot of it was having to deal... host country stakeholders, and U.S. government stakeholders, and corporate stakeholders, and... all these people, and so... when you're dealing with clinics and doctors... being able to kind of pull all that together and not get overwhelmed, I mean, that's probably the biggest thing that I use.

Similarly, Kara, a high-risk juvenile probation officer, described drawing on her emotional intelligence skills when disagreeing with providers' recommendations. She explained, "Because of what I do for a living, and working with children, where we teach them, if you're going to scream and yell, nobody's going to listen to what you have to say."

Zoey and Diana also described drawing on their professional experience. As a microbiologist working in pharmaceutical manufacturing, Zoey described TPN administration as familiar rather than frightening. She explained,

The whole... basis of sterile technique is what I had done for a living for years. So when the nurse was training us, I was like, I already do this... and so that was not scary to me.

It was a very easy transition.

Diana, whose background was in business administration, described this same responsibility as "horrificing." She explained,

I mean, he was in a NICU... those people were very highly specialized nurses that went to school for years, passed exams and licensing... And in order to bring my baby home, I had to do it... I felt incredibly ill-equipped.

Paralleling Diana's experience, Donna recalled her prior experience being "thrown on a ship" with minimal training. This once-in-a-lifetime professional development experience informed a "figure it out" mentality she's drawn on as a caregiver. Donna explained:

You've got to know it, and if you don't know it, you've got to be able to figure it out fast, or learn it fast, and retain it quickly, and make your best guess, because you don't have time to ask all of the time. And that very much applies to caregiving. Especially with a medically fragile kid, where he's got a trach, and we are... pretty close to an hour from... the nearest hospital that could actually do something with him if something was wrong. So... if I don't know my stuff... I gotta guess, because the only other people that are coming to my house are also gonna be guessing.

Like Zoey, Jessica and Selina had professional experience adjacent to health care. Jessica discussed work experience as in case management:

I was a case manager or family support worker and worked with high-risk families in our community. Not... necessarily special needs—high risk, but high risk as far as like low income, low education, young parents. So I did a lot of parent education in my career and worked with families to get services for them. So I was unique in the sense that I was aware of services that were available and resources because of my previous career.

Jessica described this experience as allowing her to anticipate her son's needs, even prior to his birth as evidenced by her attempt to sign her unborn child up for her state's birth-to-3 program. Similarly, Selina described working peripherally to health care as a community educator. She explained:

I was a liaison, before the babies were discharged home... We had nurses that were out in the field, so I would attend these discharge planning conversations... they'd say... this

baby is ready to go home, and it's like, no, wait... they don't have lights on, or the housing is unstable, they can't go home yet... those kinds of things. So... by the time [son's name] came along, I knew a lot from having worked in the periphery.

Other participants also referenced drawing on their academic and professional experiences. Donna described drawing on her career as a process engineer to streamline processes at home and in the hospital. Cassandra described drawing on a “driving need to know” stemming from her “background in print journalism.” She explained, “The best decisions are made when you are fully educated about your choices.” Susan also explained drawing on her professional training:

I am an attorney by trade. I think that helps a little bit as far as... reading the fine print on things, advocating for what [son's name] needs... You read the letter that they send. You research, what does this mean? You see how to appeal something. You go in and tell your sob story to somebody to make something happen. You know, you take recommendations from other parents... I often think about... what if I had been... a single mom who worked at Burger King, or something like that.

As a recent Ph.D. graduate who had spent the last two years conducting qualitative interviews with government officials, Gwen described feeling prepared to meet the moment. She explained:

Having been a recent... Ph.D. grad felt very... beneficial for the whole process, just in terms of... having... the confidence, but also... knowing... how to ask questions and find answers... I think that it did feel like, okay... I'm... prepared for this moment, and I kept thinking, too... I'm really thankful that I'm [name's] mom.

Specifically, these skills were present in Gwen's advocacy for an alternative portable ventilator to what the hospital typically used.

I... did all the research and... presented my case, basically, and they found a DME that could provide it, but they were very, like, our RTs don't know this vent, like, we have never discharged anyone home on this vent, like, and I was very clear, like, we're gonna try it, because if this vent works for kids that are two and a half kilos. Thankfully, they didn't really... have any pushback.

Gaps in Prior Knowledge and Experience

Parents identified gaps in their prior knowledge and experience, moments when this knowledge and experience alone were not enough to help them make sense of what was happening. Parents described varied levels of prior experience with: (a) pregnancy and childbirth, (b) medical complexity and disability.

Pregnancy and Childbirth

In the absence of experience with pregnancy and childbirth, participants (e.g., Carol, Diana, Natasha, Selina, Zoey) described turning to other reference points. For example, Diana recalled physical discomfort when laying down, as prompting her to seek an appointment with her OB. She recalled thinking that “something doesn't feel right,” pushing past initial guidance that she was “probably having Braxton Hicks.” Different from Jessica’s experience, Diana identified deviations from clinical routines (e.g., being sent to another physician, no waiting, request to call her husband) as significant, explaining, “And I thought, oh, this must be very bad” when the physician advised her to call her husband. The maternal fetal medicine physician’s description of “the delicate balance” between keeping her son “in long enough that he'd survive major surgery after he was born, but not too long because all of his intestine would die” has stayed with her “all these years later.”

Diana described persistent physical discomfort accompanied by culturally mediated knowledge, referencing “the quintessential book, *What to Expect When You’re Expecting*” and TV programs like “*Grey’s Anatomy*” and “*The Baby Story*,” as prompting her recognition that she was likely experiencing contractions at just 29-weeks gestational age. She explained how she subsequently felt the need to “validate” her condition before seeking further care:

I had this...in the back of my mind, like, I... want my doctor to not think that I'm crazy. Like, oh, she's just petite, she's having Braxton Hicks, and she feels like she has to come in, but, you know, we don't really need to see her. I just felt like I needed to have validation, you know? So that's why I was starting and to time everything. Because it just wasn't going away. And I'm like... this can't be ignored... something's happening here. The funny part about all of that is that I didn't qualify to go to the birthing class yet, because... you sign up when you're, like, 32 weeks. So I never got to do that. And then I also didn't get to... the breastfeeding class... I didn't get to do any of that, so I felt like, oh, I am definitely missing information here, but I felt like my body was telling me it's time to go. Time to go in, let someone who knows what they're doing take a look at you, and figure out what's happening.

Diana explicitly named a gap in knowledge she felt she should have (i.e., birthing class and breastfeeding class). Unique to other participants’ accounts, Diana recalled a birthing experience marked by excruciating pain both physical and emotional:

I did not have any pain medicine on board before, there was no spinal, that's why they knocked me out... And now I'm awake, and I have just gone through major surgery, and it feels like they have scrambled all of my insides, and I want to die. I was in so much pain that I was just holding onto [the cold bedrail] for dear life, thinking, like, oh, please,

let the pain medicine kick in. Please, somebody help me. And I'm like, where's the baby? You know, because I look down, my stomach is gone. Obviously, the baby's somewhere. Where's the baby? And [husband's name said] they took him for surgery. If I wasn't in... emotional pain before that point, I definitely was then... I didn't get to see him. I didn't get that moment where they hold him up above the drape, or they show you his face, or you hear him cry, or anything. Like, I don't know what color hair he has. I didn't get to see him. And I'm like, this is just absolutely the worst thing that could have possibly happened, besides losing my baby.

Diana's prior knowledge told her that the experience would have finite "finish line," which she described as "taking home a baby." However, she later came to realize after her son was readmitted and put back on TPN, "the NICU wasn't the marathon. The NICU was apparently pregame. Like, that wasn't even the football game. That was pregame. And now we have 4 quarters that we have to play." Jean expressed a similar sentiment, sharing, "People talk about going through a hard season. Well, that was the beginning of your season is now forever."

Like Diana, Natasha's birthing experience was characterized by a waiting period after being admitted to the hospital. Natasha shared that she "didn't really know what was happening" when she was admitted to "triage" after her "water broke at 26 weeks" due to preterm premature rupture of membranes (PPROM). "I'd never been pregnant before," she said. Her son was delivered via "emergency c-section... at 29 weeks." She continued,

I thought he looked different than other preemies that I'd... seen online while... I was... doing my research, waiting in the hospital for him to come out. But I did notice, the first time I ever met him in his incubator... that he had a very... kitten-like meowing cry... But again, I just thought all preemies... sounded like that... that was actually one of the

first things I ever said, was like, oh, he sounds like a little kitten, and then come to find out, so two weeks later, he was diagnosed, or the genetics team set up a meeting with me and told me he had [genetic condition]... kids have... a voice box... defect, which causes... among many other things, like global developmental delays and tone issues, [and] a very weak cry. (Natasha)

Natasha described drawing on both prior knowledge (i.e., sound of a kitten's meow) and newly acquired information (i.e., familiarity with the physical appearance of premature infants acquired through online research) as she attempted to make sense of the situation.

Zoey's account provides a third example of the types of reference points mentioned by parents without prior pregnancy or birth experience:

During labor, he had gotten a little tachycardic, and... it's funny, because... our birth plan was to have a natural birth, and... a lot of midwives and doulas discourage the, I can't remember what it's called, but that heart monitor of the baby. They're like, it just makes everyone overreact, and I... tend to be a little bit more compliant... I'm always trying to thread the needle between, you know, being fully compliant and doing things my way... And so, under that situation, I was like, yeah... do the heart monitor... And so, they were like, he was so tachycardic for so long... the whole surgery team was staged outside my door. They were... ready to... come in and do a C-section...

Zoey recalled turning to cues from the immediate environment to make sense of the situation.

She explained, "Having that experience right before he was born, and then having them be like, things are going sideways, we're taking him to the NICU, it was a progression that made sense to me."

Medical Complexity and Disability

Some parents described an absence of exposure to medical complexity and most participants described disability as being “pretty hidden” (Stephanie) during their youth. Donna recalled being “very shielded” from her mom’s battle with breast cancer and does not “remember seeing... a single kid with Down syndrome or any other disability.” Donna described first learning of her son’s diagnosis after he was born:

So we had a birth diagnosis, and when he was first born, it was a little bit after birth. Somebody had come in the room and said, we think he might have Down syndrome. And my husband had asked the question of, well, what makes you think that? And neither of us saw it, because... Ironically enough... I thought our first baby was ugly when she came out... I'm sure she was gorgeous, but I had a lot of postpartum depression. So I was like, I had an ugly baby, great. And when he was born, I was like, oh, he's adorable... and so, I didn't see the Down syndrome in him, but I... I go back and look at the pictures, and I'm like, oh my gosh, like, he is straight up, like, there is nothing that says no Down syndrome to him. Like, his eyes are a dead giveaway, but they had called out, like, the single palmar crease. And we were both looking at his hand, we're like, I see two lines, I have no idea what you're seeing.

Like Donna, Stephanie, “did not know anything about her [daughter’s] diagnoses until she was born.” Stephanie also mentioned having minimal experience related to health care and disability at the time of her daughter’s birth. She recalled her mom and grandma handling her grandma’s battle with breast cancer “behind the scenes.” She explained,

I know... my grandma was getting treatments and, you know, had surgery... [she] had a wig because of her hair falling out, so I knew kind of the general things going on, and

visited her in the hospital a couple times when she had... longer stays during that, but that was mostly it.

She continued,

I honestly had... very little medical knowledge before she was born, so we were, you know, in the hospital with her... NG tube... up her nose before she got the surgery, and me and my husband are like, how are we gonna ever take her home? Because she's on this with all of these machines in the hospital, and we were like, how is this... ever gonna be able to go home, and one of the doctors... sat down and had a conversation with me about the G-tube, and I was like, what is that? I was like, I don't know what this is. And she was like, it's this little button, and they put it in her stomach, and then [formula is] fed through there, and so I was really excited to hear about that because that was the first thing that gave me hope of, like, oh, we can... get her home, and she can eat, because I was like, she has to eat, or she'll die... I think that's something that has really amazed me through all of this, like, how... much medical stuff we're able to have at home... Yeah, because... going into it... before I knew anything, I was like, there's no way we're ever gonna take her home. She needs all of these things, and... Just learning how much equipment is out there or available was... Gave us hope and allows us to, you know, live our life at home.

Relatedly, Jean described first learning of a nasogastric (NG) tube during an unexpected hospitalization, noting that she “had never heard of a feeding tube before.” She explained, “We don't know what's going on, but we know our kid's not eating.” Compounded with this ongoing uncertainty, the news that a member of the health care team was going to “come in and place the feeding tube” exceeded her immediate capacity for making sense of the situation. She recalled:

I need you to stop talking for a minute, because I just need to process this. I will let you know when we can continue this conversation, but I need a minute. Like, I couldn't even hear it. Because I was just like, I have no idea what is happening.

Like Stephanie and Jean, Gwen encountered medical technologies that disrupted her prior understanding of the boundaries of medical care. Gwen described not previously knowing that “you could even discharge home on a ventilator” or “that [they] would have to change it,” referring to her daughter’s tracheostomy tube. She recalled prior medical experiences:

Very normal, basic... experiences with our first, with, like, regular pediatrician appointments. Like... she had a lot of ear infections... she had tubes placed. I thought back then that was stressful and scary and intimidating, and God bless my little naive heart back then.

Gwen went on to explain, “I was not in any way, shape, or form prepared to navigate, like, the health care system, other than you do it because you have to do it, and so it just happens.”

Unique from other participants’ accounts, Carol described a close relationship with her sister who experienced multiple disabilities, and, for at least part of her life received nutrition through a G-tube. However, Carol also described moments when these experiences no longer helped her make sense of what was happening. She explained,

[A doctor] said that he has no anus, and we were like, what? You know, we didn't even know what that meant, so... We did unwrap him, unswaddle him, because...he had been handed to us swaddled, and his bottom [was] completely smooth... no hole at all, no butt cheeks, just smooth. And we were just shocked, because we didn't even know that could be a condition.

Carol also described encountering gaps in her knowledge and experience when taking her son home for the first time, new to colostomy cares. She explained:

They did not set us up with a medical supply company and tell us where to get it from.

They gave me a paper, a printed-out list of some pharmacies that they said would have the supplies. And I remember we finally got him home, and, you know, I think they sent

us home with 3 changes. Well, he's recovering from surgery, he's little, he's squirming,

he's crying, because it's exactly at the surgery site that you have to put this bag on. And

so he would cry and scream, and then poop would come out, because he's crying and

screaming, and we'd have to, like, restart... So the 3 changes they sent us home with were very quickly disappearing. And, and so I start calling all the lists, and no one has...

pediatric sizes. And... we were just, like, starting to panic, and after, I think we'd been

home... like, a day and a half, we were back at the NICU, because we had no supplies,

we didn't know what to do... We had to go back there and have the wound nurses help

us.

Carol explained how her and her husband relied on the information provided to them as well as existing problem-solving skills (i.e., “trying to call the manufacturer”) only to have to return to the hospital.

Doreen also recalled attempting to make sense of her then foster now adopted daughter's condition sans experience with “personal hospital stays, ...extensive medical care,” or “other kids.” She recalled her youngest daughter being 2 months old at the time of her hospitalization due to “non-accidental trauma.” Doreen shared being notified of her daughter's significant injuries (e.g., “3 brain bleed which caused strokes,” and “fractures in her legs, her arms, her neck, broken ribs”):

I knew it was serious, but how long-term things would be, I just kind of assumed, you know, that she would... get out of the hospital, and we would just kind of go from there, and things would be okay... She was probably 6 months old or so before I finally realized that our life was gonna be different. I guess I just was a little naive in thinking that she was just gonna... I mean, I didn't realize the long-term effects of... a brain injury... because I had never been exposed to anything like that... I didn't have time to sit and process... I think about, you know, her laying there... She had... a little neck brace on, and a drain coming from her head, and... the feeding tube, things like that. And it's so scary to look back and think that they just gave her to me... in such a... condition. But at the time... I don't think I realized how permanent things were gonna be, with her... medical complexities and I... just kind of naively thought that they wouldn't send her home until she was better... But I didn't have any other kids either, so I don't think I realized how bad it was.

Not Knowing What You Don't Know

Parents described experiences where they were unaware of the limits of their knowledge and experience, situations they would come to realize inhibited their understanding. These blind spots are organized into the following subthemes: (a) significant disability and medical complexity, (b) systems navigation, or (c) vision for the future.

Significant Disability and Medical Complexity

Some parents described being unaware of the limits of their knowledge and experience related to medical complexity. For example, Diana described her experiences with bedside rounds. "They sort of come in, take all the information, produce orders for the care team, and then are gone." Specifically, she recalled being informed that "they were going take out his

intestines, and it's... kind of like your appendix... he'll be fine." She went on to explain her experience trying to make sense of her son's worsening condition for more than six months absent relevant medical terminology. She explained,

I didn't have the right information to look up what does short bowel syndrome and malabsorption look like. All I knew was that he was stooling, stooling, stooling, stooling, stooling, but I couldn't connect that back to the medical reason why, because I was never given the terminology. Even if it's above my education, I felt like... those were important pieces of his care. But I couldn't learn more about it because I didn't have the right language.

Other parents also recalled situations where they were unknowingly missing information, only to find out afterward. Gwen recalled "[having] no idea what to look for" in terms of "work of breathing" or "respiratory distress" when she first took her daughter home after a 5-day NICU stay: "There's a lot that...arguably went sideways and wrong the first time, because how did I not know how to look for signs of respiratory distress in my baby?" At 9 days old, her daughter experienced a cardiac arrest that led to a hypoxic brain injury. Felicia concurred, explaining the responsibility she felt as a parent for being informed and raising concerns. "Unless you go into an appointment with these concerns. You know, you wouldn't know."

Some parents (e.g., Gwen, Carol, Jean) described attempts to make sense of their child's first seizure, without seizure related education and knowledge. Jean explained,

We had actually been told by our neurologist, who is a, you know, world-renowned epileptologist... I know seizures, this is not a kid who's going to have seizures... You know, and I don't fault him for that, because [son's name], you know, even with his overall diagnosis, still remains a mystery in many ways. So we knew pretty much

nothing... We didn't know that rescue meds were a thing. And, I mean, I think that is wildly irresponsible to not even have that conversation with parents of seizures are scary... here are medication options that you can safely give him at home. And even after the second time, we called the squad and went to the hospital... for a seizure. It took the third time until they said, like, oh, have you heard about rescue medicines? And we're like, no, tell us more!

Like her interpretation of their seizure journey, Jean explained that her son “had to prove that he could interact with the [speech-generating] device before the school would give him one,” something that she had not been previously aware of. She continued,

When he started early intervention and speech, they started with the PECS book... the picture exchange, very early, and holy cow, like, he didn't have the fine motor [skills] to do that, and they were just pushing that for years, and I didn't know better. But he certainly could have hit buttons... on an iPad.

She recalled this gap continuing even after her son received a device:

I had no education on the device, no one trained me, nobody talked to me about it, and they were like, oh, don't bother pulling it out at home, we'll just work with him at school... And because I knew nothing, and I was trusting them because they're the experts... So he had this device literally four years that mostly sat in his backpack. ...End of third grade, I was asking questions about it, and the speech therapy office would be like, yeah, we're working on it with him, you know, he's not figuring it out. He just kind of stims on it and just presses a button over and over and over. I found out that they had been getting it out during the school day for 10 minutes during calendar time. And then putting it away, and then it was done... And in an IEP meeting, end of third grade, the

speech therapist at the school wrote into a report that he was, quote, incapable of learning to use a device, it was getting in the way of his education, and we needed to discontinue it immediately. To her credit, the word incapable sure got me to, educate myself real fast... So that was in March, end of March. In June... he started working with... someone who knew how to teach him. And in August... like two and a half months later, we were sitting and eating breakfast, and his brother [older son's name] had been at sleepaway camp, and I said, okay, [son's name], after breakfast, we're gonna get in the car, and we're gonna... I'm gonna cry. We're gonna go pick up [older son's name] from camp. And he, on his device, totally on his own, said, excited, love, [older son's name].

She continued,

He puts together multi-word sentences, he asks for things, he participates in class, he tells us he wants to go to Trader Joe's or to the movie theater, you know, he asked for his brother to come over, and then says, go away, and laughs. You know, he says underwear and laughs and then says joke. Like, he has so much ability and personality and autonomy.

Like other parents, Raven's and Carol's accounts depicted the relationship between the prior subtheme, gaps in prior knowledge and understanding and the subtheme of not knowing what you don't know. Raven recalled:

I felt like I didn't have a lot of support medically... I understand a lot of doctors have no idea what my son has. So when we asked for a second opinion, they told me to go to genetics. So I went to the genetic department, we made an appointment... They had scheduled me an appointment. Then they called me the next day and canceled, and then they rescheduled me again, and then they canceled again, and it was just... even to get an

appointment was a pain. Then I had to send them everything that, like, his genetics testing and everything... So I went there, thinking they would look at everything, and they would redo the testing. They would... look at things, they would kind of check everything that he's kind of had done... I talked to the genetic counselor. The doctor maybe came in for 5 minutes. The genetic counselor brought up Jacobson syndrome, and it was made very clear that my son does not have Jacobson syndrome. And they gave me a Jacobson syndrome packet. And I said, my son does not have this. And they said, you should still have it. You should still have this packet. And I don't want to sound mean, but like, if you look at a kid with Jacobson syndrome, and you look at my child, there's no similarities, like... I feel bad saying this, my son, like, looks normal. Like, you look at him, no one can tell anything's wrong with him. You look at someone with Jacobson syndrome, you... their facial features are off, you know? So... I felt, like, very unheard. They're giving me this packet, they're teaching me about Jacobson syndrome, which my son does not have. And then, they asked about our genetic stuff, and... I had already sent our genetic testing over... What happened with [son's name], what they call it, like, de novo, it... just... randomly happened. And that was it, and then the doctor came in and literally looked at me and says, I'm sorry, why are you here? Like, what do you want a second opinion for? And I was like, well, I wanted him to kind of get retested, I just wanted to make sure, because... I just like [wanted] a second opinion, and she's like, we don't retest for genetic disorders. We go based on what your doctor already did. And that was it. And we were there for almost four hours... So it was just very discouraging, and then, like, I had to take a day off from work, and... driving to [eastern city], so... I feel like because [son's name] diagnosis is so rare... people don't really... take it seriously.

Like, people just don't look at him... as a complex child, but... there is a lot going on with him, and... That's why I feel like in the medical field, some doctors, if they're not passionate about... certain things, like, they just kind of brush him off, and I felt very brushed off in [eastern city], and everyone talks about how great [hospital name] is, and it was awful.

Raven described making decisions aware that she had an incomplete understanding of her son's condition while not knowing what she didn't know about how genetic medicine works. Raven described how this experience contributed to a disruption of her beliefs about the health care system, which will be discussed in the next section.

Like other participants, Carol described situations where she didn't know what she didn't know. For example, she explained attempts at consoling her son following the removal of a Foley catheter unaware that a person's bladder can burst:

He had a Foley catheter in after a major surgery at six months old, and we came back to the hospital six hours away to have it taken out after 2 weeks. It was a checkup, and then we left. And... he wasn't peeing. And we kept checking for wet diapers, and we called, and they're like, oh, it can take a while for his bladder to wake up. I had one of the most horrific nights of my life. We ended up stopping at a hotel 2 hours from the hospital, not making it all the way home... [Son's name] was in so much pain, crying, screaming, purple, still no wet diapers, but he had nursed. And I was just rocking him. I had to pace around the bathroom the whole night for him to not scream. And in the morning, he was starting to turn purple. And of course, I had been calling, of course... and they kept assuring us. We talked to someone, like, at 8pm, I remember, and they're like, oh, just give him some Tylenol, his bladder's still waking up. And in the middle of the night... I

couldn't get ahold of anyone, and the phone message kept saying email, so I was emailing, and finally in the morning, we still couldn't get in touch... And so we drove back, and [her son's name] is screaming bloody murder... finally the doctor came and took the bladder, like, a wand or whatever, and his bladder was completely full. He still had a dry diaper. And so, once they, like, put a catheter in him, and he could... release... he was... calm... at that point, from when they had taken the Foley out, it was almost 24 hours without him emptying his bladder. And I read later, your bladder can burst... They put a new Foley catheter in, and we went home. We came back two weeks later to have it taken out and this time, we stayed around... for a day, and he was still not peeing on his own. So, they showed us how to do an intermittent catheter every 2-4 hours, around the clock. Two months later, he did start peeing on his own again and we stopped doing the catheter process, but later we'd learn he was peeing from bladder spasms. A year later, a specialist would tell us he had a neurogenic bladder and would always need to be catheterized.

Systems Navigation

Some parents' accounts described being unaware of missing information as it relates to systems navigation (e.g., Carol, Natasha, Stephanie, Felicia). For example, both Natasha and Stephanie described not finding out that their child qualified for Medicaid until months after their births. Stephanie explained,

Our doctor's office nurse case manager... was like... you guys...should apply for Medicaid... and she was like, I'm sorry no one has told you about this yet... you guys... should have been able to do this from day one... like, obviously... we got on that, and we got it organized, but that took a while to get organized. It was a lot of paperwork. I didn't

understand anything about Medicaid. I didn't have anybody to walk me through that part, so I remember spending hours googling... Social Security income, Medicaid... like, all of that. And no one told us about any of that, and it's like, that's pretty important because we're having thousands of hospital bills, and I mean... it was kind of too late, like, Medicaid wasn't gonna go back and cover things from months ago.

Like Stephanie, Natasha only learned of her son's eligibility for Medicaid following his discharge from the hospital. She recalled,

[son's name] was in the NICU for 125 days, diagnosed with a syndrome, left on oxygen and a feeding tube, and... nobody in the hospital ever once mentioned Medicaid to me. Not once... I didn't even think to ask, even having disabled parents. Like, I didn't live with my parents since I was 9... I went through the foster system, and then my grandma adopted us, and... I only just learned that all foster kids get Medicaid... I had no idea... even though I was on it as a kid... Like, I'm not gonna be asking about that.

Different from Stephanie, Natasha described a conversation with an administrator that led to Medicaid covering all but maybe "\$500" that she "paid out of pocket" for her son's initial medical expenses. She shared,

I remember talking to the administrator, and I was like, hey, I just don't know if people ask this, or if this is... okay to ask, but... I didn't find out about [name's] diagnosis until after he was born... and I didn't know about Medicaid until now... do you guys cover any bills from before we were on Medicaid? And that's when I learned about the 90 days backdating.

Different from Natasha and Stephanie, Felicia only recently secured Medicaid support for her daughter. She repeatedly and explicitly stated, “you don’t know what you don’t know,” when recalling her caregiving experiences. She explained:

When we were there six and a half months, [the social worker at the hospital] never helped us at all... I went to her begging, I'm like, hey, what can I do? You know, knowing this stuff that's going on, when she comes out [of the hospital], we can't put her in daycare. And her dad was in another state... and I'm like what am I supposed to do? And she was like, oh, well... normally people just quit their jobs. I'm like, I have another child, I have a house, I have bills, you know... Like, how do people do this? ...And then not only that, the level of care that she needed, it wasn't like I could just get a babysitter, you know? And I tried looking for a nurse... just to pay. Well, Jesus, they were making, like, triple what... what I was making an hour, and I'm like, well, that doesn't make any sense... Insurance wouldn't pay for it. We found a special medical daycare, and insurance would only pay for 90 days at 70%, and even then... we're talking it was like \$300 a day, and I'm like, that's insane. That's after the coverage, you know, and so at the end of 90 days, it would have been even more than that. So I mean, honestly, like, I really feel like this system failed us, as far as supports went. And of course, we'd have to ask the doctors [for them] to be like, oh, I don't know, I don't deal with any of that, you know, that's something that the social worker should help you with, or call these people ... Or it's like, oh, just... apply for... disability. And I had asked when we were in NICU, I asked a social worker, I'm like, well, would she qualify for disability? ...And she's just like, well, no, because... at the time, we didn't have any diagnoses.

Vision for the Future

Felicia, among other parents, described later coming to realize information that contradicted with their earlier visions for the future. Felicia explained,

We're just in the hospital for six and a half months, waiting on a surgery, and they were telling us at that point, like, she's gonna be normal. All we... like, she'll have some scars from surgeries, but she'll be normal, and can be a normal kid. Like, she might have some digestive issues, but that'll be it. You know, that's what they told us that whole time, you know, and it... and so I thought, once she got her ostomy repaired at two years old, that I could go back to work. But that didn't happen because we had a lot more diagnoses... So I ended up having to leave my job and sell my house and move.

Like Felicia, Doreen described not knowing what her daughter's traumatic brain injury might mean for their future. She explained:

I remember one doctor telling me, that we didn't know what the outcome developmentally would be, because we didn't know what... she was gonna be before the injury happened, so she kind of explained it to me, like, she might have had the capacity to be a rocket scientist, and now she's just gonna be a teacher. Or... like, we didn't know what her potential was before to know what she would be like now. And at the time, I really clung to that and thought that that was very helpful, and it made me feel better, but now, looking back, I think it kind of gave me... a false sense of hope. I think... it's hard to hear bad news, but I kind of wish somebody had said... these are the things that you're gonna have to deal with, this is what your life's gonna be like.

For Carol, this sentiment reflects a cascade of medical interventions that she later questioned.

He had... that surgery for the colostomy on day three, and then, he's had eight other major surgeries, seven of them have been related to an imperforate anus. And we went out of state to see a couple specialists, to talk about what happens next. And they all said, oh, you're gonna have a surgery for him to have an anus... it's called a pull-through surgery. It'll be functioning. He has this more severe form of it; he'll either need laxatives or enemas for life, but he'll be able to stool out of his anus. And I just had this gut feeling of, like, why... I don't know that this is right, but we listened. And it wasn't the right answer for him. Almost every other child it is, perhaps, but he was so, so unique, but we didn't know how unique he was... But ... he is back to a colostomy. And he had seven surgeries... we just kick ourselves sometimes, because we're like, if we had just stuck with that colostomy, he would have been spared seven more surgeries... But I don't know, you know, how do you... we don't know what we didn't know, and that's what all the surgeons are telling us to do, is to go forward with these surgeries.

Experiences Disrupt Expectations

As the previous section introduced, parents described experiences that disrupted their expectations for parenting. Participants' accounts are organized into three subthemes: (a) acute medical events shock the system, (b) normalization delays disruption, and (c) caregiving as the constant.

Acute Medical Events Shock the System

Participants (e.g., Cassandra, Susan, Gwen, Stephanie) explained how acute medical events or a series of events that immediately disrupted their expectations for parenting and their understanding of their child's condition. For example, Cassandra described initial uncertainty

following a cardiac event. She described her daughter as being “born blue” and “airlifted” to a larger medical center. She continued,

Her heart actually stopped right after the [pulmonary banding] surgery... Her blood pressure was at zero, so they had to bring her back. And it kind of just set the tone for...we could lose her at any time. This is our life now. I held her with a very open hand, and...I tried to split my time. Like, I recognized at that point, even though [oldest daughter's name] wasn't diagnosed, that she needed structure. So I tried to... be home in the morning and get her to daycare. Then drive to the hospital, which was an hour away, and spend the day with [youngest daughter's name], and then drive home in time to get [oldest daughter's name] from daycare and be home with her in the evening. And we did that for almost 6 months. Now, once I kind of got my feet under me after [youngest daughter's name] was born, so 3 to 4 weeks, after she was born... I started doing my research on infant heart transplant. (Cassandra)

Cassandra explained how her research led her to request a transfer to an alternative medical center.

I found out that [university health system] had done no infant heart transplants in like the past couple of years. But that [university health system-2] which was...very close to [university health system] had done several within the last year. And so... at that point, [I] said you know what... if I was...hiring someone to paint my fence, I'd give you a shot, [university health system], but this is my daughter's life and her heart. So [I] started the process of transferring her care to [university health system-2] which was a whole thing with insurance and both of the hospitals... accepting it. Now [university health system] kind of gave me a hard time about changing.

Like Cassandra, Gwen recalled the “terrible date” when her newborn daughter experienced a cardiac arrest and the moments that followed. She shared,

My husband did CPR, and the... paramedics came and took over, so following them... we just... assumed that our baby was gone... That was... a terrible drive to the hospital, and then... made worse by walking in and them letting us know that the chaplain was gonna come meet us... I was... this is not a good sign, like, a chaplain means that someone died, and so it was just... this... obviously terrible, experience... So very traumatic day... At that point... finding out soon after that they... did have a pulse, but looking back... I had no idea what that meant... I didn't know anything about... brain injury... I had no idea what any of this would mean. But what I did know was that we made it very clear that we would do absolutely anything to support [daughter's name] and to help her as long as she was actively leading the way.

Some participants described experiences that combined the elements of non-disruptive information and immediate crisis. Donna recalled,

Somebody had come in the room and said, we think he might have Down syndrome... We're gonna do some genetic testing, and we'll see... there was no positive or negative with that. And they kind of walked out of the room and left us with that, and, you know, our statements to each other were just, this doesn't change anything, guess we'll just keep doing our thing. And my husband had left the room then and was going to get some stuff from the car. My daughter was with my stepdad going to get snacks, because that's what you do when you're 6 years old. And... my mom and I were in the room, and I was breastfeeding him, and he turned blue as blue could be, and coded... So whisked off to the

NICU at the local hospital, where we were literally told the words, we don't know what we're looking at, as they were doing the echo of his heart. Not very comforting.

Donna described the health care provider's suggestion of Down syndrome as nonsignificant until a medical emergency and provider uncertainty disrupted the perceived normalcy.

Normalization Delays Disruption

Several participants described receiving news that did not initially disrupt their sense of understanding. For example, Carol recalled,

I was... just trying to be in the moment... They did the [APGAR] test, you know, they checked him, he's fine.... My mom had come down from New York... She was there, my parents-in-law were there, and so we were just... happy. We were eating pizza in my hospital room. And then, they moved us to a different room for the night out of the delivery room. And we were just settling down to go to bed, and I...had him in the crook of my arm, just right here, and I was like, I did it...he's here, he's alive, he's fine.

Like Carol, several parents described at least one incident where they received information that failed to initially disrupt their understanding of “normal.” Jessica described multiple times when potentially alarming news did not disrupt her understanding, including her initial lack of concern after being informed of “excess fluid behind... the fetus’s neck.” As previously discussed, she interpreted this finding as benign, focusing instead on the opportunity for another ultrasound. She also recalled, “the only time that we saw the genetic doctor was... post birth saying, hey, we think he has Down syndrome.” This information aligned with her understanding, which was disrupted by news that the secondary heart defect would require surgery and a transition to the PICU. She explained,

He [had] a laundry list of... premature, and this birth weight, and NG tube-fed, and heart defect this, and heart defect that... Down syndrome was... at the bottom of concerns because everything else kind of trumped it at the week mark... He needs to be moved to the PICU. I remember that being... a whirlwind because we were in NICU and [the PICU] was in a whole different unit of the hospital. So we went from... a NICU room to like an intermediate room [waiting for a PICU room to open] ...we sat in there for a long time with... my suitcase. My husband was with me, and I remember just crying because I was like, we were supposed to be going home. This is not fair. This is stupid. Like I don't even know where we're going and what they're going to do to him.

Susan also described processing an original diagnosis, an understanding that was disrupted towards the end of her pregnancy. She recalled,

Towards the end of the pregnancy, they suspected there was something else going on ... We were already kind of resolved... with the heart condition and what that was going to take, and then to find out that there probably is something else wrong. I think there was... sort of a... shock, I guess, a little bit of panic, but... that wasn't until the end of the pregnancy that, sort of, the more emotional, like, what else is going to happen kind of feelings were going on.

The following account from Jane also illustrates a more gradual disruption, such that she described relying on her existing understanding for a substantial amount of time prior to experiencing a significant disruption. She explained,

[Daughter's name] was 4 when my special needs son was born. So we knew from birth to 4 what was supposed to happen. But... we were kind of told along the way that boys develop slower. After [son's name] was a month old, he was really fighting us on

feeding... The day he was born, the day after he was born, he did really well feeding in the hospital, but we came home, and it was taking us, like, an hour to get through 1 ounce or 2 ounces, and so after a month, they put us in the hospital because he was a failure to thrive, because he was still losing weight. So they tried all these different things, they couldn't figure it out. We had a mom friend tell us that her son did the same thing and ...switched him off of soy formula and went to something else. So when we did that, he started gaining weight. And I tell you all that because we were under the guise that we thought all of his problems were based on that feeding issue. So the first, few months go by, and we are trying to get him to not throw up, because we want him to gain weight, because he started losing weight too early, too fast. So we didn't put him on his stomach, we didn't make him try to hit those milestones. So every doctor appointment we went to, they said, well, he's not doing that. And we said, well, yeah, okay, we know that. But that's fine. But then we got to 8 or 9 months in a year, and he's still really behind. And then we started to think, okay, maybe there is a separate issue here. We went to a pediatric specialist, who... did try to evaluate him... My son didn't really do anything that he was supposed to, and the doctor was like, well, we don't know if we'll ever know what it is, so let's just put him in therapy.

Other parents described intuition-based disruptions that unfolded over time. For example: Raven described first noticing “something’s off” with her son when he was 24 hours old. She compared her experiences to feeding difficulties with her firstborn, who she described as “one of those kids [who] just developed on his own time,” but having to “finger feed [son’s name] for weeks” and persistent concern that she was “gonna drop [him] every time [she] picked him up” prompted her to push past initial reassurance from doctors. She recalled,

They just kept saying... his failure to thrive was, oh, he's a newborn, oh, he's still learning how to swallow, don't worry... babies develop on their own time. So for the first 4 months, I was not being told much other than just... this is normal. And I remember... having to... fight for someone to hear me and listen to what I was saying about my child. Raven continued, contrasting her attempts at making meaning of the MRI results, which she initially received through MyChart, and the genetic diagnosis:

Just before the diagnosis, he had the MRI done, and that scared the shit out of me, more than actually the diagnosis, because, again, I didn't... really understand the diagnosis... but with the MRI, you know, they told me [initially through MyChart], okay, the corpus callosum... it's thinner than normal... So... right there, I'm like, okay, well... is he gonna be smart? Is he gonna be able to, like be a normal kid... So they found this, like... black something on his brain, and if you research it, it literally says it's fatal. So when I saw that, I lost my mind. I kept calling the doctor, I'm like, I need a doctor to call me.

Like Carol and others, Raven turned to the Internet for support processing the results communicated through the electronic health record. This fragmented delivery of information contributed to a fear-based, emotional response, which shaped the lens through which Raven received her son's genetic diagnosis. She explained,

So then when we got the diagnosis, you don't hear, like, fatal, you don't hear... anything that's gonna kill your child or cancer or anything, so we were just, like, okay, we don't understand what this means, but we don't hear [that] he's gonna die.

Raven described her initial interpretation of the diagnosis as “nothing,” something that “can be fixed,” sharing that she didn't have an emotional response that first day. Over time, she came to understand what it would mean for her son and her family.

Other participants, including Selina, Jean, and Diana, described at least one period characterized by tension in which concerns were at least initially normalized, delaying disruption. Selina recalled her pre-birth experience, sharing, “My body didn't like being pregnant. I had late diagnosed preeclampsia and undiagnosed HELLP syndrome. I was telling them something was wrong, and I was labeled a hypochondriac.” Relatedly, Jean described,

There is an amount that even a tiny baby is present in the world, and is engaged with the world around them, and is reacting to the world around them... and that's something that is so hard to quantify. And when you are speaking with medical professionals, and you're like, he's just not present in the world. And they're like, well, he's here... I don't know exactly the point, but it was very, very clear that he was not looking at us or looking at anything. And, you know, we now know because he was blind at the time.

Diana described encountering similar reassurances when raising concerns about her son's stools and weight. She explained,

I started noticing some things that I just felt like were abnormal, and I mean, I don't have anything to compare to, but... every diaper was a dirty diaper. Every diaper. Every time. And, although he was eating, he wasn't really gaining... I took him home at 10 weeks, and then we had regularly scheduled follow-up appointments with the pediatrician... they're just like, oh, he's, you know, a preemie, he needs time to catch up... eventually he'll get on his own growth curve... as long as he's gaining something... And then I just started to feel like, I don't feel like he's tolerating... the breast milk, or the formula, or something... something... doesn't seem right, like, with his belly, because he just keeps pooping and pooping and pooping and pooping. And then he started pooping blood. I took him to the pediatrician, and I just said, I think something's not right here.

Cassandra also recalled repeated attempts to seek support following her observations of her then “5-month-old” daughter:

I was noticing that if I turned my gaze somewhere, she was not trying to follow my gaze. She was not mimicking my facial expressions. She was not really... trying to engage socially as you know an infant should. [Her state’s birth-to-three program] said that she was... too young to... have some sort of testing. But I kept calling and at nine months old they did see her in their office for an assessment. They said that she had some... developmental delays at that point... So they did start her on PT and OT and speech. And she did... all three of those kind of on and off until she aged out of that system at age three. But it wasn't until she was 5 that she was formally diagnosed with autism.

Most participants described a combination of acute events and disruptions that unfolded over time. Across participants, disruptions were rarely experienced as isolated events. Carol explained,

I feel like each time you were like, okay, this is the condition, and we learn about it, and we accept it. Then a few months or a year or two later, it's like, oh, here's another condition, here's another condition. So it's just... even if, you know, the first 3 hours, we learn about that condition, and then it's just on and on... I mean, he just got out of the hospital last week because he has a new form of seizures this summer that he's never had before, and he had to go in for EEG monitoring for 2 days, and now he's on another new medicine. So it's just always evolving.

Caregiving as the Constant

Participants described caregiving as the constant, such that experiences disrupted how they understood themselves and what was expected of them, their everyday lives, their expectations for the future, and for some, their stable belief systems.

Disruptions to Identity, Roles, and Responsibilities - Parents described experiences in the context of caregiving as disrupting how they understood themselves and what was expected of them. For example, when recalling a moment of crisis following her son's traumatic birth, a bradycardic event requiring code interventions, Diana described herself as "frozen," not moving or talking, until a nurse walked her out of the room. At the time it occurred, she had been lifting her premature baby so the nurse could replace the bedding. She could feel his small body in her hands, hear the alarms sounding, and hear the hustle take over the room. Her efforts to make sense of this crisis—informed by lab results indicating that the episode occurred alongside a staphylococcus epidermidis-related infection—triggered "hypervigilant" learning that will be discussed later in this chapter. Diana described the code event as something she could not relive: “It felt like it would break me as a person.” For Diana, this experience disrupted how she understood her role as a parent and caregiver. She explained,

At that point, at 4 weeks, like, I felt like we had come... we had walked through hell. We had gone through fire, like, we had had this huge surgery, and then he had been septic, and then he coded, and we had made it so far only to feel like it could be taken, like his life could be taken away in a moment, and that's really when I... I think I became hypervigilant.

Like Diana, Susan identified a specific experience within the hospital setting that solidified her confidence as her son's mother and caregiver and her role as a member of his care team. She recalled,

I think it... stems from one particular hospitalization, where I think we... after that point, we sort of got a lot a lot more leeway. So there was one stay where things were not looking good at all. So we had... the care team come in and talked about what we wanted to do and had sort of the end-of-life decision-making to do. And... I don't know where it came from or why... I said, we need to get him out of here... We need to get him off [medication] so he can get home ... I could see [my son] ...fading. You could just see it in his face, in his body, and all of it, and I said, you know, if something is gonna happen, I don't want it to be here, I want it to be home.

Susan continued,

[Discharge] was not happening at the speed in which I thought it should happen. I thought we should be home. And then we did have some additional members of the care team there... And they relayed the information appropriately to the cardiology team, and we went home. And [son's name] got better. So after that... if there had been any lack of... confidence in myself about what's right for him, it was gone after that, because... sometimes you just, you know... what's right for your kid.

For some parents of children who required medical technology for survival, the realization that they would be administering this type of care caused a role-related disruption. Diana described the realization that she was to provide central line care and administer her son's total parenteral nutrition (TPN) as disrupting her understanding of what was expected of her. She explained,

And at first, when they told me... he has to go home with all this equipment now. You know, like, equipment meaning, like, a central line, an NG tube, a pump, and all of these other things. And I just thought, okay, I mean, we need a nurse, right? And they're like, oh, no, no, no, no, no, no. You have to do all that. I thought I was going to throw up or faint, or poop my pants, all at the same time, really. Because I realized what that meant.

For Diana, it meant that she needed to acquire a “tremendous amount of knowledge... about sterile technique.” She continued,

This was a tremendous burden that now fell onto [her] shoulders to do this exactly right” because she’d “already seen what can happen if you're not sterile, if something happens in that dressing change or [gets] on that line, your baby can code while you're holding them.

The three participants whose children were dependent on a tracheostomy tube (i.e., artificial airway; Kara, Gwen, Diana) described a related type of role disruption as occurring after discharge. Kara explained:

In the hospital, we can feel as confident as we want, but we have an RT, a nurse, a doctor at our beck and call at any given moment if we need it. Where at home, you're the RT, you're the nurse, you're the doctor, and mom and dad.

Diana and Gwen offered similar thoughts:

I think that we didn't expect... how... I mean... you expect it, right? You're home. If you push a button, no one's coming, running to help. But I think, like, that realization of, like, oh my gosh, it's just us, like, there's no one else. That was really hard. (Gwen)

And both their accounts illustrate how the transition to home further disrupted the parental role:

When we discharged, everything was very disjointed, so the pediatrician was separate from the pulmonologist was separate from the DME company... There was no cohesion, there was no communication... it was really all on me... It was so stressful... It just felt very much... like sink or swim. (Gwen)

Donna also described a disruption following coming home, specifically related to gaps in nursing support by recounting:

There's no nursing support, so trying to hunt down... what options do you have instead of nursing to keep your kid alive and still keep your job so that you can get paid... when they don't have what you want, figuring out how to do all of the advocacy, to... go talk to your legislators, even, and getting involved in councils and boards to try to make change at, you know, a policy level. It's all-encompassing, and it can be as big or as little as you want it to be, right? Like, I could just advocate for my kid, and that could be one thing, and I could just get his stuff, but if I'm gonna do that much of a fight to get his crap sorted out, I may as well fight for somebody else to have it done already, too, so they don't have to work as hard. So I probably make things a lot bigger than they need to be, because I don't want somebody else to have to do it, too.

For several parents (e.g., Carol, Diana, Natasha, Donna), role disruption included training staff to care for their child. Kara described making sense of this experience for the first time:

I wasn't really sure what that was supposed to look like. I think the biggest [thing] that really helped kind of start the training process where it needed to start was just asking them, what questions do you have? So asking them that, and then getting their history, their background of working with anyone with a trach. I mean, because if they've worked with anyone with a [trach], so then they are familiar. Okay, next question is, have you

worked with pediatrics with trachs? Okay, no, you haven't? Okay, a lot different than with adults, but... so just kind of asking those few... very, very basic questions really helped hone in on where to start with that training. It was still very intimidating when we did the training at first with the first few nurses, I still remember the first, like, 2-3 weeks that he was home after we had trained them. I still could not let go and trust that they were going to take care of [son's name], so I was sleeping out on the couch in the living room.

For some parents, it involved being trained to provide therapeutic exercises for their children. Jane described:

[Early Intervention] used to provide those therapies outside of school, but then they changed their model so they would teach you as the parent, and you were supposed to do it. And that's when I started kind of pushing back, saying, well, I'm the mom, not the therapist. You should be doing this, unless you want to change jobs and you wash his laundry, I'll teach him therapy, whatever.

Similar patterns existed across participants. Felicia explained:

We're having to work as, you know, physical and occupational therapists, because, you know, we're doing all the exercises every single day that PT, you know, has shown us, and then we're doing all the activities that OT has shown us, or that speech has shown us, you know, all the different things to feed, and how to feed, and how to introduce her to textures, how to desensitize her, you know, to, like, the physical touch... So you know, we're doing all of those things, we're having to work on things that ABA gives us, you know, to try to help with the behaviors.

Laura described efforts related to feeding therapy:

Your kid's not going to make progress with a half an hour or an hour-long appointment once a week. But also, the home has to be a place where they can be a kid and not be a continuation of a doctor's office. So we had to figure out what the middle ground was for us. But, like, when the feeding clinic wanted us to film every single meal over the course of a week, that was just not possible, so then I had to come back and say we couldn't do that especially if I was doing most of the mealtime solo. I couldn't be feeding him and filming. Then, you know... I had another kid, and so figuring that out, and guilt for not being able to do everything. It took me a little while before I could be honest with them and say what was too much, because I felt like, well, if I was a good mom, I would somehow make all of this work. And that's just not... possible.

Raven described experiencing disruption that was at least partially rooted in payer issues. She explained,

I do get support from... Birth to Three in [northeastern state]. So it's a free service, up until they're three years old, and... he's screened in. They're... supposed to help parents... be physical therapists at home. But also, they're supposed to help me... advocate for my child. So they help me, you know, with certain finding certain support groups, or they get me actually a lot of equipment for the house... I do a lot of his PT stuff at home. I have a stander... I have certain chairs to help him at home. Outside of that, I feel like... I don't have a lot of guidance on navigating insurance. I'm currently, this week alone, in the middle of dealing with fighting for food for my child. He does not eat anything by mouth. And I have no food left for him, and no one will help me get him food. So it's very frustrating, So I feel like for that, I don't really have, like, a lot of help with that. It's more just me having to just advocate... until... I'm finally heard... He did

see... PT and OT outpatient, but again, insurance, they capped my visits for him. And he met his visits in June... June, and they don't reset until January. So in the meantime, I have 6 months of no outpatient PT, so what I have to do is do it myself at home, because I just don't want him to... lose... where he's... grown since then.

Zoey, Diana, and Laura described a planned disruption to their role, one that other participants may face in the future. Zoey explained that her son has begun to take responsibility for aspects of his own care: "We have always done his TPN and done his supply ordering, but that's now transitioned to him, so he is doing his own TPN, he is doing his own supply ordering." Like Zoey, Laura described supporting her children in taking responsibility for their care.

[son's name] is now getting to the age where he can do more to advocate for himself. But I feel like it's my job to know what's going on and then to... age-appropriately help them advocate for themselves, or to do that advocating. And make sure that they get what they need, so... Like, he is very anxious about blood draws. And so... when he was younger, I did it, and now I talk him through how to ask for what he needs in order to feel more comfortable.

Disruptions to Everyday Life - Nearly all participants also described experiences that disrupted their everyday routines. For most parents, the transition home created a disruption to everyday life. Gwen explained:

I think just, like, figuring out... just how daunting it was at first to, like, move from one room to the other. God forbid, leaving the house for appointments... I think, also... we were not prepared for just how... vulnerable we would feel there... We led a really... active lifestyle, like, we only had one kid... traveled and did all sorts of things, and... you know, for a while, until we... really got our feet under us as... really quite a kind of

sedentary... existence, because it was very much, like, then [husband's name] was back at work, and I was home with both babies by myself during the day, and... it was really terrifying to load up... a van, and a pulse ox, and a suction machine, and oxygen, and a go bag, and a whole twin baby, too, into a double stroller to, like, even take a walk... The mechanics of adjusting to life were very, like, a lot harder than... We certainly didn't expect them to be easy, but I think ... you don't know it until you live it, and so, that was... a big, big, big adjustment.

Jean also described ways caregiving disrupted her everyday life:

We do everything, our lives are therapy and driving, and specialists, and second opinions, and supplements, and alternative therapies, and... More therapies, trying this therapist, Knocking down every door constantly for years. Was it the right thing to do? I don't know. Was it the wrong thing to do? I don't know. What was right about it was that for my own mental health, which was shaky at best, I needed to not feel totally helpless. And... being constantly going, constantly in motion, constantly working... No, that's not healthy, of course it's not. But it was what I needed to keep from falling apart completely. And being a caregiver, I am not always the priority in my own life. Period. And anybody who's like, oh no, you blah blah blah, like, no! Like, if we are on seizure watch, and I've got a bag packed for the emergency room, and 911 is pulled up on my phone to just hit go if I need to call, I'm not the priority. And we've lived that for years.

Relatedly, Diana explained the daily responsibilities added by the assignments from OT and PT, which illustrates a relationship between disruption to their role and daily life.

In addition to his cares, we had assignments for things to work on with OT and then things to work on with PT. [son's name] had torticollis, for example, so we had to help

with his positioning and making sure that he was turning and using those other neck muscles, we had to, with speech and feeding, because [son's name] was very orally defensive, even though he was getting teeth in, we couldn't brush his teeth, we couldn't get near his mouth, so we had to spend a lot of time each day, like, working on [son's name] getting comfortable with us getting close to his face, not even to do care, but to just get close to his face. So it added to an already very busy schedule that we had to keep. But that was really the first time I realized how behind he was compared to same-aged peers.

Disruptions to Future Expectations - Participants also described experiences that disrupted their expectations for the future. For some, a medical crisis caused a disruption that shifted their expectations for the future. For example, Stephanie described giving her daughter CPR and the month-long hospitalization that followed as disrupting her understanding of herself as a mother and her expectations for the future:

It changed my perspective of being a mom and being a parent, because... I gave her CPR, so I experienced her not breathing. I experienced every day of her [hospitalization]... not knowing if she was gonna make it through... Before... as we were getting more and more of her diagnoses, and she was... falling behind... it was always like... she's delayed in her development, we don't know if she's gonna walk, we don't know if she's gonna talk with her spasms... that was always the thing at the forefront of my mind, like, what kind of... life... is she gonna live? ...that was what I was thinking about, like, is she gonna reach her milestones? Is she gonna be able to do all of these things? And... that hospital stay really just gave me... By the end of it, it just gave me gratitude that she was alive... all of those other things that most other parents think about, they weren't important to me

anymore, because I was just so, thankful to God that my child lived, and that she was making improvements, and that we were getting to take her home. I didn't care anymore if... she was doing the things that all other kids did, because she got to be alive.

For some participants, the onset of a new symptom, change in prognosis, or new diagnosis disrupted future expectations. After learning of her son's diagnosis, Laura recalled being told that her son's experience of the genetic condition would be similar to her own. However, a series of events disrupted their expectations for the future and everyday routines. She explained,

My mom was holding him, and she's like, he's having apnea episodes while I'm holding him. And I was like, oh, I wasn't expecting that. So we immediately took him to the pediatrician, who sent us to, pulmonology, which took a couple months to get into, so that was stressful, like, knowing that he was having apnea. And then the pulmonologist. We did a sleep study, and not only was he having apnea, but his oxygen was dropping into the 70s... And so, then he needed supplemental oxygen [and CPAP]. And I was like, okay, this is not... this is gonna be a little different than what we had anticipated. And then she did a swallow study and found that he was aspirating, and so all of a sudden there were, like, feeding therapies we needed to do, and things kind of, snowballed from there.

For other participants, encountering a new provider's perspective disrupted their expectations for the future. At two, when her adopted daughter was diagnosed with fetal alcohol syndrome, Laura recalled being "told there wasn't anything we could do for her, and we would need to try to keep her out of prison." Laura described an encounter with a new provider as disrupting this emerging lens:

[The provider] started off by talking about her strengths. And... he was like, look, she's clearly attached to you, and having good parental attachment goes a long way... We were separated for, you know, some of the evaluation where I was, like, working on questionnaires in the hall, and she was in the room with him, and he said she's a really hard worker, like, she tries really, really hard. And he's like, you can just tell that she's a strong kid, and... yeah, there are gonna be things about this that are gonna be extremely difficult, but... I think she's gonna have... a good life... She will have a level of independence; she will have a good life. And that was just so different from what the first specialist had brought up, and... when I left, I felt very hopeful. I felt like, you know, that's a different life than what we might have thought when she was a baby that we were gonna have, but it's a good... it's a good life. Like, there are a lot of ways to have a good life. (Laura)

Parents also described accumulated experience as more subtly disrupting expectations. Rather than referencing an isolated event or series of events, Natasha's expectations shifted over time. She explained,

[Genetic condition] is such a spectrum, very similar to autism, just such a large spectrum... from high functioning all the way to... you know, kids that aren't mobile at all, so... and are on trachs... My understanding has just changed in that... I really know what that means now... but... I also think I have a pretty good idea of what [son's name] is going to be like when he's a teenager and as an adult. He definitely is more severely affected, so I think that is one thing, because you have a lot of hopes when they're younger, and like, you know hope that they're not gonna be as severely affected. I think now I know that, and, like, now... we're giving him the supports and... doing treatments

and therapies that he needs in line with that... The world is not our oyster anymore, but that's okay. Like, it's something else, but, like, he'll still do a lot of great things.

For Selina, that also involved disruptions to her expectations around her son's death, something most parents do not confront. She explained,

He was born not breathing and had to be revived, right? He wasn't supposed to live as long as [he has] ...He wasn't supposed to make it out of the NICU, and he was only supposed to live a few months, but, you know, even while in the NICU, losing suite mates. So death has always been a part of... our life. And so, getting to a place in... being able to... process the other shoe dropping, right? You're always waiting for that other shoe to drop... And getting to a place of not only focusing on what a good life means and looks like, but also putting things in place, and... navigating through what it means to have a good death, not only for [son's name], but for me, too... And as we have lost friends. And having seen and been a part of a few of those journeys, being able to reflect and... hearing... what they wish they would have done differently... So that, that has been a big part... that I count as a gift, because many parents don't want to have those conversations.

Disruptions to Stable Belief Systems - Other parents, including Raven and Zoey, described disruptions to stable belief systems. For example, Raven described a challenging encounter with the health care system as disrupting a previously stable belief system:

We did go to [eastern city] for a second opinion, and it was the worst experience of my life. So I have thought about going back to a different, like, part of [hospital name] or a different hospital and getting a second opinion, but... honestly, it was so discouraging... when we went that one time, that me and my husband are kind of like, do we really want

to go through this again? So I guess I know I'm probably gonna keep doing it until finally someone listens, but unfortunately, if something bad happens, then I'm never gonna forgive myself that I didn't push harder. So it's kind of, like, balancing, you know, how hard do you push, because I also don't want to, like, cross boundaries and then have the doctors think I'm crazy and never listen to me again, so I don't know.

Raven continued,

I honestly... used to think that there was nothing wrong with... our health care system... because I... never had an issue with it, ever... I used to... sometimes think people were being dramatic about things. Same thing... I used to never think, like, depression. I used to be like, just get over it, like, you're fine, and then... I went through stuff, because even with my postpartum depression, I was fine after, like, 2 months of medication. But then when I... yeah, got diagnosed, and it was like, oh shit, like, this is real. I then kind of started seeing that, it's not fake, and... so I definitely had misconceptions of things before [my son's] diagnosis.

It's important to note that participants' accounts illustrate multiple disruptions occurring simultaneously. For Carol, this included disruptions to her post-birth narrative (e.g., "he's fine" to "he's gonna need emergency surgery"), her ability to make sense of the medical diagnosis (e.g., "we didn't even know that could be a condition"), her emerging identity as a mother (e.g., physical separation in the early hours after birth), and trust in the medical system (e.g., perception of abrupt, incomplete, and conflicting information from health care team).

Raven experienced disruptions to her expectations for early development (e.g., "something's off" misaligned with reassurances from doctors), her ability to make sense of the medical diagnosis (e.g., interpreting diagnostic language from MRI results without explanation), her emerging

identity as a mother (e.g., feeling like she had to “fight” to be heard), and trust in the medical system (e.g., fragmented communication). Raven’s account further illustrates the presence of multiple, co-occurring disruptions. She explained,

I feel like I'm his nurse... his physical therapist, his advocate, and then after all of that, then I get to be his mom. And it's so hard because... I know my husband is... his favorite, and I feel like that's because I don't get to do the mom things. I have to be... Like, I have to feed you, I have to do PT with you for an hour, I have to bring you to all your appointments ... So I feel like being his mom, I haven't been able to ... and that's why on the weekends I try to do a lot with him. It's more like... I am his caregiver, I'm not his mom first, and... it fucking sucks sometimes. I feel like people don't understand this feeling unless they've been in it, you know? And it's hard to explain that to people. Like, I'll try to talk to my sister, she's a nurse, but she doesn't have any kids, and I'll try to explain to her... how hard it is sometimes. And I love her, but she'll, like, look at me and be like, well, at least your child's alive. I'm like, no shit. But, like, you don't get it... I am his mom, and I don't feel like his mom sometimes. I literally feel like a nurse, and I feel like the mean mom that has to... hey, you have to do PT every day, and I can only imagine, when he gets older having to fight him to do PT every day, you know? Like, he's fighting it now as a baby, like, I can only imagine when he gets, like, a teenager.

Making Experiences Intelligible

Participants described efforts to make new experiences intelligible when encountering the limits of their prior knowledge and experience. Making sense of new experience often involved a combination of the following subthemes: (a) learning with the care team, (b) hypervigilant learning, (c) making it work at home, and (d) learning in community.

Learning With the Care Team

Parents described their child's health care team as a key resource when encountering their interpretive limits, especially at the onset of their journey, with a new diagnosis, or during an inpatient stay. For example, Donna recalled efforts to understand her son's congenital heart condition:

I think they drew pictures of his heart for me on paper, probably no less than 20 times, and still none of it sunk in. I googled things, I don't know how many times. My best friend from college was a nurse, and she tried to explain it to me, and I still did not understand what was happening. I... was hopping online to try to find people... [but] there was no, like, other stories out there that we could find trying to google. There was nothing out there that existed for us to really find and understand it... It wasn't until we made it out to [eastern city] that there was one specific nurse that described it in a way that I finally had it sink in and understand what was physically going on with his heart... It just... between the, you know, grief and the trauma and everything else, and I'm not a dumb person, like, I 100% know that I'm a very intelligent human being, but it was not... not sinking in, like, at all... And in the end, the only thing that did make sense is somebody talking about it like plumbing. Okay, here, this is, you know, if this was a sink, and it was backed up, and you needed to get the water to go from here to here, like, that's how they ended up explaining it to me.

Kara described learning of the possibility that her son may come home with a tracheostomy tube and ventilator early in their NICU journey. She explained,

Every so often, she started... talking about this may be the path. And... I started getting that gut feeling the very first time she brought... it up in conversation. And even at that

time, it wasn't in... the aspect that we think this is what's going to happen, we just want to put all cards on the table, like, he could turn around, and he could, you know, not need any respiratory support by the time he hits his due date and can go home. Or maybe he goes home with supplemental oxygen, or it could be a trach. So even with that first conversation about it, that's just kind of when that gut feeling set in, because it is... their job to kind of give us all the things that could happen.

Like Donna, most parents (e.g., Jane, Diana, Jean, Zoey) described seeking information regarding their child's condition from electronic and print resources, including scientific journals and other sources available on the Internet. However, their usage of these resources to extend or challenge interpretations varied. For example, Kara described asking for print medical journal articles, explaining "If I'm going to advocate for my son, I need to know every single thing under the sun about what he is going through." Zoey recalled, "I'm on my computer, I'm on my phone, and I'm pulling up all of the literature." Jane and several other participants described turning to Google—at least initially—in addition to condition-specific resources after receiving a diagnosis.

In contrast, Stephanie described taking a "see where things went" approach to learning about her daughter's rare genetic condition. She explained,

I read a little bit about her... diagnosis that the hospital gave us. I really tried to not read a ton on that, because I just didn't want to set certain expectations of what she was or was not gonna be able to do, so... I just wanted to, you know, see where things went, and let her develop. She was gonna develop however she was gonna develop, whether I read the research or not.

Similarly, while Raven initially turned to the Internet, she later reframed these efforts as a "waste of time." She recalled her son's geneticist explaining that "you could be missing this gene, but

there's not a study of you missing this gene and this gene combined.” Rather than continue to search for condition-specific answers, she shifted her use of electronic resources to navigating insurance-related issues and social services questions.

Some parents (e.g., Donna, Diana, Carol, Natasha) described participation in bedside rounds and care conferences as spaces for making sense of their child’s condition. Like Donna, Diana recalled trying to be present for rounds, asking about her son’s labs, and documenting “everything.” Diana explained how she relayed information to her husband and would call on his medical expertise when information was “above [her] pay grade.” Similarly, Carol explained that she and her husband were “always ready at rounds,” an experience she described as intimidating, at least initially. “They're all there with... all their computers, and there's a whole group of them,” she shared. Despite this, she described preparing for rounds and taking turns with her husband asking questions, including “Have you thought about this? What about that?” These exchanges functioned as opportunities to clarify and expand her understanding of her son’s condition.

Relatedly, Donna described a provider who, following a care conference, scaffolded her engagement by making the option for a second opinion explicit. She explained,

It took almost a week for them to say that they didn't think they could operate on him, that they... [they thought] he... had, like, a 5% chance of making it through, and that his quality of life, even if he did, would be so terrible that they didn't think it was worth doing. And we walked out of that care conference with no options... We didn't know a lot about the medical journey at that time and are incredibly thankful that the cardiologist that we still have stopped us on the way out and gave us the option for second opinions...

We probably would have [gotten] there eventually, but thankfully, he stopped us, and we didn't have to think that hard about it.

Donna later shared,

I have spent a good chunk of time trying to read up on studies about pulmonary hypertension and Down syndrome, and different treatments for that, because we were kind of dead-ended on that for a long time, where we were not going to be able to have a surgery because his lung pressures were too high, and we couldn't get them down. And we were already on all the medications that everybody had suggested, and just nothing was working, so I started digging into some different studies and researchers, and then trying to find, okay, well, who is actually the best person to talk to at which hospital? So who's our next second opinion person going to be?

Like Donna, Jean described a pediatrician as a key resource in her caregiving journey.

She explained,

Our pediatrician was really our biggest champion in all of this... I was bringing [son's name] to the pediatrician's office constantly in those first three months. And, you know, she said something that I wish all parents would hear. She said, keep bringing him in... So our pediatrician is not someone who specializes, certainly, in [son's name] condition, because no one does yet, but in disability. And she has been the right pediatrician for both of my kids because she said from the very beginning, she said... I might not be an expert in this, but I am willing to walk this path with you. And if you are willing to walk it with me, we will do everything we can to figure this out... And she was very upfront with, I am not going to know everything, but I will not let you walk out of this office without a path forward.

Jean continued, illustrating a specific example of the support she received during her son's first recognized seizure:

He was four years old, and by this point, he wasn't crying all the time, he was present in the world, very much on his own schedule, but was, like, a happy-aged kid. And was just off and kind of zoned out, and again, that intuition of, like... something is just going on. He's... he's just off... We went to the park. He kind of sat there, he wasn't looking at the airplanes or the birds, he wasn't paying attention to the world around him, he was just starting to get glazed over, and then as the afternoon wore on, like, increasingly glazed over, and we called our pediatrician... and... she was saying, you know, keep an eye out, look for XYZ... And he was just kind of increasingly zoned out, and you would say his name, and he would not respond, and he was just blank and was really pale. And so we were scared. We were like, something's... something's going on. And he started trembling just, like, a tiny... like, the tiniest little bit. And we're like, oh, that's not good. And our pediatrician said, get in the car, drive to the hospital, go to the emergency room. And we're like, cool, we can do that. So packed up in the car, and as we were headed down the street, it escalated. Fortunately, we were very close to home. It escalated, and he was really shaking, and that's the worst, really, shaking that we've seen, and it was scary. And, you know, eyes rolled back and shaking in his car seat. I called 911. We drove back to our house. The squad met us at the house.

Some parents (e.g., Carol, Susan, Gwen, Diana, Natasha) described questioning or resisting care plans, in an effort to reconcile recommendations with their own experiential knowledge. In the NICU, Carol recalled being told that her son would receive a G-tube after not meeting intake expectations shortly after surgery. Whereas she perceived the team to be

operating from a standard protocol (i.e., “some sort of a system at their end, where if you don't meet this, then you get a feeding tube”), she interpreted his feeding challenges more broadly, situating them within an environmental and developmental context. Carol explained, “He's a new baby. He's never eaten before. He's recovering from surgery.” This interpretation, informed by her observation of the feeding schedule, was foundational to her proposal of an alternative care plan, suggesting instead that she or her husband “would be in the hospital... on call to feed.”

Unique from other participants, Jane described a book from her local library as the impetus for her ongoing search for answers, prompting reconsideration of her son's initial diagnosis of “cerebral palsy.” She explained, “I read it, and I was like, oh, this is totally not what he has. So I kept pushing.” Her efforts led to them to a new neurologist and geneticist and a diagnosis of a genetic condition among several comorbid conditions (e.g., “heart defects” and “brain structure issues”). Jane described this experience as going “from 0 to 100 in, like, a month.” Her narrative emphasized the immediate support her family received from a family support network, a topic that will be discussed later in this chapter. Alongside learning in community, Jane shared that she “googled everything.” However, she also mentioned a desire to slow the pace of learning when things became “overwhelming.” She recalled,

I... remember thinking at one point, I don't know that I want to hear anymore... Let's back off all the specialists, I just want to put him in therapy... I can't take any more heartbreaking news, so... I don't want to check his eyes, I don't want to check his blood pressure, I don't want to check his hearing. Don't tell me anything else, I can't take it.

In addition to structured learning opportunities facilitated by the health care team, parents (e.g., Diana, Gwen, Carol) described absorbing incidental information from their presence in the inpatient health care setting. Diana explicitly referenced the benefit of “just being there and

seeing what the nurses were doing, what the NPs were doing, what the therapists that came in were doing.” She shared hearing whispers of a baby in the NICU contracting necrotizing enterocolitis (NEC), initially searching the Internet for “n-e-c-k” to learn more. She later described learning of intestinal rehab through a chance conversation with a nurse about a previous patient, information she would recall months later. She explained,

While we were in the NICU, one of the nurses had mentioned something about a previous patient. And, she had said that this previous patient needed something called intestinal rehab. And that the closest place that offered a really good comprehensive program was [hospital name] ...So I had just filed that kind of in the back of my mind.

Parents’ accounts included varied experiences with patient education when discharging from an inpatient setting. Gwen described both ends of the spectrum, first taking her daughter home from the NICU with “no education at that time” to feeling thoroughly prepared to care for her daughter’s tracheostomy tube, ventilator, and G-tube following a subsequent admission. She noted that having someone at bedside around the clock created opportunities for hands-on learning and real-time feedback. She continued,

We were just constantly talking about, like, scenarios, and what if, and what about this vent alarm, and what about that vent alarm, and, you know, like... If she's doing this, then, you know, what might be happening if she's doing that, or if there's any difficulty, always look at her first, always look at her, go from her to the trach, to the tubing, to the vent. (Gwen)

In contrast, other parents’ accounts (e.g., Felicia, Doreen, Selina) illustrate a perceived gap in preparation for administering care. Felicia explained,

They did not do anything... hands-on... on-site. They did have us watch some... YouTube videos that weren't even... from the hospital... And it was just, like, a three-minute video on... how to remove the G-tube, how to put the G-tube back in... We did not get enough training on the things that needed to be done... The supply company showed up... the day... before we were supposed to get released with the pump, which was a completely different pump than she had in the hospital setting... And they're like... this is how you do this, this, this, this, and then, oh, here's the manual. I mean... it was, like, 5 minutes. (Felicia)

Like Felicia, Doreen recalled a paucity of training during her daughter's inpatient stay:

None! And now I'm like, that's crazy! I remember asking, you know, like, about, you know, she had the broken bones and things, and I never even held her in the hospital. They told me I could, but she was hooked up to all this stuff, and they would just, like, you can hold her if you want to, and they'd, like, walk out, and I wasn't picking her up. She, like, I was terrified to touch that kid. So then it was time to pick her up, and... they're just like, here, good luck! And I'm like, what about this neck brace? And they're like, it's okay, you know, just be careful if you need to clean or anything. You know, you'll follow up with doctors, and they'll tell you what to do, basically, is what... so, I really didn't get any instruction at all.

Relatedly, Selina identified gaps between her training and what she now trains her son's caregivers to do:

The training... It was enough to get me home, but then I learned at home, I wasn't... taught all the things, like, I didn't know at the time that you should prime the line. Huh. So for a long time, I was... pushing air into his stomach when he would eat as opposed

to... but I was never taught that... In the hospital to prime the line. So my comfort level is really good. Now, I train all his caregivers, who are not medical.

Several parents (e.g., Felicia, Diana, Cassandra) described completing a 24-hour room-in period where they demonstrated competency in caring for their child, or as Cassandra described to “prove to the hospital staff that [she] was capable of doing this,” prior to taking her daughter home for the first time.

Hypervigilant Learning

Parents (e.g., Susan, Diana, and Felicia, Cassandra) described hypervigilance as a reaction turned coping strategy, skill, source of advocacy, and stressor they returned to repeatedly. For example, Gwen described this as a process prompted by her daughter’s health care team following a cardiac arrest. She explained:

It was very clear that what was going to happen was really crucial... and that no one knew what was going to happen. And we made it pretty clear, actually, in our... super shocked... traumatized state of mind that... we wanted to just... be present, and watch, and... not immediately talk about... what the bad outcome would be. I think that was obvious. And so, and so [the attending] ...was like, listen... this is what we want to see. We want to see...bloodwork normalize, we want to see urine output... we want to see... movement, it'd be ideal if she starts fighting her ET tube... which she didn't, she was really... in a coma for a couple weeks, but... I remember also... they... had placed an EEG on her head, and... I remember the transport nurse was like, she had... one documented seizure, and he's like... it's a really good sign that she had a seizure... Like, the brain has to muster up a lot of activity to have a seizure. And so... at the time, I was like, oh my gosh, this was like, great, like, she had a seizure... And then the other thing

that we were told was, she wasn't on any drips... they were like, there's a whole lot of medication we could be giving right now, like, in addition to her being... on an oscillating ventilator, and... obviously things being extremely critical and unknown, like, there's still a lot more we could be doing. So... that felt comforting, too.

Similar to Gwen, Diana described her efforts to stay informed of her son's condition after his premature birth and surgery. She explained, "I was writing everything down every single day, watching all of the trends, asking about all of his labs, and trying to monitor him so that I could relay that information to my husband." Similar patterns existed across the data set. Like Diana, Gwen recalled heightened monitoring and pattern recognition:

We noticed every tiny little trend, so anytime anything was slightly off... we noticed it first. It was always because we brought it to the attention of the nurses and the attendings, because it doesn't matter how wonderful they are, they still are not bedside every minute... Like, coming in every three hours to do cares is, like, not sufficient for... anything... It was very clear that we... were learning our daughter in a way that was better than... anyone else could have done it.

Cassandra shared a sense of "being on all the time," paying close attention to her daughter's test results, even at the time of our interview:

It's another thing that I have to stay on top of. With her labs, read over her labs every... every time and track... the trends of where they were last time and compare them to where they were when she was sick to kind of get a good understanding of where she is and if we're in any danger area. And some folks would probably call that hyper-awareness... whatever the word I'm looking for is. But just like being so on all the time. But it's like... I don't trust the hospital or for her transplant team to be looking at it that

closely. And there have been several times... that I've brought something to the transplant team or the hospital staff before they were even considering the issue. And I was the one who was right. I didn't want to be right in any of those cases, but I know my child.

Similar to Cassandra who described specific “cases,” Diana recalled a series of central line infections and independent research as sources of advocacy, experiences that led to her “becoming hypervigilant.” She explained,

So the second time around, when the NP came in to... help my baby, I just said... once he's stable, I need the surgeon to come down [to] bedside and pull that central line... I looked it up. Staph epi forms a biofilm on the line, and it will seed into his bloodstream. So as soon as all of those antibiotics were done for his bout of sepsis, he was getting septic again, because that film was present... And I'm not sure that they were expecting something like that to come out of a parent. But I felt like, this is my new job. I'm not gonna work for an attorney anymore. I don't get to have that career anymore right now. This is my new career, and I'm gonna learn absolutely everything that I can to prevent this from ever happening again... And at that point, that point right there, that was the turning point of me taking whatever physicians or NPs or nurses... were saying to me as, like, the Word of God. Like, I never in my life would have ever thought to question what a health professional is saying to me about me or about my child, really, because I just felt like they have so much more education than I do, they have so much more experience than I do, they have all the 12 letters next to their last name that say that they have reached this position, because they have done the work to get here. And at that moment, I

realized the best advocate for my baby is me... And that's really when... I think I became hypervigilant.

Hypervigilant learning was apparent for parents in learning to administer certain medical cares. For example, Diana recalled learning the “step by step” procedure for “sterile technique”:

Not only is it nursing... this is like the highest levels of nursing, because what you're dealing with here is disease prevention... the line that is placed goes right to his superior vena cava in his heart. So... if this is not perfect, this could be catastrophic... I mean, you have no choice. You have no choice if you want to bring your baby home, if you don't want your baby to be institutionalized, those are their words, not mine... I'm like... Alright, let's go... I learned it all. It, like, haunted me in my sleep, you know, I'm going through all the steps in my head. Over and over and over and over and over again. I'm like, oh my god, did I cross-contaminate? Did I just touch my sterile glove to something that wasn't sterile? Did I just put something on my sterile tray that wasn't sterile? Now we have to start over. Everything on that tray has to go in the trash. And if I don't hook him up on time, he only has a one-hour window. Then his TPN is late for the next day, and then the next day, and everything is off. So you don't get a lot of chances to get it right. But you cannot get it wrong.

Relatedly, Carol recalled administering seizure first aid to her son.

We would set a timer, so once we gave him the rescue medication, we would wait, about two or three minutes, and if he was coming out of it, or we also, like, had a pulse ox, and if his oxygen level was okay, we wouldn't call. But if his oxygen was low, or if he wasn't coming out of it, we would call 911. And by last year. His rescue medication was not working for him, and we had to call 911 every time.

She continued,

About a year ago, for instance, he... he was outside playing, and I saw him stumble. And he shouldn't have stumbled. And I was like, oh my gosh, and I scooped him up and raced him inside, and he did indeed have, like, a tonic-clonic seizure. We had to call 911. So something like that. I think that's why, I try to be the one observing him, because someone else would totally have missed that, or just been like, oh, he just, you know, stumbled. I know what he should be doing, like... how he moves around the world.

Felicia described her daughter's care as involving a mental "flow chart" decision-making process:

So you know, she has the G-tube, we have a feeding pump... I feel like I've gotten a crash course in, like, being a dietitian... and really in nursing... if she threw up, okay, how much did she throw up? How many calories do I have to replace? You know, we have a daily calorie goal and... a daily hydration goal that we're trying to reach, so you're constantly doing that math... and we have to time it, right... we can't feed too close to a nap [or at night]. Like, if she's tired—because her digestion slows—then she'll just throw it all up. And then... with the medications, we've had all this juggling with... what medications we're taking, when can we take them, what medications can... can and cannot be taken together... we're constantly monitoring... how much output she has... because with that, you're playing a dangerous game... of, are we getting another obstruction? Do we have another narrowing? Because she's highly at risk for that, since she's had so much abdominal trauma... we just went through something the last two months where... she had a bunch of diarrhea, and... I mean, this went on for weeks, and I'm like, what is going on? And then I'm like, well, maybe it's her... allergy medicine

because she was having really bad seasonal allergies. And I looked it up, I'm like, oh, one of the side effects is either diarrhea or constipation. I'm like, well, I guess that's what's going on, so let's try a different allergy medicine. So then we went from Zyrtec to Allegra, and... then she was constipated. But... also, she started having an increase in vomiting, and I'm like, is she vomiting because she's having all this post-nasal drip, and it's... irritating her? Or is she vomiting because we're getting an obstruction? ...and with her, you know, with her bowel movements, they were so inconsistent... both with, like, the quantity, like, the physical size of them, plus... the consistency, you know, if they're thick, thin, or whatever. And so we're, like, we're constantly having to watch that, and we had another imaging study done, well, we had it scheduled because of what was going on. I'm like, you know, on the safe side, we all agreed, like... we should do this just in case, because we're a year out from the previous surgery. You know, so I... we're doing all those things. We're having to work as, you know, physical and occupational therapists, because... we're doing all the exercises every single day that PT... has shown us, and then we're doing all the activities that OT has shown us, or that speech has shown us, you know, all the different things to feed, and how to feed, and how to introduce her to textures, how to desensitize her...to... the physical touch, So... we're doing all of those things, we're having to work on things that ABA gives us... to try to help with the behaviors, you know, dealing with her autism, and it's always hard to say, it's like, well... is it from the autism? Is it from, you know, the brain damage? ... like, we don't... she's an onion, you know, there's all these layers, and... it's like, what is causing this problem today? It can never just be, oh, here, take some Tylenol, we're good, because with her, it's

always... it's like a flow chart. It's like, okay, where are we at? Okay, it's not this, so we need to go down this side.

She continued, comparing the stress of this type of hypervigilance to that of her work as a police officer:

The first and easiest thing is, like, feeding... I know that she's gonna wanna eat, like, every three hours. And so... if she starts getting cranky or whiny, it's like, hey, are you hungry? ...Do you want a baba? ...and normally she'll be like, yes, and then she'll get happy with that. She'll be like, yes... but she doesn't, on her own, come out and say that. I look for... stomach distension... I check her stomach... for gas... especially... when we're having issues with her output, you know... I know... to look... at what color [the stomach content] is, to see, like... are we digested? Is it stomach acid? Is it bile that's backing up? ...all things, unfortunately, that we've had happen, so I know to look for it just in case. And just ...just seeing how uncomfortable she is. Because she's not just... she's not just whiny... if she is crying, there's a reason... Or if she's not wanting to move around. Now that she's mobile, like, she wants to do what she wants to do. So... if she's not doing that, then that indicates to me that there's something going on... She has sleeping issues... she'll wake up crying, and I don't know if it's... like, from pain, from, like, muscle spasms, or if it's, like, did she have a bad dream? Because she can't... She can't tell me... help me. But, you know, normally, like I said, I look for the food, I look to see how hot she is, because [daughter's name] runs very hot. She doesn't like blankets, you know, she doesn't like... things on her feet because her feet get really hot, and if she gets hot, she's very cranky. So like, we have a fan that we carry at all times in her stroller. We have, like, communication cards... and, like, one of the cards is... it's, like, 4 things

to help her calm down. So it's like, oh, do you want your fan? Do you want a hug? You know, can you count to 10? We're trying to teach the breathing, you know, in and out. [She] doesn't understand that yet, but, you know, if she's counting out loud, then she's breathing, and, you know, she's at least distracted, and that helps calms her down. I know that we have to be careful... like, when we're out in public, to make sure that she's not getting too overstimulated... like ... we can't go out to eat... we've tried it, but it's like, she doesn't want to sit still, and then there's other things going on, and so it's too much. So then we end up rotating who's going outside to walk her, you know, with the stroller, versus who's eating, you know? And just as far as, like, what do I know? I know that this is not a road that we're gonna be able to get off of anytime soon. I know that it is likely that she'll probably need supports for the rest of her life. At least... physically. I know that with her GI symptoms, that is something that's gonna have to be monitored. For the rest of her life, because she's always gonna be prone... to having... like I said, the stricturing and stuff with the intestines... And just... because of the hydrocephalus, we always have to be aware of... any change in her symptoms because of... because of that. So like, I just... you just have to be hypervigilant. You know, I spent almost 20 years in law enforcement being hypervigilant every day, you know, and... I'm gonna tell you, I would much rather put on a uniform and go drive and be in a patrol car and deal with that stress than this stress, because this is a completely different, you know, a completely different type of stress. And again, when they can't tell you, when they can't communicate with you, that just adds, you know, another level of stress... and fear.

Susan explained, “There's a hypervigilance that's required for someone like [son's name], because some very small thing, as we've experienced a few times, really quickly turns, like, really, really quickly.”

Making it Work at Home

Across accounts, parents described learning in the context of caregiving in terms of making it work. For example, Carol recalled her first experience changing their son's colostomy bag at home:

You know, we're trying to remember the steps we have to do for the colostomy...I think it was just... we didn't have the experience yet to know how to do it quickly and smoothly, and to know our system... We found something on YouTube for the colostomy where they suggested, like, cutting around the edge of the adhesive that goes on the belly to fan it. And that really helped, actually, once we started doing that, and we had, someone else... doing like, a blow dryer to not only distract the baby, but just to, like, help with some of the steps, and, you know, so it's like we had to do some of our own research, too, and trial and error.

She described being “inventive” and trying “to make it fun,” an approach she has continued as they have had to adjust to life with seizures. She explained,

I decorated the bathroom with Christmas lights, I hung up some toys, I put... a nice little pillow in there for him to lay on, and... he was so happy, and he would just kick his little legs during his catheter and ostomy bag care times... we just wanted him to not have to be traumatized, too, by all the processes, so we tried to make it fun. I would sing to him through the colostomy changes. [Her husband's name] would do faces, he would let him touch his hair, and we called it, you know, touch the floof... I guess, part of the

acceptance and just dealing with it process, that we didn't have to do at the hospital because they were so fast with it. And there were multiple people helping there, so when you're left with one or two of you to do the care, you have to get more inventive.

She continued,

By the time he had his surgery, when he was 8 months old and he stopped having the colostomy for a while, I was very good at it. I could do it in a few minutes, and I always prepped everything, and... I had the routine down, but it took a while.

Relatedly, Gwen described mastering seizure response with her local emergency medical services team, recalling a conversation with her husband following his first seizure experience:

You knew exactly which medicine, and that it needs to be... intramuscular, and it needs to be injected into her thigh, and... he's like, you were really so on it... it was all so... clearly... rehearsed. We had done this a bunch of times with... the same little rural, paramedic team.

Similar to what was discussed during the early days of parents' caregiving journeys, most parents described learning and responding to their child's subtle cues in their home environment.

Kara shared,

Well, for starters, we've taught him sign language, so that helps immensely. So if we start hearing I don't even know how to describe the sound, and I can't even make it, but we hear, like, a specific sound with him that indicates to us that he needs to be suctioned, and so we'll, like, we'll sign suction, like, do you need suctioned? And... he's now in the phase where everything is no, but... but there are times where... you know, he will say yes, or we just kind of hear that sound, we're like, okay, let's go suction you. Or we've noticed that, like, if he starts to cough a lot, but he's not sick... his trach ties are probably

too loose and need readjusted... So things like that. If he's starting to get under the weather, we can tell, he's just not as chaotic. He's a lot calmer and snugglier. But... I don't know, I think it's just kind of come with time that we can... I mean, kind of like with any kid, like, you start seeing these mannerisms repeat in these certain situations, and you just know.

Relatedly, Donna described learning her son's individual needs and how they cascade across systems:

Post-anesthesia, if you don't start his bowel regimen, like, immediately, you are gonna be in full of regret within 3 days, because he still will not have pooped. You know, you can't do IVs in certain places. And it's all, you know, historically... he clots easily. It's all trial and error, and it's things that we've learned through... doing, and experience, and learning. Other things are, you know, it took some thinking to understand, like when he gets IVs, he has no problem giving you his arm... but the second you try to block his view from what you're doing, it becomes a complete nightmare of he has to see what you're doing. And it took a while to figure that out, because by default, they want to block you from being able to look at it... it's all trial and error to some extent, and then once you figure it out ... you get to be very good about saying... nope, he needs to see that, or, you know, whatever you do when you're done drawing blood and everything is finished, do not, under any circumstances, say yay and clap. Because that results in an absolute meltdown, because after being in the hospital for a first year and having to do tons and tons of heel sticks and pokes and things, like, that's how they would get their numbers, and then it would be, yay, we're all done, and clapping. And then we go to school, and everybody celebrates when you're done doing something by saying yay and

clapping, and he has epic meltdowns. Anytime somebody says yay and claps, and we're like, [what] is going on? Finally figured out that there was an association between blood draws and celebrations, so we're like, we have to break this, because... you can't melt down every time somebody celebrates. So it's just... you learn by doing, to some extent, and then as he gets older, he starts communicating, and you learn a little bit that way, but most of it is just experience.

Some parents (e.g., Kara, Donna, Diana, Natasha) described adopting hospital routines, preparing schedules, logs, and care manuals. Donna explained, “So in my professional life, I'm a process engineer in the first place, so that was the easy part for me. I needed to keep myself busy, so I had a lot of it kind of pre-planned beforehand.” She also described instances where things weren't “up to snuff.” She said:

If I wasn't up to snuff and I wasn't checking supplies on the right date, we'd be like, well, we're out of HMEs, so you're gonna have to go to the DME, and you're gonna have to pay out of pocket 5 bucks a piece and get... five of them, and pay 25 bucks, and... it adds up real fast when you screw things up... I mean, there were times where it cost us... thousands of dollars because we couldn't get a med in time... I just knew that we needed to... have things organized, and then I had to accept that not just did they need to be organized, but also I needed to have my husband on the same... page as me for organization, because... There's definitely times when the overwhelm hits me, and I'm like, I am out of executive functioning skills. That's literally the phrase I use with him, is tell him I'm out of executive functioning skills. And that means that he has to take over for just the moment until I can catch back up.

Donna also shared using a journal and AI to help her stay organized:

So we keep a journal that has... the log of all of our appointments and what we talked about last time we were in there. So... if I go to the pulmonology page, I can see what our notes are from pulmonology last time, and kind of what we have historically been talking about. But I also keep, in AI, in ChatGPT, I keep a running log of, this is what we talked about last time as well. I usually... just take a picture of my notes and load it into ChatGPT and load it into there, and if there's something we're talking about or analyzing, I honestly talk it through with AI and say, this is what we talked about, this is where we're at, and if I have questions before I even go to the appointment, I will ask AI about it, so that I'm kind of more prepared by the time I get in there. And that means I can also knock out some of those, like that obviously is not a real thing, you can't do that questions, because there's things that I'm like, I wonder if we could do this, and AI's like, no, you're insane. And that's fine, like, I'm okay with that, and... not that I can't ask that of the providers, because I absolutely can, but sometimes it's easier to get my questions, like, honed down and very specific and in the right language, so that when I'm asking it, I know that they're going to understand what I'm saying. So I kind of have a conversation with AI to kind of piece out what it is that I need to sort out, what I need to know, and then at the end, I ask AI to give me a bulleted list of the things that I need to discuss with the provider.

Like Donna, Diana, and Kara, who developed materials to support their children's health care providers, Laura adopted a practice she learned on Facebook to communicate FAS-specific information to her daughter's teacher:

I found this in one of the... [fetal alcohol syndrome] FAS groups. I started making brochures... that I update every year with some information about... so it's, like, this is

[daughter's name], and some of the things that she currently likes, a little bit of information about, kind of, who's in our family, and then information on what works well and what does not work for her. And then on the back is information about FAS specific to the classroom. So I reach out to the teachers by email the first week of school, and I send it to them along with a handout called Seven Keys, which is FAS-specific about the classroom again. And then, ask if we can have a check-in in, you know, three or four weeks into the school year to see how things are going, see what questions they have because we only have the IEP meeting once a year.

Learning in Community

Participants described learning in community, which for some included: (a) members of their immediate family, (b) formal and informal support networks, and sometimes, (c) collaborative care.

Immediate Family - Some parents (e.g., Raven, Donna, Laura, Gwen) described engaging in interpretation and meaning making with their husband or another immediate family members when assessing their child's condition in relation to medical guidance. For example, Stephanie described her daughter's care team and her husband as meaningful contributors to shared understanding, explaining,

It was, like, a two-day... handoff, basically, where... we did everything while we were still in the hospital... So it was... really just... us doing it after they had trained us on it for a couple days. And then they also gave us, like pamphlets and handouts, with directions... on how to do the G-tube. And then same with... when she got her infantile spasms diagnosis, because we had to do... steroid shots, and so they trained us on... how

to administer the injection, how to draw up the vial, and then give the vial. And had us... do that for a couple days at the hospital before we went home.

She recalled reteaching that took place at a follow up appointment:

The surgeon... went over the G-tube, and how to replace it... Like, after three months, she had... a follow-up appointment, and so they had us come into the clinic, and then they went over it with us again at that point... they went over... how to clean it, and treat it... if it gets infected... the staff did a really good job of telling us about it, but it was intimidating, because I was like, I don't know any of this, I don't understand it, and I was definitely nervous. My husband did a better job than me with... retaining the information.

Raven also described making sense of her son's changing respiratory status in partnership with her husband:

Anything with his breathing, that's where it's like, do I need to rush him or not? They say he... consistently has fluid in his lungs because of the aspirating. So anytime it's... a breathing thing... I hook him up to his pulse ox, and then it's... Do I need to rush him in? Do I not? And then, I feel like a psycho mom... This just happened this Friday... I came home, my son... spiked 103° fever, and he was, like, panting, and his heart rate was 190. His oxygen was fine, but his heart rate was super high, and he was just panting like a dog. So I called my husband, who was at work, and I'm like, I need to call an ambulance. And he's like, no, just call the pediatrician, and I'm like, no, I need to call an ambulance, and... I ended up just calling the pediatrician, and they let me bring him immediately in.

Relatedly, Donna recalled a mismatch between discharge instructions and recognizing signs of stroke. Understanding the discharge instructions "didn't stop me from looking at him and

going, let me send a picture to my husband. Does his face look wrong to you? And him going, yeah.” She continued,

It's just there's so many things to look for... it's just, you don't even know... We were more focused on keeping him breathing than looking for a stroke, to be honest, because as far as we knew, that was pretty darn stable, and then all of a sudden... he's kind of looking a little like Popeye over here.

Gwen's account illustrates the changing conditions within which she must learn—collaboratively processing her daughter's first observed seizure with her husband and then responding independently during his deployments:

So we had... a little episode that happened in... November... of [year]... where I walked in. I was... getting ready to get her out of bed... I heard that she was awake, and I... screamed for my husband... It honestly looked like she was just gasping for air, like if she got water down her trach... which it seemed really weird and... unlikely, but it looked very much like... gasping for air. And... as soon as he came in... that was it... That little episode, we just explained away as... she had a moment of... needing to catch her breath. I don't know, it was over as soon as it started, and there was no change in... heart rate or her oxygen levels, and we just got up and... had a normal day, so I just... we just didn't think anything else of it... And then my husband deployed, and the week after he left, I woke up and she was, like... clearly having a huge seizure. And it didn't... it wasn't stopping, and I didn't know really anything about seizures, except for I knew that they should not last forever. So at, like, the five-minute mark, I called 911, and then they got there, and they administered... rescue meds, and it still didn't stop, and so we went... all lights and sirens to meet [hospital name] transport.

Like Donna and Raven, Carol's spouse served as a resource for collaborative interpretation:

My spouse and I always try to make sure one of us is [at the hospital] ...we are always ready at rounds. We're looking for the doctors so we can talk to them, and my husband's always doing research too and has good ideas for things to ask, and so we're always taking turns at, you know, asking, have you thought about this? What about that? So it's definitely... a partnership with the hospital and the staff. I can't imagine... I know there are parents who have to leave their children there because they can't get off work, they're a single parent, they have other children, whatever circumstances they have, and I just... my heart breaks for them and for their child to be alone there, because I think of how many times, like, our... our child needed extra pain medicine after surgery, and no one was going to get that for him, but we know that he's in pain, we can see that he's in pain, and they're not observing him, and things like that, where if you don't have someone with you who knows you, it's not... you're not gonna be well taken care of or advocated for.

Carol's example of her son needing additional pain medication begins to illustrate her perspective that quality health care is dependent on collaborative relationships between families and hospital staff.

Other participants navigated caregiving experiences more independently, even when married. Diana's account illustrates how her husband's work as an emergency medicine physician constrained his availability for shared learning. She explained,

There are many, many, many, many, many, many, many, many, many times where my husband is physically and emotionally absent, because he's... saving other people... It's very, very stressful for him also. So I have to compartmentalize and... put things in order

to give him, like... a professional history and physical assessment of our child when I get to talk to him. Because his time is limited. Usually, if I can get him on the phone, it's very limited. And often, I don't bother him with any of it, unless it's critical. Because I just know that, you know, if... if someone's had a heart attack, he's the one managing the heart attack... So there's a lot that my husband doesn't know, or doesn't experience, or doesn't understand. And a great example of that is... when I got in the back of the ambulance and left to go to [name of hospital] with [son's name]. My husband stayed home, and I was bedside for 5 weeks. And my husband only came... maybe four times while we were there, and it's a very different experience when you're visiting a hospital versus living in a hospital. So there are elements of care that he just doesn't have a frame of reference for... like, feeling trapped in a hospital room. And you can't leave because... your child requires your care, along with, you know, a medical team 24-7. There are a lot of things that... I wish my husband could share the burden of... with me but physically, emotionally, he's unable to do that because he's not present... I am the primary caregiver 90% of the time. Like, if he had to list his meds, he can't do it. If he had to list the doctors, according to specialty, he can't do it. If he had to know where the doctor's appointments were, or therapy appointments, I have to text him the addresses, like, if... for some reason, I'm not taking him to the appointment, even though we've been going... for 8 years, he doesn't know. And so there are some things like that, that add to the burden versus having someone who's participating in it 50-50. Or maybe who you get to see your spouse every day where I don't have that opportunity, and so I can't unload, like, what's happened during the day, or the complications, or even the achievements that [son's name] had, you know, until the next day or even the day after that.

Jessica and Gwen's accounts reflect how their spouses' deployments also created physical separation, shaping learning from caregiving experiences. Jessica described her husband as her "runner" after her son's birth and also explained that his extended trainings, including "basic training and various other trainings where he worked to become an officer in the guard" affected her and their household. Her husband was deployed to Iraq in [timeframe], and they are "in the midst of [their] second year-long deployment." Similarly, Felicia described the challenges of juggling her daughter's "medical complexities" and son's "psychiatric and learning difficulties" during her husband's work assignments. As time has passed, she reframed his continued schedule changes and unexpected travel requirements as "easier" suggesting it became part of their everyday life, explicitly acknowledging a person's interpretation of "easier" as influenced by perspective. She explained,

She likes structure and she likes routine, so we try to keep to her routine as much as possible, but... if dad's gone for an extended period of time, that is not normal... Even when he's here, he'll randomly get put on nights... and then essentially when he's on nights, she doesn't get to see him... None of us really see him because we're normally doing stuff during the day, and he's gone... by the time we get back. But... since she's gotten older, it's gotten a little easier... even then... when I look at everything that we do, I don't think that anybody from the outside would say, oh...it's so easy for you...how you interpret it's easier... it's very different depending on your perspective, and your experience. So I mean, it's still hard...

Jane and Cassandra described their spouses as becoming disengaged from caregiving, resulting in them taking on primary responsibility for their children. Jane described finding the strength to divorce her husband:

He kind of escaped the... the world we were living in by using video games and alcohol and drugs, and it just kind of got worse when we moved back to his hometown. So as I was doing... all of the extra stuff for both of the kids, and... trying to work full-time, my husband wasn't helping. So I decided that I was gonna divorce him, and it took me a year to figure out if I thought I was strong enough to do it. So I divorced my ex-husband, taking on a daughter in middle school... and my special needs son, and knowing that I had been doing everything by myself. So that was kind of the last, you know, mindset change was... well, I can do everything by myself, with this kid and my daughter, and... figure it out along the way. So then we moved away from [western city] because his parents weren't helping us... it's hard to shovel the driveway to get the wheelchair to the bus at 6 o'clock in the morning, so... we moved. So now I just think I'm a... kind of a badass.

Cassandra recalled,

After my ex left, he took us off of his insurance... After that, I lost my job, and so...we had no insurance, and we had no income. And I stepped up in a hurry to say what resources are out there for single moms, for kids with autism, for kids with ADHD, for kids with medical needs... for unemployed adults, unemployed parents... I just started making lists of what was available at the local, state, and federal levels and then took the time to start applying for everything. So the girls and I were all on Medicaid, and we did get a significant amount of SNAP benefits, and the girls were getting free breakfast and lunch.

Three participants reported being single at the time of their child's diagnosis, although only two discussed this aspect of their family structure as framing the caregiving experience. For

example, Doreen's introduction to parenting and caregiving began in her mid-twenties when she accepted temporary placement for two young girls, the youngest of which had been hospitalized because of non-accidental trauma. Doreen explained,

I got a call that there were two kiddos that needed foster care placement... I was told that the youngest, who was 2 months old, was going to the hospital to be checked for possible abuse... They didn't seem like it was anything major in the conversation, so I went and picked up the sister, you know, kind of just waited to hear, and next thing I know, they're flying my youngest out to a hospital about an hour away... And they're telling me that she... they're not sure that she can see. She was... completely unresponsive... So over the next couple days, I learned that... she had three brain bleeds which caused strokes. She had fractures in her legs, her arms, her neck, [and] broken ribs... She was on a ventilator... I don't think I understood just how... I mean, I knew it was serious, but how long-term things would be, I just kind of assumed, you know, that she would... get out of the hospital, and we would just kind of go from there, and things would be okay... She was probably six months old or so before I finally realized that our life was gonna be different.

In the absence of spousal support, Doreen described turning to her immediate family for support. She shared,

I really just kind of went in feet first and didn't have a clue what I was doing. Like I said, we... no medical background, nobody in my family had any medical background, any experience with stuff like that. They've always been super helpful. We stayed with my mom for the first... I guess, month or so, because [daughter's name] was so fragile, and I was honestly just kind of scared to take her home by myself, because I was afraid... I

didn't know what to expect, and I was afraid something would happen, and I'd be there by myself. Because we really... I didn't know what to expect, and it was just kind of a learn-as-you-go type thing.

Relatedly, participants, like Laura, Carol, and Kara, described their mothers, who had their own experiences parenting a child with significant disabilities, as a significant resource. Carol shared, “My mom had the experience of also raising a child for 12 years... with disabilities... So my mom was... a source of comfort for me.” Kara echoed these sentiments: “My mom was a massive support for me, because, I mean, she went through this as a mother as well.” Gwen also described her mother, who was an administrator at a rehabilitation hospital as a resource. She explained,

I think it was... very helpful... that my mom spent every night there... she spent time... with the nighttime attendings and everyone... I think it was probably also really helpful having her kind of serve as, like, a behind-the-scenes liaison of, like them, and us, and, like, what to expect... I remember her being the first one to say, like, hey, just so you know... if this extubation doesn't go well... they will talk about a trach, and like... these are all the reasons why I think that you should... you know, like... it sounds like a really scary thing, it feels like a really scary thing, but, you know, these are the reasons why it's actually, like so wonderful. Like, it really might be so, so good for her.

Formal and Informal Support Networks - In addition to their immediate family, parents described learning with members of their formal and informal support networks. This included extended family, support groups, and social media groups. For example, Laura described connecting with a friend who was a lawyer while navigating her state's early intervention program. She shared,

I had a friend who was a lawyer, so when [son's name] was diagnosed with autism and we were navigating the early intervention system, she provided me with, like, oh, here's the state law for early intervention, and I realized I needed to read up on that, and then I networked with other parents ended up joining an autism parents group in [western state] where we're living. And so, even when we knew we were moving back to [midwestern state], I had seen how they navigated that transition from early intervention to the school, or different things within the school... And we immediately ran into issues, and so I was able to call them up, and they talked me through it. Then I went to the rights law class. So just started adding on and then I would seek out other families, and then soon, like, some of the teachers were connecting me with families, or people would ask questions in, like, the school parent Facebook groups, and then I was answering them, and so, kind of developed a reputation that way.

Like Laura, Jane recalled being connected with another “family who had the exact same genetic disorder,” after receiving her son’s diagnosis, which was a “huge shock to [her] entire family.” She recalled,

I don't know how to process this, I don't know where to go from here, so having come across other parents in that stage, we were very lucky to get that family support network at the very beginning. So I definitely felt like I was trying to traverse a lot of that by myself, but I always had somebody I knew I could call.

Also similar to Laura, Jane explained, “I have tried to duplicate that family support network in the two communities I've lived in since.”

Jane also described efforts to prepare for the possibility of her son experiencing seizures. She explained,

Most of the kids are prone to seizures of different severity, so that was something we'd never come across... I was reading, well... What do we do? What do they look like? ...I'm a super nerd, and I thought, if I could just be informed about it when it happens, it might take some of the shock away.

Jane's preparation for the possibility of seizures also involved seeking information from a family member who worked as a nurse. She shared,

My ex-husband's sister is a nurse, and she said, write everything down, because they're gonna ask you everything. Like, what time did it start, what time did it end... His first seizure happened in the middle of the night when he was awake wanting to eat, and so I wrote everything down... Still, to this day, I handle seizures very calmly... because I feel like... I knew what I was getting into, and I really feel prepared for it.

Jane described spending “probably a year, year and a half... knowing what [seizures] were supposed to be like in theory.” Like Diana's account where she remembered learning about intestinal rehab prior to her son requiring that type support, Jane described applying advice from her former sister-in-law when her son experienced his first seizure, knowledge she felt initially helped her feel prepared for responding to this medical event. She described shifting to a more responsive approach over time:

Then we went through a couple years where he was definitely having them, and we got used to those, and then they kind of ended. So during that time, I was looking at, even to the epilepsy websites, and saying, okay, well, this is what we have, and this is what we can have, and this is the medicine that's best for these ones, and this is what an EEG looks like ... I try to do all of that, but I've kind of found that I have no idea what they're

going to look like until they just kind of show up, and so I don't know that I could be any more prepared at this point. I just kind of go on the defensive.

Like Jane, Carol also turned to her personal network with questions about seizures. In contrast to Jane's experience, Carol's account suggests that she did not feel prepared for the changing presentation of her son's condition even after receiving education on seizure first aid. She explained:

When I did take him in after the two seizures that were unprovoked, like no fever, [they] gave me... a seizure action plan document and talked to me about seizure first aid. But when he had the status seizure, it started differently. He did not fall down. He just said, I don't feel well. And then, his left limbs started moving on their own, and soon his eyes were locking left, and he couldn't answer questions... We actually called a neighbor... [who] is a nurse, and she came over right away... She was the one who told us we needed to call 911, because we had never seen a seizure like that. I've only seen him drop down and... start shaking... I probably was too optimistic... but I had never seen a seizure like this... So if she hadn't told us that, I'm afraid we could have lost him, because we wouldn't have acted fast enough, because... as soon as the medics arrived, he needed oxygen.

When facing unmet informational and support needs, parents described engaging in self-directed learning and turning to peer networks, often via social media. For example, Susan described information gathered on social media as contributing to "a very big turning point" for her son:

He spent a year, like, vomiting every meal all the time, and... he was very ill. And... I have a friend in the [condition] sort of [Facebook] group of moms, it's across the world...

who was talking about doing a blended diet, or giving her son food, and so... we were sort of desperate, and I will say that that's the one area... nutrition, and maybe even GI, but, nutrition support was awful. So, just on our own, we started giving him baby food through his G-tube, and then we started realizing it's silly to buy little jars of baby food, so... we got a... a high-speed blender, and we, you know, would cook a sweet potato, and then blend it with some fluid. And so, eventually, we transitioned to feeding him regular food through his G-tube, and it was life-changing. And that was with, zero support from anybody. That was just us doing it. And actually, [hospital name] was not that great about one of our admissions... they didn't make it easy. But now is a different story. So the last time we went there, the nutritionist was actually advocating for other people to do a blended diet.

Similarly, Donna shared,

On top of that, you know, we've had enough of a journey where people have said, dead end, you're out of options, there's no more here, that we've had to go out and... talk to other people and see what their journeys and their experiences were like.

Like Susan and Donna, Natasha turned to a Facebook group for support with understanding her child's condition, describing the resources provided by the care team as "very outdated." She explained,

I had never heard of it, no one in my family had ever heard of it, most people I know, most doctors I know have never come across a kid with [genetic condition] ...I found the [condition name] Society, and they almost immediately... let me into the closed group, and, like, the first thing I saw was... pictures of kids smiling, and all the things they were

doing, and... So then I was crying, because... there's, like, hope here, like, these kids are wonderful.

Relatedly, Laura encountered minimal support from the diagnosing physician when delivering her child's fetal alcohol syndrome diagnosis. She explained,

When we got her official diagnosis, we're told there wasn't anything we could do for her, and we would need to try to keep her out of prison. And she was 2 at the time which was really depressing information. And they were just like, here's all the things that are gonna go wrong with her by her by, like, the given age. And we hope you have a supportive family, because you're gonna need it, because it's gonna be a mess. We were told it could affect a lot of different parts of her, both... things with... her muscles, and then intellectually, impulse control.

Laura went on to describe minimal familial support which led her to social media, although her experience was unique from most parents. She recalled,

My brother asked if we could give her back. My sister was like, this is why we didn't want you to adopt, you're gonna get... a messed-up kid. My mother-in-law made prison comments. And so, we went to Facebook groups, to try to talk to other parents, see what was working or not working for their kids. It was overwhelming. There are a lot of parents in those groups that don't seem to like their children, but we did connect with another specialist in one of those groups, who was a lot more positive in his assessment.

She described encountering and making sense of conflicting information across providers:

He started off by talking about her strengths... He was like, look, she's clearly attached to you, and having good parental attachment goes a long way... And he said she's a really hard worker, like, she tries really, really hard. And he's like, you can just tell that she's a

strong kid, and... yeah, there are gonna be things about this that are gonna be extremely difficult, but I think she's gonna have a good life. He said, I've evaluated... he had some exact number of kids, and he's like, this is kind of what I envision for the future, like, what I would predict for the future for her. I think she's gonna have a job, I think she's gonna have an apartment, I think that... you need to be in control of her money, and I think, you know, there's always going to be some level of extra support that's going to be needed for her... She will have a level of independence; she will have a good life. And that was just so different from what the first specialist had brought up... When I left, I felt very hopeful. I felt like, you know, that's a different life than what we might have thought when she was a baby that we were gonna have, but... it's a good life. Like, there are a lot of ways to have a good life. We did have a specialist locally later who was horrified that he would make any prediction, and she was like, I would never say that about a child. I'm like, well, I also... am realistic. Given her disability, she's not gonna... go be a rocket scientist for NASA. Like... there are some ceilings. I don't think there's anything negative about the type of work that she might do or needing some extra support from us to be able to manage things like finances. Like, that, to me, is not a failure or anything bad... especially compared to what we were originally told.

Collaborative Care - Some parents described caregiving in terms of collaborative care, such that they take on responsibility for bringing ideas to the care team and participating in shared decision-making. For example, Natasha described the difference between a NICU experience and her experiences with her son's rehabilitation doctor:

I'm gonna be his strongest advocate... like, the only person that really knows him holistically... I feel like in the past, I just thought, like, okay, if a doctor said it or a

practitioner said it, then... that's it. Like, they know best, and now I'm like, okay, but there's so much we don't know. Like, a lot of times, the syndrome gets treated and not the child... I love the doctors that are so willing to... be educational... I had an ongoing problem with the head nurse... of the NICU because she felt that... my questions were an attack on her expertise. And, like, that was my way of... dealing with what was going on. For me... to educate myself is... a way to deal with the anxiety and... the angst, so... I kind of need to do that process... and... I'm asking the people who might have the answers... His rehab doctor, who's probably our favorite practitioner, he's just so good at... saying things in a way that don't insult your intelligence, but also, you know, is just very informative and... very... willing to take... the feedback, and... he will always answer my questions if I send something in the portal.

Natasha detailed a specific example of how they tried “Botox in one of his legs”:

...we thought that [Botox] would help... Combined with stretching and AFOs, and... it got worse. So like, getting that feedback to Dr. [name] and... then him being like, you know what... we were hoping it would work, but now what we know is, like, he's not strong enough to keep his leg straight, so really, like, reducing the tone there just didn't help... And so... that kind of back and forth ... I guess my point is that having great practitioners and seeing how that give and take really leads to... some good decisions... We've decided now... we're regressing on the AFOs and going back to one that gives him a little bit more support, and kind of locks his knee in place a little bit more... I'm more than happy to do... that when I know why, and we... have that give and take.

Like Natasha, Gwen described “advocating” for a specific treatment (i.e., “tobramycin nebulizer”) prior to her husband’s deployment, “if, just for my peace of mind, for, like, one more

thing to prevent any possible thing going sideways.” Relatedly, Donna described creating a “check-in sheet” that she provides hospital staff when her son is readmitted. She explained,

I have a check-in sheet that we've actually already made for the hospital that has all of the steps of, these are his meds, these are the times I need to be scheduled at, that's lined up exactly with Epic for how they need to put it in, so I don't have to talk to them while they're doing it, because that was a nightmare, every time we would get admitted, trying to get all that done, so I learned very quickly how to, like, make that process smoother... I even have, like, a list of these are the things we need in our room, and these are the numbers in your system for what they are. So you can go find them and bring them in for me and don't have to ask me what I need in the room, in terms of, like, what size of suction catheter, what size of diapers do we need, like, which diaper creams? What creams do you need for your trach that aren't, you know, prescription orders? Like, all of it on a list. Just take this and go over there so I can stay with my kid and focus. Because otherwise you're pulled away while they do all that, and I couldn't handle that when he was critical.

Parents also described entering health care encounters with existing perspectives on topics such as vaccines (e.g., Laura, Jean), breastfeeding (e.g., Jessica), and procedures (e.g., G-tube, Doreen), often informed, at least in part, by informal networks. Doreen’s account illustrates how learning unfolded over time, as clinicians provided education alongside informal inputs. She recalled,

That was one thing I was always terrified of, was her having a G-tube... that was just something I had... heard about [from a cousin] and learned about on Facebook groups, ...and I was like, I never want her to have that. So they came in, and they're like, you

know, this is a possibility. This is something we could do later on, you know, how do you feel about it? And I'm like, no, I really don't want that. And the more they educated me on how it worked, and how easy it was, and easy the surgery was, and how it would probably be beneficial to her since she wasn't eating solids or anything like that, we decided to move forward with getting one once she got over her strep and flu and stuff... After that, and she has been a totally different kid since. I don't think I realized how much she was lacking until she got what she needed. Like, she was getting enough to survive, but she wasn't thriving.

Doreen described a learning community comprised of her family (e.g., cousin, mom), other parents on social media, and members of her daughter's care team. She shared,

So I saw a kid using... knee immobilizers to practice standing, you know, just things like that, and I'm like, hey... is that something we could do? Is that something we could get? How does that work? And actually, the doctor's like, oh yeah, some of those in the office, let me just go grab you a couple... It's never anything, like, super crazy, but they're really good about... telling me, you know... we don't really do that... Our therapist had seen braces that would go over the knees, and she was like... maybe we should look into getting some of those for when we practice standing, you know, do you want to ask the doctor... what they think, and if they want to write an order for that? And the doctor told me, like, it wasn't something that he would recommend for her, and that he didn't feel like it was really necessary... They're never like, oh my gosh, I can't believe you asked that... they're good about, you know, saying yes or no, and explaining why, but... I think they appreciate me asking questions... But like I said, we've been with them for so long that... I think they hopefully understand that... we're just trying to do the best we can.

Like Doreen, Jean described her son's pediatrician as meeting her where she was at:

I was curious about, hey, I want to vaccinate my kids, but how do you feel about a delayed schedule, or this schedule that I saw, or... and she engaged with a conversation about it, in a total objective, neutral, level-headed way, and we... we talked about it, and I felt like she was not trying to sway me, but she absolutely did sway me, because she knows science better than I do, in just thinking differently, and I really enjoyed the totally neutral, objective dialogue.

Distinct but Inseparable from Parenting

Parents described learning from caregiving experiences as distinct but inseparable from parenting. This section details the following subthemes: (a) false equivalence, (b) planning for everything, and (c) finding their own path.

A False Equivalence

Parents described learning a version of motherhood that was, at least in the beginning, characterized by a “constant triage mode” (Jean). Most parents emphasized “an importance in differentiating caregiver and parent” (Selina), even though not always in those words. For example, Doreen shared, “It’s totally different than everybody else’s life. I couldn’t imagine it being any different... it’s a different and a special kind of life to live.” For Diana, the distinct roles of mother and caregiver began before she even saw her son. After his birth, she recalled asking questions about her son’s medical status (e.g., “is he breathing”)—questions that elicited information about “resuscitation” and “surfactant”—while also inquiring about personal details (e.g., hair color, 10 fingers and 10 toes). This experience was further layered by her own medical crisis (i.e., feeling everything after C-section), a parallel that continued throughout Diana’s narrative. She explained,

For a very long time, I hated my job. But I loved my child. Because I wasn't getting to parent him. I had to be his advocate, his nurse, his therapist, his... financial advisor, his scheduler... all of those things. And what got lost in a lot of that was the mothering. Because I had so many other jobs to do. And there wasn't, like, a division of labor... where I had somebody working on billing, somebody else working on the DME company, somebody else doing all the scheduling of all the appointments and all the therapies, somebody else doing the pouring the feeds into the bag every 4 hours, somebody else helping with dressing changes that could, you know, don't mess up, because it could kill your kid. And then doing the school...teacher. I would say that it's only more recently as [son's name] has gotten older. That I have stepped into that mothering role.

Like Diana, Jean described caregiving as occurring alongside parenting:

You know, there's... go out in the world, go to the park, walk your dog, go to the movies... the... regular parent stuff. But on the caregiving side, and ... something I say often and loudly is that caregiving is a job, and caregiving is a job in addition to parenting. For many of us, it is full-time, and it is forever. So... you know, of course we're all exhausted and overwhelmed and burnt out, because we have the job of parenting, we have the job of caregiving, and we have the job of whatever else, whether it is outside the home career, inside of the home career, whatever that is. So... there's... all of the, like, paperwork, planning, organizing, scheduling, you know, which just the... administrative part of it is an enormous burden on my time. And I use the word burden because no one wants to do this much paperwork, ever. No one wants to call the pharmacy and fight with the pharmacist, ever. So you know, the administrative piece, is

not nothing. The... weighing pros and cons of every single situation. He wants to go to Trader Joe's at 6:30 at night, but he's tired. Is it worth leaving the house? Is he going to melt down? Is it going to be hard? Is it going to be great? But then he comes home and melts down. Some of our best friends said, hey, do you guys want to come over for dinner Sunday night? And I was like, no! We don't. My husband's out of town, and I love the offer, but... and they were like, oh, if it's easier for [son's name], we could come over to your house and bring food. And I was like, honestly? Like, it's just exhausting... He is this wonderful, amazing kid who is constantly on the move, constantly needing somebody to just have an eye and ear on him. He can be in the other room, but he's not safe, not 100% safe, so you're always looking... We have full-time help, which is enormous, and is how I'm able to function decently well. But even managing the caregiver schedule, and like, oh, I wish they had asked a few days ago for dinner Sunday night because then I could have scheduled her. Do I want to schedule someone else? Do we want to pay for someone else? Like, is it worth it? ...my brain is always working, because I'm always thinking of the feeding tube schedule, and every two and a half hours, this. Well, he was a little bit off this morning, so we're adjusting the food, or he was a little bit constipated, so we need more water. The feeding tube math that's always in my head, I feel like my brain is never allowed to shut down, ever... And the stress of every time we leave the house, you need everything, you know. I blend his food, so not only for every single meal he's going to have, but all of the supplies, and what if we can't get his seizure medicine, his rescue medicine refilled, feeding tube supplies, his... what if we forget his adaptive bed? You know, like... everything is a calculation. Every morning, making sure his backpack is packed with all the things, making sure I'm communicating

this and that with his teacher and his aide... It is constant. So yeah, caregiving is... Such a mental thing, as well as the physical.

Even in accounts that resemble typical parenting, parents described subtle differences (e.g., engineering experiences, caregiving across the lifetime). For example,

We are very comfortable with uncomfortable. You know, things that other people tend to be embarrassed about, it's like... it's a part of life, and we are all going to need support at some point in time. Ours just happens to be now. And being able to educate and say, you know, we're... members of society, and [son's name] deserves to be a part of society, and not only does it benefit him, but it benefits other people... I wanted him to have experiences that I did as a kid, and that I enjoyed, and part of that was going to summer camp... This was not a special needs camp, it was... a, you know, typical camp. He had an aide who went with him. And the instructor was just great with working to find the tools... that would work for him. And as she adapted some of the session, the pieces for him, the other students wanted to do what he was doing, which was really cool. But he did some... The end of that session, the end of that week, he made... he had some really good art. And, I had shared, I had just asked if people would be willing, you know, to... if I've turned them into cards, would they support it? And, they said they would, and... And they did, and the whole thing about [Name]Land Art came about because at 7 years old, even before that, I knew that [son's name] would not be employable by... regular standards. So as he got older, he was not gonna have a job. But looking at, okay, art is a way that he could, have income. (Selina)

Jane described her perspective on caregiving:

I mean, when you're a mom, you do whatever you can for your kids, so I feel like I'm not doing anything special... He was born this way, this is my job, it's just different than what everybody else's mom job looks like.

Thinking of Everything

Parents described learning a new version of motherhood as involving thinking of everything, including current and future needs and preferences, what society says, and navigating the systems.

Current and Future Needs and Preferences - Parents provided in-depth descriptions of “negotiating systems” (Gwen) on behalf of their children. Across accounts, parents described the lengths they go to meet their child’s current health care needs. Carol described the challenges she has faced negotiating her son’s care needs in both hospital and school settings:

We do not leave him alone, because we know the staff are busy... we've always had really great staff, but they are stretched thin often, and they're all over the place, and... he is so specialized that people aren't always tracking or understanding everything that he has going on, and so we always have to advocate and make sure we're the ones on top of it. Even, like, going into the hospital this time, I have a suitcase of all of his catheter supplies and all of his medicines... going in there in a cooler with one of his medicines that has to stay refrigerated... and indeed, they didn't have one of his medicines at the hospital... They didn't have his catheter size, so I have to come in prepared with all of the gear that I know he has to have, and I... just to be ready, so I don't rely on the hospital, really, for some of that stuff. I just know I have to take care of him. I have to pack it up. I have to be ready.

Parents described having to think of everything to make things work at home. For example,

We had some real behavior problems, and I have a front door to repair. Yeah, my, you know, [daughter's name], as I've mentioned, she's DMDD and ADHD. There's a lot of difficulty with impulsiveness and just regulating. So yesterday morning, I was not I was not allowing her to verbally abuse her older sister, [older daughter's name]. And she decided that was grounds for her to pack up and run away. Now I have combination padlocks on all the exterior doors... they're usually unlocked, but, when she was like, okay, I'm packing. I was like, okay, I'm locking. And, when she couldn't get out of the door, she... broke the frame of the door. (Cassandra)

Natasha described being a single, first-time parent to [son's name], now five, as part of her layered analysis of medical recommendations. She described differing perspectives between her and providers regarding her son's care plan:

We have three shitty options. One is we just keep vomiting, the other one is we get a GJ tube, which just doesn't really fit [son's name] lifestyle, and like, the fact that he is so mobile, and he doesn't have the tone to wear a backpack with a feeding bag or tube on it. Plus... the way he puts himself to sleep, like... we had a surgeon tell us, like, oh, well, all you're losing is time, and I'm like, no, that is not all I'm losing... [son's name] loses a lot in terms of... you know, his ability to be mobile, but I also lose, like, a bit of sanity and mental health... and... also money, because I'd have to completely change his... the whole bed system around, so I'm not just losing time... As a single mom with a kid that's gonna be feeding around 20 hours... I mean... I get that I can set the system, but... also, with my anxiety, would like... I mean, we'd have to be on a pulse ox again, and... there

would just be... a lot involved for me to... be able to do that, and... he wouldn't qualify for overnight nursing either, because he doesn't have a trach.

Diana also described a need to think about her son's needs holistically:

I have to... be looking at the entire picture of [son's name] and what [he] needs in all facets of his life all at the same time. And I can get emotional about it later... having that separation, is very hard because in some ways, it doesn't allow me to be fully present emotionally in situations.

For other parents (e.g., Susan, Selina, Jessica, Natasha), current needs revolve around "routine." Susan explained,

He goes to school every day, and on a bus, and he has the nurse with him, and things are different because... he has to pack a bunch of meds with him, and he has to have a special chair, and he has to have a particular kind of lunch, and, you know, a stash of diapers all the time, and, like, those kind of silly things are different, but... routine-wise, he's with us whatever we do. My daughters ride horses, and if we're going to the barn, then [son's name] goes to the barn... Other than, you know, dealing with the events, medical events that were happening his routine... kind of settled in as early as we could, especially around when school started. I mean, and the routine is shaken up often. So it's the routine, but then all of a sudden, you're in the hospital. It's the routine... and then you're in the ambulance.

What Society Says - In addition to current and future needs, parents described, both explicitly and implicitly, thinking of social messages communicated by peer groups and the media to make sense of their caregiving experiences. These messages related to parenting and childbirth, disability and medical complexity, and social services participation.

Parenting and Childbirth - Participants' accounts reflected their experiences of parenting and childbirth in relation to others in their social groups and broader society. For example, Kara recalled feeling "a lot of anger... at God" following her son's premature birth. She described comparing her experience to that of a colleague, explaining,

And I started noticing a lot of jealousy with my friends whose children were born healthy or had a healthy pregnancy... One of my coworkers, who is a good friend of mine, she... was supposed to have her daughter two months before I had [son's name] ...and just looking back and seeing how her pregnancy was just such a walk in the park for her. Her daughter was born fat and healthy and beautiful. And then, like, her getting to leave the hospital with her child... There was a lot of conflicting emotions, because at the same time, I'm very, very happy for her.

Some parents' accounts suggest that more standardized narratives, reinforced across peer groups and media channels, served as points of reference. For example, Diana, a first-time mom, described grieving the experience she expected following her c-section, illustrating exposure to a widely circulated birth narrative: "I didn't get that moment where they hold him up above the drape, or they show you his face, or you hear him cry, or anything." She explained,

There's no part in the What to Expect When You're Expecting book of when your baby goes to the NICU at 30 weeks. Like, that's not in there. There's no guidance for how to navigate any of this. So I mean, again, it was kind of trial by fire and fly by the seat of your pants. But don't get it wrong because if you get it wrong, then somebody might die. None of my friends had experiences like this. I mean everybody had very healthy, happy pregnancies, very traditional labors and C-section deliveries. I mean, they were, you know, standing up the next day, and caring for their baby, and bringing their baby

home... They were pregnant at their baby shower. They got to go to the breastfeeding class. Nobody was experiencing what I was experiencing, and so I felt like I didn't have anyone to turn to when things just were... what I felt like were just so incredibly demanding that I felt like I was drowning. But... you're your own life preserver. So like, if you're not saving yourself, no one's coming to save you. So you better keep dog paddling, like, keep your head above the water type situation.

Kara offered a related perspective:

I remember the first time they wanted us to participate in his trach change, and... You know, we're mom and dad. Society tells us that we are all our children need. We are enough. So then being in a situation where, very clearly, we are not enough to keep our child alive and we're having to be taught by somebody who started out as a complete stranger... how to take care of your child, I mean, that can feel so defeating... I think for my husband... he didn't feel as attached to [her child's name] as he thought he should at that time, because I mean, who pictures becoming a parent like this, you know? Like, we're all painted this beautiful picture of what it's supposed to be like, so then when you're... put in a situation like this. I mean, there's no handbook or guide on how to deal with it.

Some parents accounts suggested they felt personal responsibility for their child's outcome. For example, Carol recalled feelings of relief following her son's birth: "I was like, I did it, like, he's here, he's alive, he's fine." In contrast, Diana recalled the introduction of formula, feeling that she was "failing [her son] one more time." She explained, "My body failed him to carry him to term, and now I'm failing him again because I can't provide the nutrition he needs." She would return to this idea of failure numerous times throughout her account. Diana's

emphasis on “bringing a baby home” suggests an attempt to at least initially situate her experience within broader expectations around childbirth, which she inevitably abandoned. She explained, “In my very naive mind. I thought that when we left the NICU, it was over, that we would start to have the life that I saw many of my friends living with their children. That never happened for us.”

Relatedly, some parents described an internalized cultural narrative around what it means to be “a good mom” in the context of caregiving. For example, Gwen felt compelled to make sure her daughter was participating in PT, OT, and feeding therapy:

And then we ended up going to... a private therapy center. Way more germs because it's a private therapy center, and... if you make your money by... doing therapy, then you obviously have... a lot, a lot of kids coming through. And it was a risk that we chose to take, but also it was... the sickest year and a half, and looking back, I wish, like, I definitely have gotten more confident with time, because back then it felt very like, for some reason, I felt bullied into, like, oh, if you're not doing all these therapies all the time, then... she won't make progress, or reach her full potential... whereas I wish I could have just been like, we're sick all the time, and this sucks ... we're not doing this.

Similarly, Laura explained,

It took me a little while before I could be honest with them and say what was too much, because I felt like, well, if I was a good mom, I would somehow make all of this work [e.g., filming every meal while feeding her son alongside parenting another child]. And that's just not possible.

Parents also described specific mediated narratives as providing a point of reference for making sense of their situation. This included reference to specific, bounded works as well as

narratives reinforced across multiple inputs. For example, some participants drew on narratives that resonated with their perceptions when their persistent concerns were not resolved by reassurances from others. Carol described a specific mediated narrative from a memoir “about a woman who was traveling internationally” who “went into labor early and lost her baby.” This memoir offered a reference point through which Carol interpreted her upcoming travel plans, which she ultimately canceled out of concern for something happening while she was “halfway around the world” despite reassurance from a physician. Raven also described a specific mediated narrative as providing a point of reference following the birth of her second child. When her son was just 24 hours old, she recalled sensing that “something’s off” and telling her family, “He looks like him,” referencing a film character with a facial difference depicted wearing an “astronaut helmet.” Raven described family members attributing her concerns to pregnancy-related hormones. Like Carol and Raven, Felicia drew on a specific mediated narrative that aligned with her experience when she lacked another point of reference. Felicia explained:

I was considered a high-risk pregnancy... because I was 36, and then I was type 1 diabetic. So those are things that require extra monitoring. I didn't know anything about preeclampsia other than what I saw on an episode of Downton Abbey. I don't know if you've watched Downton Abbey, but... one of the girls in there ended up dying because she had that. I'm like, oh my god, what is that? I had no idea what it was, until the doctors come into the room telling me that I'm gonna die in 24 hours if I don't get the baby out of me, that you have preeclampsia. And I wish I would have known more about that... because I couldn't make an informed decision because I knew I had nothing to base it off of.

Disability Narratives - Parents also recalled encountering narratives around disability, both prior to and in the context of caregiving. For example,

Now I look back and think about all of the awful messaging about disability that came my entire life before now, of like, don't look, don't stare, pretend you don't see that kid in the wheelchair, that kid who walks funny, that, like, they're over there, and disability was just this, like, tragic, this is the worst thing that could possibly happen, oh, you poor thing... I was getting all of that messaging, and then everybody just giving you that look that you never want to see of the, like, aww. And everybody's saying, this is so hard, this is terrible, I don't know how you're gonna do this, I wouldn't be able to do this, you know, all this stuff, and like, oh, you're so strong, you know, the silver lining, and you know, God only gives special children to special people... (Jean)

Like Jean, other parents' accounts illustrated the enactment of broader societal narratives through platitudes. Jane explained, "The one that I think everybody hears that I abhor is, oh, God only gives you what you can handle... or... a lot of people will say, I don't know how you do it."

While some parents described disdain for this type of message, others used similar sentiments to make meaning of their situation. For example, Raven shared, "I've kind of embraced that I know there's a plan for everything, and there's a reason why he's doing what he's doing." Similarly, when asked what she has learned, Kara shared, "God has given you this child for a reason."

Many parents' accounts reflected institutional and interpersonal enactments of the broader societal narrative in which significant disability and medical complexity exist separately from everyday life. For example, Jane recalled her son's diagnosis as being "a huge shock to my entire family, because we just... it wasn't around." Stephanie explained, "I feel like it was pretty

hidden.” Relatedly, Susan couldn’t recall an “interaction with anybody with a disability,” sharing,

In my family, I'm not sure we ever had any kind of discussion about that at all. I had a, like, step-grandmother who had a daughter who had Down syndrome, but that was in the era where they were institutionalized right away.

Felicia recalled a recent institutional enactment of this narrative in her school’s district’s policy on vomiting, noting that kids “gotta be vomit-free... 24 hours” which would exclude her daughter despite “99% of the time [her vomiting] has nothing to do with being ill. It has to do with her other conditions.”

Participants’ accounts also reflected broader societal narrative of discomfort with disability, enacted through practices such as pity and avoidance. Doreen illustrated, “Kids ask questions all the time, and the parents, kind of, cringe, and they're like... you can't say that.” Doreen’s experience as a parent closely reflected other participants’ childhood experiences. Carol recalled, “When [sister’s name] got the electric wheelchair, we would be out and about, and we didn't really see a lot of other people with disabilities out and about, so we would get stared at.” Cassandra recounted meaning she associated with messages not to stare:

If there was something different about them, you know, my mom was one of those, like, don't stare! You know, just keep walking, don't stare! And so there was this internalized, sort of, there's something not acceptable about this person, that I shouldn't be engaging with them.

Relatedly, Doreen described early attempts to “make things normal.” She explained,

I always found a way to make things normal even when they weren't normal, and I think that that was wonderful, but looking back, I think it kind of I kind of convinced myself

that we could just do that forever, and, like, nobody would notice, and I wouldn't notice, and things were normal, and I don't think I knew what normal was. I didn't have anything to compare it to. Because I didn't have any other kids, and... I don't know if that made things easier or harder. And it wasn't until she was probably year and a half, two years, that it started becoming harder. You know, you couldn't disguise the difficulties and the delays and things as much anymore, because it was becoming more obvious to other people which made it more obvious to me.

Participants' accounts also demonstrate how societal norms related to parenting, disability, and health care can intersect. Doreen explained her initial reaction to the placement of a G-tube in terms of personal failure:

It made me feel like I had failed. I'm like, eating is so simple. Why can't I get my kid to eat or drink? It was really frustrating to feel like I couldn't help her do something that everybody else just does so naturally.

Further, participants' accounts illustrated institutional and interpersonal enactments of a pervasive societal narrative that frames people with disabilities through a deficit-oriented lens (e.g., "try to keep her out of prison," Laura) that emphasizes cost and resource use (e.g., in the 80s, and... early 90s, it was... a pretty common cultural value that, like...disabled people are a drain on society," Zoey; "they don't want to incur the extra expense for the district," Felicia). For example, Felicia shared being aware of the Disability Rights Act and the presence of accessible parking, ramps, and elevators, noting that she had not previously understood "the importance, or why they were there, or how they got there.

Systems Participation Narratives - Participants described experiences of caregiving in relation to broader societal narratives around participation with health care, special education,

and social services systems, including who holds legitimate expertise, interactions with providers and educators, and expectations of compliance with professional recommendations. Most parents described limited personal or prior familial experience with these systems.

Participants' accounts (e.g., Cassandra, Felicia, Raven, Doreen, Diana) demonstrate societal narratives related to medical hierarchies, such that expertise is thought to be concentrated in urban areas and, more specifically, larger medical centers. Cassandra recalled,

So, she was born blue... We were at a rural hospital, and the doctor didn't know what he was looking at. So, he did an echocardiogram. It's like an ultrasound of the heart and livestreamed it to [name of larger health system]. And the doctor there said, [I] know what she has, and she needs to be here now. So, at that point... 12 hours old, she was... airlifted to... [eastern city].

Raven's narrative also illustrates this norm: "[Eastern city] is... the place for everything, you know?... All those hospitals are known for being great. There was another hospital out in [midwestern city]."

Parents experiences (e.g., Jane, Kara, Jean) also illustrated interpersonal enactment of societal norms related to "appropriate" ways to participate with "the doctor, physician, therapist, school, teacher" (Jane). Jane explained,

I... have met some parents who try to go in with the aggressive, this is the way it's gonna be, and it just doesn't turn out well, but... If you go in as the... hey, this is our team, we need to coordinate to make things happen, and... if I don't agree with you, we can try something different, we can try it your way, we can try it my way. I just think that... having that, openness, to do it in more of a friendly manner, is so much easier... I think there's a quote by Al Capone, and it says something like, you can get further with a nice

word and a gun than you can on a nice word alone. So, like, I feel like, you know, you gotta have the backup there, but, you know, you do have to start with that nice word.

Similarly, Jean offered,

If you walk in with already knowing what you want to hear... no, that's not the patient people want... they'll still treat your kid, but, like, if I'm googling everything and telling them what I want them to say, that's not how medicine works.

Parents' accounts (e.g., Diana, Natasha, Susan, Felicia) of their child's early encounters with the health care system emphasize compliance with recommendations, noting deference to medical expertise. Diana shared,

I never in my life would have ever thought to question what a health professional is saying to me about me or about my child, really, because I just felt like they have so much more education than I do, they have so much more experience than I do, they have all the 12 letters next to their last name that say that they have reached this position, because they have done the work to get here.

Diana's account also illustrates underlying power dynamics, generally accepted within clinical encounters, where physicians hold authority and specialized knowledge. Notably, Felicia described her experiences with a school district using nearly identical language ("I never thought that I would be arguing"), revealing power dynamics that parents encounter across systems. She recalled,

I never thought that I would be arguing with the school about having handicap access for my disabled child. Like, this is a public school... there's ADA regulations... for both my kids, I've had to educate myself on how all of those rules work... because... the staff... they don't know. They don't realize... because they've never encountered it, or some of

them try to avoid things because they don't want to incur the extra... expense for the district.

Awareness of these and related norms were identified in how some parents described negotiating interactions with health care professionals. For example, Zoey, a Chinese American woman, described a situation where she followed protocol to avoid potential consequences:

When he has a bloodstream infection... they have to take a sample from a central line, which obviously doesn't hurt. And then they also have to do a peripheral, and he hates that. And I will not advocate for him to get out of that situation. And I told him why. I didn't tell him until after he turned 18, and I said, the problem with that situation is, every time we push back on that, the nurse has to chart it... And we get charted as being non-compliant. And the more that happens... the higher risk we have as your parents of being considered, medically negligent...or medically abusive... and then we run the risk of having our parental rights stripped. And... that puts you, right, in a... medically unsafe position.

Relatedly, Laura, a Hispanic woman, recalled a situation where a member of her son's care team explicitly mentioned a call to child protective services (CPS):

We had a 2-bedroom apartment, but I couldn't have the boys share a room, because I didn't trust [older son's name] with the equipment... we had a walk-in closet and so [younger son's] bassinet went in there, and then the oxygen tank and... the CPAP ventilator machine was on the other side of the door, so the door was open, but, like, that's where he was. And one day... the guy came to switch out the tanks, and he saw the bassinet in the closet, and he's like, your baby doesn't sleep in there, do they? And I said, oh no, we just store it in there during... the day so it's out of the way. He's like, okay,

because if your baby slept in there, I would call CPS on you. And, like, there's no way to... win. If I had him in the bedroom, and something happened to him, that would be a problem... It's not like he's shut in the closet, you know, but people just, like, made the assumptions, and we're trying to navigate all of this, and not having any experience with it, didn't know other [condition] families at that point whose kids were on oxygen and things.

In contrast, Diana, a white woman, described using her resources to escalate the situation and compel action.

We're not gonna stay here if you're just going to watch him. Something is wrong, and he needs a higher level of care. Like, those words are important, you have to say those words. I said, I want a medical necessity transfer... At the time, one of the people that I knew knew the chief nursing officer of that hospital. I called her, and I said, look, I don't know what to do here, but I need help. I need someone to come into my room and help me, please... So the chief nursing officer comes up to my room. I explain what's going on, and I said, I need a medical necessity transfer. And I specifically said to [hospital name], they have a great intestinal program there. Something is wrong with his intestine. And you don't have the capability to help him here. So she talked with the GI, and then GI did a physician-to-physician call at [hospital name].

These narratives depict parents using different strategies in navigating related systems.

Parents' accounts (e.g., Carol, Donna, Felicia, Gwen, Stephanie) underscored societal norms related to knowledge, parenting, and responsibility, such that parents hold responsibility for raising concerns without explicit knowledge of the possibilities. Felicia explained:

It's easy to say... everybody needs to know about this stuff. Well... that's not possible. There's just a plethora... of medical complications that you can get, and unfortunately... until you're in it or know somebody that's been exposed to it, it's not even on your radar... And that's with anything, even outside of medical, like, you know, disability rights, things with special education, like, you don't think about those things if they're not affecting you.

Like Felicia, Stephanie experienced an enactment of this norm. She explained, “At that point... it was kind of just, like... learning what they told us, but we didn't know what questions to ask.”

Parents described encountering interpersonal and institutional enactments of a broader societal narrative that public systems are accessible and provide the resources that families need. Felicia recalled,

We're trying to raise money for a different style walker. [People are] like, oh, well, insurance will cover that. Oh, there's... these grants... like, oh, you should... like, people just think that they're gonna give us stuff. Just like when [daughter's name] got released from the hospital, they're like, oh, well just get a nurse.

Like Felicia, parents described institutional enactments that trouble this norm across systems. For example, Diana recalled

I did not know at that time that once he [was] inpatient for 30 days, he's considered institutionalized, their language, not mine, and he would qualify for institutionalized Medicaid. That could have helped us tremendously with his NICU finances. But we were never made informed.

She later shared,

Moving to [midwestern state-2], he had to be completely re-evaluated by our new school district, even though he had an IEP in [midwestern state]. And it was for other health impairment, which is a chronic medical condition that will not change. It will never change. It will always remain the same. When he was re-evaluated here, they said that he did not qualify for any services.

Gwen described recognizing differences in allotments for medical supplies across different states:

Supplies were so different... In [southeastern state], we 1000% could not get any more than four suction ballads a month. And here [midwestern state], ...they're like, you get 30 a month, like, what are you talking about? And I was like, I have never seen so many... Or... in [southeastern state], we always had to refill the heater pot with... [bottled] sterile water, and here... we hung a bag. Like, that is so much, like, user-friendly. Like, that makes parents' lives easier.

It's worth noting that at least two participants' experiences involved direct interactions with their state's child protective services division. Parents described encountering other enactments of prevailing narratives through institutional policies and protocols, which will be discussed in more depth in the following section.

Navigating the Systems - Parents described learning a different version of motherhood as involving navigating the systems. As discussed throughout, these systems often included multiple health systems, educational systems, social services systems, their workplaces, and more. To illustrate the range of experiences, Gwen's account of navigating two different health systems is included prior to discussing the overlap across parents recalled encountering. Gwen shared,

When we discharged, everything was very disjointed. So the pediatrician was separate from the pulmonologist, was separate from the DME company, was separate from... like, there was no cohesion, there was no communication... like, it was really all on me. There was no, like, oh, ENT just sends the order, and then it, like, shows up... it was so stressful... So... when we moved here, and, like, the RTs just showed up with all this stuff, and, like, they just got orders from the doctors, and, like, everything was just so... well-oiled and interconnected and, like, within the same medical organization, I... I was so blown away, and I was like, wow... like, this is how this part should be...

Like several other parents (e.g., Jane, Carol, Zoey, Laura), Gwen also described her daughter as receiving care across multiple health care systems: “We're at [hospital-2] for different things now, we go to Mayo Clinic for different things, like, it's not, you know, like, obviously second and third opinions really, really matter.”

Most parents described learning to negotiate the overlap between multiple systems, although their experiences varied. For example, Selina described the overlap she experienced between a medication prescribed by a physician, her state's Medicaid system, the drug company, and her employment. She explained,

There was a medication, a seizure med. Medicaid would not pay for it because it had not been approved for kids under four. I had reached out to the drug manufacturer because they have those programs... if you can't pay for your meds... They wouldn't cover it because he had Medicaid, but Medicaid wouldn't pay for it. So [we were] in this forever loop. And I think we ended up getting it through a different Medicaid program... I mean, we're in a situation now where... he has a waiver, eligible for nursing services. They won't... So we've spent two months going around in circles for them to send us to a

different waiver program. So it's... where people don't know the process, which is why it's been important for me to learn the process. So when I know the process, I can let the people who work and get paid for this to say... here's where the breakdown is. This is where you need to fix things. So it's hellacious because it's a lot of time, energy, and no money on my part... I'm losing money because I'm having to take time off of work. But I'm doing other people's jobs that they're getting paid for.

Selina described a “forever loop” in which she had to educate paid employees to resolve a breakdown. Relatedly Jessica explained the importance of anticipatory planning in ensuring her son’s needs are met:

...trying to know what his needs are going to be before they're his needs because things take so long. For example, he does have a wheelchair for long distances, and... we just had to get a new one. So that's fresh on my mind... You have to wait roughly five years before insurance will pay for a new one. But he was outgrowing it, and the process can take six to eight months. So being able to say, OK, we're going to hit the five-year mark in March, it takes six to eight months. So we could start that in October. And to start the process, you have to have a physical therapist doctor's order. You have to have a doctor's visit with primary care that is only specific to wheelchairs. So it can't be at the same time as discussing well-checks. It can't be at the same time as discussing diapers. It can't be at the same time as like a strep throat issue. It has to be just to discuss a wheelchair, you know, so, so eight months before we qualify for him to get a new wheelchair, I have to be making appointments with his primary care, talking to his physical therapist, finding a medical supplier so that in eight months from now we could have a new wheelchair.

In contrast, Felicia, Raven, and Cassandra described experiences that reveal a disconnect between effort and knowledge and access to services. Felicia explained,

[Southern state] is not great about supporting people with special needs whether it be... in a home setting or in a school setting. We don't have a lot of resources here. I know some states, you know, pay a parent... if they have to stay home with a disabled child... Instead of hiring a nurse, they'll pay the parent... [Southern state] only has one waiver program that my daughter would qualify for, my son doesn't, even though he has level 2 autism, he can't be left alone and has an IQ in the 70s. She is the only one that would qualify for the medical waiver, which is the [program name] ...However, we've been on that waitlist for over a year. I did not find out about that waitlist until a year ago... and that was because other parents told me about it... not because the social worker at the hospital did. And so basically that waiver would allow her to keep Medicaid regardless of what my income is. So right now, she has Medicaid, but it is because I am not working, and her dad and I are not married, so we qualify for Medicaid just based on the income aspect. But it... that is extremely difficult because... I don't have any other money coming in. And yeah, I have a nurse... she goes to ABA... for a 6-hour window. But if I work too much, then we lose Medicaid, and I lose that nurse... and then we can't afford ABA... we couldn't afford her therapies, like, ...we have so much medical debt right now. Just from her NICU stay, the hospital billed us \$500,000 outside of what insurance covered... we've been fighting that for a while, because I'm like, my maximum out of pocket was, like, seven grand... you know, seven grand. How, how, how? You know, like, oh, you didn't get prior authorization, oh, this person's out of network. I'm like, my daughter was inpatient at a hospital that was in network. I have no control over what

those people do. I can't ask, oh, time out, radiologist! You know, are you on Blue Cross Blue Shield? ...[Early Intervention program] mentioned to us, like, oh, hey... have you looked into any of these things? But it's more of like, hey, here are some things, we don't know what you qualify for, but go out there and be somebody. I can tell you. I have just run into wall after wall after wall. It's like every resource they tell us I go to it, and it either doesn't exist anymore, they lost their grant...or... you know, there's always some reason or some caveat in there to where we can't get it. Disability, so technically, both of my kids have, like conditions that qualify for Social Security Disability. However, because... I own a 20-year-old horse trailer that caught fire 8 years ago, that can't be sold, they count that as an asset. And so I'm over the limit because, oh, well, this trailer should be worth at least \$6,000. I'm like, first off, I bought it for \$4. You know, 15 years ago, and it's a 20-year-old horse trailer. Like, it wouldn't be worth that, even if it was in good condition, but it's not even usable, but they still hold it against you. Like, I sent them pictures, I sent them quotes of what the repair bill's [sic] like. And so neither of my kids qualified. Because of that, I'm like, this doesn't make any sense... I mean, they have strung that process out for, like, 10 months... Actually, it's almost been a year... I mean, it's just... there's not any resource, and it's so frustrating... I can tell you that I tried to get attorneys and advocates, and I went through [organization name] before all of the federal cuts that were made recently. They told me that they didn't have enough people on staff to take the case, and so they sent me a list of people. Well, all of those people charge... I got an advocate, they were charging \$125 an hour, and that was just an advocate, that wasn't even an attorney. Then a year later, [organization name] was like, oh, hey, we found out about this new resource called [organization name-2]. You should apply to

them to get help, because we still can't help you. So I applied to [organization name-2] a couple months later... I qualified financially, [but] by the time we had the... intake meeting... they're like, oh, we just lost all of our grant funding...so now we can't help you. So it's like, every time I think like, oh God, thank you, God, help is coming, and... and then it's not, you know? So, it's... it's... extremely difficult.

While Felicia described sustained efforts to access resources for her children, she encountered numerous barriers. Relatedly, Cassandra described how a “\$2,000 [annual] raise” pushed them “over the limit... for SNAP. They shared,

Which means we lost the free breakfast and free lunch. And then the recertification for the girls' Medicaid happens... and they sent me a letter saying, we're terminating both girls' Medicaid... Both the girls are on specialty medications that are hundreds of dollars. Medicaid is our secondary, like, we're all on my employer's insurance. But Medicaid has been the secondary for both the girls. In the last year... and I know they pick up a lot of the difference. And I'm not gonna be able to do that. So I am very concerned. I'm not sure how I'm gonna navigate it. But... I will figure it out.

Like Felicia, Raven described challenges she faced navigating payer issues. She explained,

I don't have a lot of guidance on navigating insurance. I'm currently, this week alone, in the middle of dealing with fighting for food for my child. He does not eat anything by mouth. And I have no food left for him, and no one will help me get him food. So it's very frustrating, So I feel like for that, I don't really have, like, a lot of help with that. It's more just me having to just advocate... until... I'm finally heard... He did see... PT and OT outpatient, but again, insurance, they capped my visits for him. And he met his visits in June... June, and they don't reset until January. So in the meantime, I have 6 months of

no outpatient PT, so what I have to do is do it myself at home, because I just don't want him to... lose... where he's... grown since then.

For some parents, navigating the systems involved ensuring their child's health care needs were met across contexts. For example, Carol described having to ensure her son's catheter cares were completed, negotiate the school's seizure protocol, and respond to disciplinary actions related to medication-induced behaviors.

So, at first, [husband's name] and I were taking turns and doing all the cathing at his public school kindergarten, then the aide got trained. And she was supposed to do the morning cathing, and I would come in the afternoon. And the day that I found out she never did the morning cathing because he refused... we had to stop having her do it, because that was unsafe for him. He could end up in the hospital... And that's on top of, like, trying to deal with the seizure... protocol, you know, managing all of that, and then... then he started to have the behavior stuff in January of kindergarten year because of the new seizure medicines, and the staff started to call and say he's suspended, he's hitting, he's running around, he's not listening. You know, he's hitting staff, we're locking him in a room with a staff member, all of this stuff.

Carol explained that she currently began receiving a part-time hourly wage to support her son:

I am part-time. And it took a while, but by last September. we were... we qualified for 35 hours a week, and it's... about \$17 an hour, but not taxed... But yeah, we are dealing with issues now, I know Medicaid... is under attack, but also, like, the agency we're working with to set up the attendant care for me to be the consumer-driven program, like, it seems like they must have messed up, because I have been on the phone with them and with Medicaid, like, the last three weeks, because they... denied us any attendant care

hours... But we don't know if our hours are going to be cut. I am in a special, like, a group for moms with kids with disabilities in my area, and a lot of them in [eastern state] are getting reduced hours right now.

Multiple parents, including Carol and Donna, described becoming agents of change. For example, Carol recalled,

I... had to go to the school board level to just get rescue medication to be by him. They had it locked in the health lounge, which is why his seizures kept getting to the point where he'd have to be hospitalized. because they couldn't get it for him quickly enough.

Additional example will be discussed in the next section.

Finding Their Own Path

Parents described learning in the context of caregiving as involving an ongoing process understanding themselves and what they wanted for their lives. Many parents described learning about their capacity. Selena shared, “I have learned that I am stronger than I ever imagined that I could be.” Raven echoed, “I'm strong as fuck... I feel like Wonder Woman.” Gwen explained,

You can keep pouring from an empty cup, like, even when, like, there's... no time or space or anything to have any kind of, like, fuel, you still can somehow keep going... There's... just no end to... what you are willing to do, and what you can do, and what you do do... I think that... it just kind of comes down to that.

In addition to narratives about strength, parents also described “growing into” disability parenthood. Gwen described processing advice she received from a respite provider:

Just so you know, like, you don't need to do this to yourself... you are clearly so... run down, and... I can imagine that if you didn't have all of those appointments, you would feel... better.... It was, like, a couple weeks of just being mind-blown, and my husband

being like... yeah, I've been trying to say this for, like, two years... I don't know, I just kind of had to get to the point of, like... And I think also you grow into disability parenthood a little bit. Like, I remember at the beginning, like having a child in a wheelchair felt like the worst thing in the world, and now I'm like, wheelchairs are so cool! Like, how awesome! ...So that was kind of... every phase we've had to grow into, and I think, obviously, especially when you start with, like, a teeny tiny baby, and then the world is your oyster, you of course want and hope that the outcome is... a perfectly healthy, like, able-bodied sweetie pie who can communicate and do all the things that they want to do easily. And when that's not the case, it's fine once you get there, but it's really, really hard to think about that at the outset, and so I think, like... just being her mom over time helped me get there... And so it was just kind of, like, bending all of the things that were, like, in my nature, right? Like, I... protect bedtime, and I protect nap time, and, like, these are... this is the time off that I need every single day, like, so... So then when it turned into, like, sorry, those are the only therapy slots, and she needs to do, like, PT twice a week, and OT twice a week, and feeding twice a week, and...it just became... so not doable, so... anyway, it ended up being... that was kind of, I think, just, like. Our respite provider being like, hey, you don't have... it doesn't have to be like this. And then I was like, yeah, actually it doesn't. And so then we just... I call it, like, our breakup. We, like, broke up with our therapy center, and it was... Amazing, like, it was so liberating. Which is, like, so silly to even say out loud, because, like... It... really should not be like that... Research suggests that, like, therapy breaks are just as important as, like, the periods of therapy themselves... But yeah, I do think that that confidence inherently comes from, like, being her mom for... an extended period of time, and...

seeing her thrive in her own way, in ways that would have... that did feel impossibly scary, or... terribly not okay, at the outset. So... even when we were like... we're willing to do whatever... it was... still in the back of my mind... like, okay, but I... Now it's like those are small potatoes. That's fine. So... just kind of feeling our way through as we go. And, you know, it helps that. like... You just love your kids, like, so freaking much that the rest just kind of follows.

Like Gwen, Raven discussed shifts she had identified in herself:

I'm just happy that I've kind of gotten to that point where... I, like, slowed down my life a little bit. I was always like, go, go, go. Feeling like my oldest, like, needed to... like, I was so embarrassed when my son... I was so embarrassed when I was telling people he was in birth to three, because he wasn't walking, and now I'm like... who cares? Like, I am so proud of every little... we call them inch stones, actually. We don't call them milestones, they're inch stones. So every single inch stone now that's met, so I've just learned, like. I'm strong, and I'm able to, like, slow things down and just enjoy, like, literally just enjoy everything about life now.

Donna also shared her path forward:

I am still learning things about myself. I'm trying to unlearn a lot of things about myself from this journey, because I definitely... did make the pretty common mistake that I think a lot of people on this journey make of it became my whole identity, because it had to. There was just nobody else to do a lot of the things, and I didn't have a lot of trust after certain things happened, and... It definitely became... a very large part of my identity. And knowing that my kid has already outlived his life expectancy more than once, and we're going in for, like, these massive surgeries and big high-risk things. It's a

little frightening, because if your kid is your whole identity, and all of a sudden that's not a thing anymore, you know, what does that leave you with? So that's something I've already been working on for a long time. I don't know if that's where you're going with it, however, that is definitely something that has been on my mind for a while, probably the last maybe six years or so... It's no longer just about him, you know, it's been something that I'm like, okay, it's not just him, like, it's now kind of evolved into, this is important to me, and how do I make that, you know, more, broad than just my kid, and, you know, do something with that that applies to the you know, who I want to be as a person, not just who he's made me be... forced me to be. He's forced me to be a lot. And so, trying to make it more elective of who do I really want to be, and how do I want to be in this space.

Natasha described letting go of long-term expectations and finding their path. She explained:

I know that I cannot set expectations. I feel like I did that early on... I mean, we still have goals, we have so many goals, but, like, I wanted to be off the feeding tube by the time he was two, and... I wanted him to be walking, but... I just know that, like, [son's name] gonna do things in his own sweet time... The best thing for [son's name] has just been consistency. And when... we've... been consistent... he really does catch on... I mean, that's been true of... the signing with more, that's been true of the potty training, of... when we do switch buttons, or, you know, it will be true of the AAC device...

Nearly all parents reported some type of transformation, some more positive in the current moment than others: “the dream was never to be a stay-at-home mom for me... I have to stay home,” Felicia; “getting to a place of not only focusing on what a good life means and looks

like but also... navigating through what it means to have a good death,” Selina; “life is possible, even with all of her diagnoses.... we can still go out and do fun things, and try new things, go new places, and live our lives,” Stephanie; “I worked so hard to have these babies, and they're here falling asleep on my arms... and that is where, most of the time, that's where I want to be, is with them,” Carol; “I couldn't imagine it being any different. Like, I'm appreciative of everything that I've learned, and the opportunities it's given us,” Doreen; “as hard as this is... I'm really thankful that I'm her mom... even amidst all of the... trauma and... horror of that time, it also was very clear to me, like... I'm her mom, and... that's a good thing,” Gwen; “the way it broadens your mind to think about what is a disability, and what does it mean to be a human,” Susan. Zoey described her experiences with her son as “saving her life.” She explained:

I entered this whole parenting adventure as a pretty terrible person. I was very much, you know, a nihilist: you know, you die, and then you're dead, so you may as well just get what you can and scrap for it, and, you know, if someone gets a punch in the nose, then that sucks for them... Now I am a devout progressive Catholic, and it is such a huge part of my spiritual life. And I am definitely a less terrible person. So [son's name] saved...my spiritual life, and how I define myself is so different.

Chapter Summary

This chapter introduced the demographics and social characteristics of this study's participants and discussed the themes and subthemes identified through systematic data analysis. The themes following themes answer the research question, “How do parents of children with significant disabilities describe learning from their experiences in the context of caregiving?”:

- Limited prior knowledge and experience with significant disability.
- Experiences disrupt expectations.

- Making experiences intelligible.
- Learning a different version of motherhood.

Each of these themes was supported by rich, thick descriptions. In the next Chapter 1 - , I situate these themes within the knowledge base and present implications and recommendations for future research.

Chapter 5 - Discussion

The purpose of this study was to explore how parents of children with significant disabilities perceive learning from encounters within complex systems in the context of caregiving. Specifically, it explored how parents of children with significant disabilities make meaning from engaging with these interrelated systems. This study aimed to address the following research question:

- How do parents of children with significant disabilities describe learning from their experiences in the context of caregiving?

Recall that for this study, health literacy referred to one's ability to find, understand, and use health information to inform decisions and actions (Office of Disease Prevention and Health Promotion, n.d.). Health literacy has been posited to arise "from the interaction of the individual and the health context" (p. 109). As such this study employed a multi-theoretical framework, layering Bronfenbrenner's (1977) ecological systems model and Jarvis' (2009) experiential learning theory to examine parents' interactions with systems (the "what") and the internal processes of learning from those caregiving experiences (the "how"). Using a qualitative methodology, I conducted 36 interviews with 18 parents of children with significant disabilities. This data was systematically analyzed and coded, and four themes and 13 subthemes were identified through thematic analysis. In this chapter, I discuss these findings in relation to related scholarship and my multi-theoretical framework, and I present implications and recommendations for future research.

Discussion of Findings

Health literacy represents both a public health outcome and a determinant of individual health and health behavior (WHO, 2025). Existing public health approaches emphasize the

importance of addressing social determinants of health—structural realities thought to influence parents’ approach to navigating health care systems (Gengler, 2014). In response to Healthy People 2030’s call for novel approaches to researching health literacy (Office of Office of Disease Prevention and Health Promotion, n.d.), the present study positioned caregiving as a learning context and caregivers as active learners, using an ecological systems (Bronfenbrenner, 1977; 1994) and experiential learning (Jarvis, 2011) multi-theoretical framework. Through a series of interviews, parents recalled their caregiving experiences and their lifeworld before taking on the caregiving role. The findings suggest that for parents of children with significant disabilities, the development of health literacy (i.e., one’s ability to find, understand, and use health information to inform decisions and actions; Office of Disease Prevention and Health Promotion, n.d.) could be understood as a biographical process, such that parents arrive to caregiving with full yet often insufficient biographies for independently making sense of their child’s complex needs, biographies that are continually constructed, tested, and reconstructed through the experiences of caregiving, among other life experiences.

Socialization Into a Distinct Role

Parents accounts suggest that learning in the context of caregiving involved socialization into a role that although distinct remains inseparable from parenting (e.g., “He was born this way, this is my job, it's just different than what everybody else's mom job looks like,” Jean). A key premise of Jarvis’s (2009) scholarship is that people learn within their lifeworld. While Jarvis’s (2009) framework accommodates secondary socialization (e.g., like to one’s “job,” Jean Diana, Jane, Jessica, Laura), it does not readily account for the socialization of parents into a role where there is no established script, institutional procedures, or readily available communities of practice to learn from (Kirchner & Yelich Biniecki, 2024). Diana explained, “there wasn't a

manual for what we were doing for caregiving... there's no guidance for how to navigate any of this.” While Bronfenbrenner’s (1977) ecological systems model doesn’t provide a manual, it reveals the system-level demands experienced by participants in this study, aligning with participants own words (e.g., “you're always maneuvering different systems, whether that's health care, whether that's education, whether that's social services, and trying to make sure that things are okay for your child,” Gwen).

Microsystem

Parents described enacting the caregiving role across multiple immediate settings—what Bronfenbrenner (1977) called the microsystem—including health care institutions (e.g., hospital and other clinical encounters, therapy appointments, medical supply companies); family systems (e.g., immediate family, extended family); and education systems (e.g., early intervention services, public and private schools). Many of the systems parents encountered existed with their own norms, languages, and hierarchies that influenced learning.

Each parent’s relationship with their child constituted an immediate learning environment at the center of caregiving. Like other systems, this relationship required that parents learn their child’s language, often a combination of communicative systems, through which they expressed their needs, wants, and personalities (e.g., “he clearly communicates things to...me,” Jane). For most parents (e.g., Gwen, Jean, Doreen, Carol, Jessica, Diana), this involved learning augmentative and alternative communication (AAC, such as signs or gestures, picture cards, speech-generating devices; Holyfield et al., 2023). Further, parents’ relationship with their child involved developing fluency in subtle cues (i.e., tacit knowledge; Huisman et al., 2025) that often served as the basis for decision-making, care administration, and advocacy.

Health Care Systems

Participants' accounts demonstrate the complexity of their encounters with health care systems, which included direct interactions (i.e., microsystem, Bronfenbrenner, 1977) with hospitals and other clinical settings, pharmacies, durable medical equipment and medical supply companies, public and private health insurance companies, and social services agencies. While the number and duration of specific encounters varied widely by participant, the hospital represented a common institutional culture that parents (e.g., Zoey, Carol, Felicia, Kara, Jessica) encountered in the caregiving role. Some others (i.e., Jean, Jane, Raven, and Laura) were initially supported by their child's pediatrician or early intervention services provider (i.e., Cassandra). Parents' accounts included interactions with professionals including doctors (often multiple specialties) and nurses, respiratory therapists, lactation consultants, pharmacists, speech-language pathologists, occupational therapists, physical therapists, therapists or counselors, and social workers. Several parents described unit or hospital transfers early in their caregiving journey (e.g., "we sat in this like purgatory room waiting for a bed to open in the PICU, and then we took this daunting walk through the hospital," Jessica; at "12 hours old she was... airlifted to [city name]," Cassandra), sometimes separating them from their child by distance or equipment and (Terp & Sjostrom-Strand, 2017) exposing them to different organizational or unit cultures and practices. Several parents described navigating multiple health systems (e.g., Carol; Donna; Raven, Cassandra), sometimes across stateliness (e.g., Carol, Laura, Gwen) and even internationally (e.g., Doreen).

Parents referenced numerous structural characteristics that varied across hospital systems including

- the number or consistency of inpatient staff (e.g., “seeing a bunch of different doctors, and they all had different opinions on what was causing this,” Stephanie; “we went, like, two months and never saw the same nurse twice,” Felicia),
- unit acuity (e.g., “my son's critical but not like gunshot wound car accident critical,” Jessica; “in the NICU, losing suitemates... and so... death has always been a part of our life,” Selina),
- protocols (e.g., “chaplain was gonna come meet us,” “hospital only used... a certain vent... they were... fully prepared to have us stay until she was five kilos,” Gwen; “cannot teach parents how to replace NG-tubes,” Raven)
- care schedules (e.g., “nurse would only come every three hours,” Carol; “his preference that... [the nurses] space out the vital checks as far as possible so he could get as much sleep as possible,” Zoey),
- access to supplies or medication (e.g., “they didn't have one of his medicines at the hospital... they didn't have his catheter size,” Carol),
- and participation in rounds (e.g., “this is his CBC, this is... what was in the culture of his line,” Diana; “tried to be there when they did the rounds with the care team, especially because we had some ongoing issues,” Natasha; “they all come... at rounds... with... all their computers, and there's a whole group of them,” Carol) or care conferences (“we walked out of that care conference with no options,” Donna).

Parents also shared interactions that reveal the combination of communication practices they encountered in this context. Some described clinical, risk-focused language (e.g., “here's all the things that are gonna go wrong with her by her by, like, the given age,” Laura; “if we keep him in too long, and all of the intestine dies, then he will not be compatible with life,” Diana).

Others shared encountering hopeful narratives (e.g., “she might have had the capacity to be a rocket scientist, and now she's just gonna be a teacher...looking back, I think it kind of gave me a, like, a false sense of hope,” Doreen). Still others shared their experiences with “wait and see” approaches (e.g., “we can't tell you what his future's gonna look like, we can't tell you really what this diagnosis is gonna do for your son or your family,” Raven). Some recalled attempts by providers to use plain language or limit the amount of information shared, like recommended by AHRQ (Brach, 2024), which, in some cases, was perceived as a barrier to engagement and advocacy (e.g., “we’re gonna take out his intestines, and it's... kind of like your appendix,” Diana; “she didn’t tell us the name, so we’re googling no butthole,” Carol). While each of these approaches failed to produce the practical understanding that most were seeking (e.g., “nobody just laid it out for me,” Doreen; “could you give me a guess,” Cassandra), other parents’ accounts pointed to long-term, relationships, where answers were pursued collaboratively (e.g., “keep bringing him in... we will always listen to you,” Jean; “fortunate to have people that we work with regularly that are willing to fight for what she needs, and... go through that process of getting it for her. It takes a lot of burden off of me,” Doreen).

Most participants’ accounts suggest they were situated within the health care systems as lay health workers (Lewin et al., 2010), taking on roles that would have otherwise been occupied by trained clinicians (e.g., “very highly specialized nurses that went to school for years, passed exams and licensing, and in order to do this care,” Diana). Sixteen parents reported managing technology-dependent care at some point, including cares associated with invasive and noninvasive respiratory support or enteral and parenteral nutrition support as well as intake and output monitoring, medication administration, and informal documentation. Some parents with adolescent children (e.g., Laura, Diana, Zoey) described supporting their child with taking

responsibility for aspects of their own care (e.g., “we have tried to get the kids both [her children’s names] understanding their meds from a young age,” Laura; “he is doing his own TPN, he is doing his own supply ordering,” Zoey). In addition to administering care, parents discussed their role as involving tasks related to medication and supply management, constant observation, exploring alternative treatment or equipment options, and, in some cases seeking second or third opinions.

Like previous research on tracheostomy training programs (e.g., Graf et al., 2008; Tearl et al., 2007), parents recalled receiving varied amounts of training (e.g., “the training... was enough to get me home,” Selina; “nobody even taught us how to do trach CPR,” Donna; “they did not do anything like, hands-on... They did have us watch some... YouTube videos,” Felicia; “we were so empowered to care for her... we really knew what we were doing, and we went home and we felt really very supported,” Gwen) and guidance (e.g., “the hospital... told me this amount of formula at this time, at this rate, and then this time for TPN, Diana; “there’s absolutely no doctors helping us, we’re just figuring it out ourselves,” Carol; “we transitioned to feeding him regular food through his G-tube, and it was life-changing. And that was with, zero support from anybody,” Susan) and frequently described a “trial and error” approach. Notably, one parent described her appreciation for a surgeon who revisited G-tube cares (i.e., “how to replace it... how to clean it... and if it gets infected, what to do,” Stephanie) months after the surgical procedure, and another described needing to “schedule an appointment, which [they] couldn’t get for, like, three months... to do the training [on hearing aids]” (Natasha) after she was unable to recall “how to put in new tubes” and was unable to find relevant online resources. From an experiential learning perspective (Jarvis, 2009), these skills only become part of parents’

individual biographies after they have had the chance for repeated practice. Even then, the new context, as illustrated in Stephanie and Natasha accounts, creates a new learning experience.

Some parents (e.g., Gwen, Kara, Donna, Jean), described the presence of private duty nurses and personal care attendants in their homes (e.g., “our house is not just our house,” Gwen) as identified in other studies (Leaf, 2018). This intersection situated parents in an employer-like relationship where they “interview,” “hire,” and “train” staff (e.g., “we don't let them be alone with him until they've demonstrated that they could do a trach change 3 times,” Donna) while, in some cases, still learning themselves (e.g., “same full-time day nurse since the day we brought him home... renewed sense of confidence in our abilities, because then we had to train our nurses how to take care of our son,” Kara). While some parents (e.g., Gwen and Kara) described consistent full-time help, the absence of qualified nursing or attendant staff (e.g., “could not find someone that would be trustworthy,” Carol) positioned other parents (e.g., Carol, Jean, Diana, Felicia), at least temporarily, as their child’s primary caregiver (e.g., “the day-to-day care, it's on me,” Carol), work for which some received modest compensation (e.g., “35 hours a week... \$17 an hour,” Carol) through a program only available in certain states (USA.gov, 2025). Emergency medical services (e.g., Gwen, Carol, Jean, Stephanie, Susan) represented another unique aspect of several parents’ caregiving microsystem. These parents described soliciting emergency medical services in response to acute medical events (e.g., “she stopped breathing at home one night so... I did CPR,” Stephanie; “she was... clearly having a huge seizure, and... it wasn't stopping,” Gwen).

Family and Community Systems

Parents recalled immediate and extended family relationships as influencing the caregiving experience, similar to prior research (Teicher et al., 2023). Fifteen participants

reported being married or living with a partner at the time of their child's birth or diagnosis. For some (e.g., Carol, Raven and Donna), their spouse served as a consistent collaborator in making sense of caregiving experiences. Parents accounts suggest that early caregiving experiences were characterized by "constant triage" during which many turned to their spouse for support making sense of new situations (e.g., suspected stroke, Donna). Several participants (e.g., Stephanie, Raven, Carol, Carol) positioned their husbands as co-learners across multiple points in their caregiving journey (e.g., hospitalizations, new diagnoses), during which they shared cognitive and emotional labor (e.g., "my spouse and I always try to make sure one of us is there," "my husband's always doing research too," Carol). For other parents, marriage and later divorce situated caregiving as a more isolated endeavor (e.g., "A lot of it is done on my own. Their dad peaced out... He was tired of parenting to special needs kids," Cassandra). Notably, several parents described their significant others' employment—as active-duty military service members (i.e., Gwen and Jessica), a physician (i.e., Diana), and a border patrol agent (Felicia)—as shaping their caregiving experiences (e.g., seizures began "a week after he left," Gwen; "we are... in the midst of our second year-long deployment," Jessica; "try to keep to her routine as much as possible, but... if dad's gone for an extended period of time, that is not normal," Jessica; "There are... many times where my husband is physically and emotionally absent, because he's... saving other people," Diana). Some parents' (e.g., Cassandra, Jean, Jane, Donna, Susan), descriptions of caregiving included relationships with older children, often necessitating split time (e.g., "be there in shifts," Gwen; "I had my son... he still needed me to be a mom... so I had to split my time between the both of them," Felicia).

Participants recalled varied levels of direct support from extended family, friends, and neighbors, for some fading as time passed (e.g., Jean, Cassandra, Carol). Some parents recalled

being comforted by relatives with related lived experience (e.g., “my mom had the experience of also raising a child for...12 years with disabilities,” Carol; “mom was a massive support for me, because, I mean, she went through this as a mother as well,” Kara) or professional expertise (e.g., “my mom spent every night [at the hospital]... she's an administrator of a [rehab]... really helpful having her... serve... behind-the-scenes liaison,” Gwen). Other parents described ongoing support with caregiving (e.g., “we stayed with my mom for the first... month or so” because I was honestly... kind of scared to take her home by myself,” Doreen; “my mom gets... paid to be a caregiver for her when we're working,” Stephanie) Some parents described more fragmented extended family and community systems (e.g., Laura, Diana, Cassandra), with some recalling friends’ or family members’ negative (e.g., “if we could give her back... you got a messed up kid... prison”) or well-intentioned yet misaligned comments (“it’s great that he's sleeping, you're so lucky,” Jean; “it's your hormones,” Raven). Several parents also discussed receiving information and support from relatives or neighbors with health care backgrounds (e.g., “our across-the-street neighbor... is a fire chief” told them to “just call,” Jane; “ex-husband's sister is a nurse,” provided anticipatory guidance related to seizure response, Jean).

Education Systems

The health literacy demands participants navigated extended beyond clinical encounters into other contexts inhabited by their child, including education systems. Education systems introduced their own health literacy requirements: their child’s participation in public or private education often required parents to communicate aspects of their disabilities and medical needs within a separate institutional culture, one with its own language, norms, and hierarchies. Parents described participation with in-home, early intervention services in addition to experiences within public and private school systems (e.g., preschools, elementary schools, and middle

schools, or high schools), depending on their child's age. Across the education context, parents' accounts included interactions with professionals, including teachers and paraprofessionals, speech-language pathologists, occupational therapists, or physical therapists. Relatedly, some parents' accounts included interactions with applied behavior analysts (e.g., Cassandra, Felicia, Laura, Jane).

Parents referenced numerous structural characteristics they perceived to shape the caregiving experience within education systems, including

- diagnostic and service provision protocols (e.g., “she was... too young to have some sort of testing, but I kept calling,” Cassandra; “[son's name] had to prove that he could interact with the device before the school would give him one,” Jean; “we only have the IEP meeting once a year,” Laura),
- need for qualified staff trained to provide care (e.g., “they're going to have a nurse who will be able to [catheterize him], and they did not... they trained an... aide... and... [son's name] would... refuse... I was back to going over twice a day to do his catheter,” Carol; “my son's school aide had a family emergency... and our backup person wasn't able to do it, and then I'm next in line,” Jean),
- medication protocols (e.g., “locked in the health lounge” where “they couldn't get it for him quickly enough, Carol),
- disciplinary procedures (e.g., “behavior stuff... because of the new seizure medicines... they started suspending him, like a 40-pound 5-year-old, and... putting him in isolation room,” Carol), and

- siloed services (e.g., “no one trained me, nobody talked to me about it...don't bother pulling it out at home, we'll just work with him at school,” Jean; “fallen through the cracks of all of the schools that we've been with... communication,” Jane).

Mesosystem

Nearly all parents described coordinating care across microsystems to ensure their child's needs were met (e.g., “currently, this week alone, in the middle of dealing with fighting [insurance] for food for my child,” Raven). Across the child-health care microsystems, all participants described their role as involving advocacy on behalf of their child, and some (e.g., Diana, Laura, Zoey) described modeling these behaviors for their children (e.g., “he has watched me advocate for him in real time his whole life,” Zoey). For example, Zoey described noticing an uncommunicated medication change. Drawing on her familiarity with treatment routines, she recalled questioning, “Where's... antibiotic X?” After learning that the medication change had been ordered by a fellow without communication to her or the floor nurse, Zoey described being “furious,” communicating judgement that her son's safety had been compromised. Zoey situated the incident within expectations for “person-centered care” and the unit's commitment to collaborative rounding, explaining, “They will not start rounds until that patient's floor nurse is there to lead the discussion.” Zoey also challenged the physician's process, asking whether infectious disease was consulted and about the responsibility for monitoring vitals, illustrating advanced knowledge of clinical workflows. She escalated her concern to attendings and set boundaries such that the fellow would no longer be caring for her son.

Parents described primary responsibility (e.g., I am probably what's keeping him alive,” Carol) for establishing and maintaining care routines (e.g., “he needs to see that, or, you know, whatever you do when you're done drawing blood and everything is finished, do not, under any

circumstances, say yay and clap,” Donna; “we walk in, and they check us in, and I say, it's croup... he needs an epinephrine treatment, and he needs a steroid shot,” Jessica; “check-in sheet... made for the hospital that has all... his meds, these are the times... that's lined up exactly with Epic,” Donna). Some parents (e.g., Gwen, Carol, Jean, Susan) recalled recurring incidents (e.g., “never stoppable with rescue meds, always a 911 call, always an ER visit,” Gwen; “it's the routine, but then all of a sudden, you're in the hospital. It's the routine...and then you're in the ambulance,” Susan), that Gwen recalled contributing to her ability to “control... the whole situation... even when EMS arrived.” Some parents described their role as involving administering medication and cares within school systems (e.g., “I go over and do his midday catheter, ostomy bag care, [and] medicines every day at school,” Carol) and ensuring “supports... [are] put in place” (e.g., OT, one-to-one nurse, Zoey; “we programmed it ourselves and put in his own things that he needs to... request, and... the things that would be meaningful for him,” Susan; e.g., “arguing with the school about having handicap access for my disabled child,” Felicia; “reach out to the teachers by email the first week of school,) while also considering financial ramifications (e.g., “scares me having to call an ambulance... a big part of it... is billing,” Raven).

Parents’s (e.g., Carol, Diana, Raven, Felicia) accounts suggest that the persistent demands of coordinating care across multiple systems (e.g., “the doctor and the therapist and the medical supply company and the insurance company, somewhere someone drops the ball,” Jessica) represent a “burden” (Carol), negatively impacting their health and well-being. This finding aligns with existing literature related to emotions and mental health in this population (e.g., Holmes et al., 2024). Many described these demands, at least at some point, as incompatible with other roles, such as mother (e.g., “I don't get to do... the mom things,” Raven;

“I hated my job [i.e., caregiving], but I loved my child because I wasn't getting to parent him,” Diana), employee (e.g., “it is a different level of having to... have a job and manage everything else for him,” Carol), and friend (e.g., “it’s just exhausting,” Jean). Like most participants, Carol’s narrative included consideration of how her son’s condition, social and academic skills, medication changes, relationships among peers and teachers, school policies, her and her husband’s capacity, and environmental factors interacted to influence his overall health and well-being. Further, she described advocacy with the school board to have rescue medications placed in close proximity to her son. Notably, two parents described navigating unfounded investigations by police and child protective services as part of the caregiving role.

Exosystem

Similar to research conducted with patients living with chronic illness (Lloyd et al, 2014), online peer support networks represented an influential, and often immediate, source of information and support outside of formal health care structures (e.g., “learned more from... the parent groups that I'm in” Felicia; “real parents really doing this every day with their kid, and experiencing... what works good for their kid, what kind of tricks do they have to manage the feeds or manage the supplies,” Stephanie) and the parent-child microsystem. Parents described seeking advice related to a range of questions, including about medical supplies (e.g., “Facebook groups are amazing... I had no idea about, like, Tegaderm,” Raven), challenges (e.g., “ran the lipids at the TPN rate... I'm on Facebook at 3am... did anybody happen to do this,” Diana), and procedures (e.g., “always terrified of her having a G-tube, learned about [it] on Facebook,” Diana).

Participants accounts suggest an ongoing need to exert influence across structures influencing the mesosystem and what transpires in those environments (Bronfenbrenner, 1977).

Parents mentioned encountering state and federal legal structures, including the Americans with Disabilities Act (ADA) regulations (e.g., Felicia), special education law (e.g., Zoey, Donna), and state and federal Medicaid regulations. Parents' accounts demonstrate the time and energy they use in attempt to exert influence at this level (e.g., "I start having conversations, and we start working on the... this medical daycare service and trying to get that passed through with the legislative teams," Donna). In some instances, health literacy, at any level, proved insufficient, at least as of the time of their interview, to exert that influence (e.g., the hospital billed us \$500,000 outside of what insurance covered...oh, you didn't get prior authorization, oh, this person's out of network... my daughter was inpatient at a hospital that was in network. I have no control over what those people do," Felicia).

Several parents (e.g., Carol, Jean, Zoey, Selina, Donna) described efforts to exert their influence on not only bettering their family's experiences but that of other families (e.g., there wasn't a support group for special needs parents, and so I started one," Jane). Participants described blogging about their experiences (e.g., Donna, Laura) so parents new to the journey "would find something or somebody, and it wasn't a dead end anymore," (Donna). Relatedly, Jean wrote a book after interviewing "40 experts... many of whom are disabled themselves." Several also described engaging with advisory groups (e.g., Carol, Diana, Selina) and advocacy organizations (e.g., Susan, Laura), participation that shifts based on their child's care needs

Macrosystem

Parents also described acute awareness of some macrosystem influences (e.g., sociocultural dynamics) on their caregiving experiences. Several parents wondered about others who may have different backgrounds from them (e.g., fewer financial resources, less education). However, their accounts also demonstrated more deeply held beliefs, including norms related to

pregnancy and childbirth, disability and health care, and social systems participation.

Participants' descriptions suggest these narratives functioned as reference points for their own experiences.

Parents' accounts illustrate social narratives, including pregnancy and childbirth being predictable, emphasis on a "healthy baby" as the primary outcome, assumptions that parental effort determines a child's outcome, and the use of planning as a mechanism for control. For example, Stephanie described feelings of disappointment and anger when her experience deviated from these commonly held expectations. "We didn't know beforehand that she was gonna have any of these issues, so... we thought we would have our baby, come home, and... have everything... ready, so it was nothing like I expected." Other participants' accounts highlighted survival and well-being as markers of a successful birth experience and position the parent as responsible for achieving this outcome (e.g., "I did it," Carol). In contrast, yet still illustrating these broader societal norms, other participants described feeling they had "failed" when their experiences deviated from the norm. For example, Diana described being unable to meet her son's nutritional needs with breastmilk as "failing [her son] one more time."

Chronosystem

Parents described shifts at the microsystem level, such as changes in the caregiver-child relationship. These changes related to aging and shifting care needs (e.g., "For a very long time... I wasn't getting to parent him... only more recently as [son's name] has gotten older that I have stepped into that mothering role," Diana; "I felt like... I'm the right mom for him, and it was a privilege... it definitely has... become a different beast with the seizures," Carol; "there were not routines at the beginning... as he got older, the routine is not that different from the

girls,” Susan; “when he was younger, I did it, and now I talk him through how to ask for what he needs in order to feel more comfortable,” Laura).

Microsystems changes also included health care systems such as different providers or changing relationships with providers over time (e.g., “doctors that we work with have come to recognize me as that parent, and they give me... some patience,” Cassandra; “for a while there, we... knew them well, and they knew us,” Jean). Parents also recalled shifts in immediate and extended family systems (e.g., marriage or divorce, deployments, expanding their family, death of a loved one, changing relationships with family over time).

Parents also reported changes in microsystem relationships (mesosystem) over time (e.g., “I have never been able to go back to work full-time, I don't get to see friends very often,” Carol; “the older he gets, the more we rely on ourselves as opposed to medical teams,” Susan; after my ex left, he took us off of his insurance... months after that, I lost my job, so we had no insurance... were on Medicaid... did get... SNAP... got a raise, like \$2000, can't get any more SNAP, Cassandra). While complications disrupted expectations, some parents' accounts reflected efforts, at least initially, to preserve dominant norms.

Events Led to More than Disjuncture

While analysis of the findings through Bronfenbrenner's ecological systems model reveals the complexity of the caregiving role, alone, it is insufficient for answering the research question. The next section presents an analysis of the findings through an experiential learning lens (Jarvis, 2009). Participants described specific events that contributed to an awareness that their existing biography was insufficient for making meaning of new experiences (i.e., disjuncture; Jarvis, 2011). However, data from this study demonstrate that learning occurred in the continued absence of “flow” following an initial disjuncture.

Initial Disjuncture

Some parents' (e.g., Carol, Diana, Susan, Jessica) expectations were disrupted following an in-utero diagnosis, leading to what Jarvis (2009) labeled disjuncture. For example, Jessica recalled learning that her son may have a condition "incompatible with life" during what she expected to be "just... another ultrasound." When lab results revealed that he had Down syndrome, like many parents, she began to question what the diagnosis might mean for him (i.e., "how will his disability affect him") and her family (e.g., "what are we willing to do or not do"). Notably, these questions were largely bounded by her biography (e.g., "what do we ask"). While accounts from both Jessica and Susan suggest that early diagnosis allowed time for processing initial disjuncture (e.g., "we were already kind of resolved... with the heart condition and what that was going to take," Susan), neither was able to practice a resolution and return to a state of "flow" (Jarvis, 2011) before unanticipated complications further interrupted the narratives each had begun to construct (e.g., "[Down syndrome] became part of our story and our announcement," Jessica). Susan recalled finding out towards the end of her pregnancy "there probably [was] something else wrong," that led to further disjuncture (e.g., "what else is going to happen kind of feelings").

For other participants (e.g., Cassandra, Gwen, Stephanie, Donna, Diana), an acute medical event marked initial disjuncture and questioning. Laura described how her early understanding (e.g., "he would be affected like me) shaped her expectations (e.g., "we were not expecting him to have any medical issues for a long time") after her son's birth. These expectations were disrupted by a cascade of medical conditions—including "apnea," "unrelated" desaturations, and aspiration—along with the treatment plans and therapies each required. Laura explained, "Things kind of, snowballed from there." Like Laura, Gwen described prolonged

disjuncture following her daughter's cardiac arrest. She recalled, "finding out... they... did have a pulse" after arriving at the hospital, although she explained she had "no idea what that meant" or what brain injury would mean for her family. Across her daughter's initial hospitalization, Gwen described multiple events spurring disjuncture (e.g., "I didn't actually know until the trach was placed that we would have to change it," "we had no idea that you could even discharge home on a ventilator"). Relatedly, Stephanie's ability to make sense of her daughter's condition after unexpected post-birth complications was limited by her prior knowledge and experience. Whereas this disjuncture (i.e., "how are we gonna ever to take her home") was seemingly resolved when she encountered new information (i.e., conversation about the G-tube), genetic test results led to further disjuncture (i.e., "it didn't tell us a whole lot about what to expect of her life") before she could practice a resolution and return to "flow."

Learning in the Absence of "Flow"

Across accounts, parents described disjuncture as reflecting, "this is the condition, and we learn about it, and we accept it, then... later, it's like, oh, here's another condition" (Carol), learning that rapidly cascaded across systems (e.g., specialists and health systems, durable medical equipment providers, government assistance programs, school systems). As the examples in the previous section suggest, episodes of early caregiving involved numerous events, many of which generated its own disjuncture. Jarvis's (2009) model does not readily account for the number of simultaneous events occurring across a single caregiving episode, particularly when further disjuncture occurs before resolution.

Felicia's account of her daughter's NICU admission, occurring at least initially alongside her own inpatient health care encounter (i.e., "they were trying to get my blood pressure to come down") and then full-time employment as a police officer, exposes the complexity of this

learning context. Her account of her daughter's NICU admission included surgery for a ruptured colon ("we thought that was gonna be the end of it), brain bleed with repeat imaging, two weeks of TPN, second surgery revealing intestinal disintegration ("they don't know why it happened," "we're here for a long time"), ostomy, bloodstream yeast infection, heparin to treat a suspected blood clot ("should we be giving her blood thinners when she has this brain bleed"), nystagmus, EEG, hydrocephalus diagnosis, and G-tube placement. Felicia also recalled experiencing disjuncture (e.g., "how do people do this," "would she qualify for disability") related to a future she could only partially see (i.e., "knowing this stuff that's going on, when she comes out, we can't put her in daycare"). Further, her account demonstrates disjuncture that extends beyond understanding her child's condition and care needs: she had to learn how to operate (i.e., "diligent in our observations, and taking very detailed notes") within a system that wasn't functioning (i.e., "her nurse was changing every single day... continuity in her care was terrible) how her prior experience suggested it should.

Whereas Felicia's account reveals numerous events across a single caregiving episode, in this case hospitalization, other participants (e.g., Jane, Raven, Jean) described disjuncture that unfolded over time, such that their concerns were initially normalized and, in some cases, minimized. For example, Jane explicitly connected her interpretation of her son's development to that of her older child (i.e., "we knew from birth to four what was supposed to happen"). This remembered biographical learning (Jarvis, 2009) was overridden by social inputs (e.g., "boys develop slower"). Jane interpreted "feeding issues" and her and her then husband's subsequent behavior (i.e., "we didn't put him on his stomach; we didn't make him try to hit those milestones") as explanation of her son's developmental delays. Awareness of disjuncture (i.e., "how do I figure out what's wrong with my son") resulted from a pediatric specialist's

acceptance of unknowing (i.e., “we don’t know if we’ll ever know what it is”) and resignation to “just put him in therapy.” Relatedly, Raven and Jean described their initial concerns as being minimized by health care professionals (“oh, he’s fine,” Jean; “babies develop on their own time,” Raven) as well as friends and family (“isn’t that lucky your infant sleeps,” Jean; “it’s your hormones,” Raven), experiences that expose social structures working against rather than in support of resolving disjuncture. In contrast, Donna’s account (i.e., being given “the option for a second opinion” after they walked out of the care conference with “no options) demonstrated how a clinician’s effort served to reduce her cognitive load (i.e., “we didn’t have to think about that”) and deepened system-level understanding that she returned to during subsequent periods of uncertainty (i.e., “who’s our next second opinion person going to be”).

Participants also described experiences where they were unaware of the limits of their knowledge and experience—they didn’t know what they didn’t know. In the context of caregiver education, health care professionals could be seen as occupying a position of power, controlling the content that is transmitted (Jarvis, 2025). Over time, parents described these situations as inhibiting their understanding of their child’s condition or a procedure, health and social systems navigation, or what their future might look like. For example, Diana described attempts to make sense of and seek further care for her son’s worsening condition for months, without the knowledge that he had “short gut syndrome.” Gwen recalled having “no idea what to look for” in terms of “work of breathing” or “respiratory distress” when she first took her daughter home after a five-day NICU stay, language that reflects the knowledge she has acquired since her daughter’s cardiac arrest, hypoxic brain injury, and years of experience providing tracheostomy-related care.

In some instances, parents (e.g., Jean, Gwen, Felicia, Doreen) recalled clinical assurances (e.g., “this is not a kid who's going to have seizures,” Jean; “she can be normal,” Felicia) rather than educational messages. Jean explained that she didn’t know “that rescue meds were a thing” until “the third time” her son was transferred by ambulance to the emergency room for a seizure. This finding suggests a significant health literacy issue, such that the gap extends beyond finding, understanding, and using health information (Office of Disease Prevention and Health Promotion, n.d.), and represents the absence of knowledge that information is needed or exists at all. It's worth noting that parents described varying degrees of these cognitive blind spots from those with potentially life altering implications to others like not knowing the purpose of a second opinion appointment with genetics (Raven). This theme was also present across contexts. For example, Jean described not being aware that her son could use an iPad as a speech-generating device, and Donna described not being aware of what she could ask for related to IEP accommodations. Parents also described not knowing what they didn’t know related to their state’s Medicaid program leading to missed opportunities for financial support (e.g., Diana, Stephanie).

Meeting Parents Within Their Own Story

Participants accounts suggest that each approached the caregiving journey and context as a whole person (Jarvis, 2009), with varied personal histories, educational backgrounds, and professional experiences. Most parents drew on aspects of their prior experience—what Jarvis (2009) referred to as remembered biographical learning—to explain their early caregiving experiences, often before the topic was formally introduced.

Some parents (e.g., Carol, Cassandra, Gwen, Felicia, Jessica, Laura) explicitly connected prior experience to how they made meaning of early caregiving experiences, while biographical

influence emerged indirectly in others' accounts (e.g., Cassandra, Diana, Jean, Zoey). For example, Felicia described explicitly drawing on her training as a police officer to interpret what she was seeing in the weeks following her daughter's premature birth: "So I had noticed that she had... nystagmus... I'm a police officer, and that's the only reason I recognized it... because I'm trained with that for DWIs." Similarly, Zoey, who later shared her background in microbiology, explained her understanding of the diagnostic processes that followed her son's birth: "And as they do, you know, they start Occam's Razor, the most obvious thing is what they're gonna look at... And so, they started to do a workup. And under these circumstances, the workup starts with infection control."

Not all parents named biographical influence so clearly nor was it limited to professional or parenting experience. For example, Raven described "mom's intuition" as informing her concern that "something's off," when "he was 24 hours old." Several parents attributed awareness to intuition, what Gengler (2020) referred to as "embodied feelings" (p. 181), using terms like "mom gut" (Kara) "gut feeling" (e.g., Kara, Carol, Jean, Susan), "maternal instinct" (Diana), and "trusting one's gut" (Susan). Though they refer to intuition using several monickers, each participant's description of their associated experiences (i.e., what they noticed and why it concerned them) points to accumulated learning, aligning with Jarvis's (2009) position that "'intuitions' are learned, and they reflect our analysis of the situation that we are in" (p. 168). Raven recalled comparing her son's appearance with that of the film character "who wore... the astronaut helmet" (i.e., from the movie, *Wonder*). She went on to describe prior parenting experience with her older son who was "really delayed" and "developed on his own time." Similarly, Nathasha described noticing her son's "kitten-like meowing cry" prior to receiving any diagnostic information. While she initially "thought all preemies sounded like that," she

would later learn that it was a sign of her son's congenital condition. Her immediate association as a first-time mom points to remembered biographical learning (Jarvis, 2009), drawn from experience completely outside of caregiving. This type of knowledge, which is deeply personal and often difficult to describe, is thought to be gained through incidental learning over time (Huisman et al., 2025; Jarvis, 2025).

The previous accounts illustrate distinct biographical lenses, individuality that becomes most apparent when examining similar situations side-by-side. Both Carol and Jessica reported a history of pregnancy loss and infertility. Both parents mentioned pursuing alternative options for expanding their families, with Carol turning to adoption and Jessica to foster care. Both parents described becoming pregnant and receiving their son's initial diagnosis during a prenatal ultrasound. Despite these similarities, the meaning they made of them varied significantly. Carol connected her prior experiences to persistent concerns throughout pregnancy with her oldest child. She explained, "I... worried about losing him the whole time... I'd just come off of two early-term miscarriages, as well as a failed adoption within the prior year, so I know that was contributing to it." Whereas Carol was persistently worried before any clinical indication, Jessica described her initial interpretation of the finding of "excess fluid behind the... fetus's neck" and the need for a follow-up ultrasound as benign, explaining, "...since I hadn't been concerned... my husband didn't go with me or anything. This was our third child... I just thought I was getting another ultrasound."

Parents also described experiences that reflected the limits of their biographies. For example, Donna recalled not initially recognizing the markers of Down syndrome (e.g., facial characteristics, "single palmar crease") following her son's birth, some of which she could identify in retrospect. She recalled her and her partner's response when physicians "called out

the single palmar crease... We were both looking at his hand. We're like, I see two lines, I have no idea what you're seeing." Relatedly, Gwen, Stephanie and Jean described encounters with medical technologies that exposed the boundaries of their biographies. For example, Gwen understood a binary of life support or death because she "really didn't know... that [a ventilator] was a piece of equipment that could come home with you if you had a trach." Doreen, as another example, explicitly referenced this limitation, "I didn't realize the long-term effects of... a brain injury... because I had never been exposed to anything like that."

The data corpus suggests that parents' biographies were inseparable from their experiences with caregiving, underscoring the importance of attending to what each parent knows but also what is not yet knowable. The importance of meeting parents within their own story was evident across accounts, including when Donna described attempts to understand her son's heart condition. Despite explanations from "12 people," including her best friend, the information did not "sink in" until a specific nurse used a plumbing analogy, bridging cardiac anatomy with Donna's existing biography. While particularly salient in clinical encounters, this finding extends across situations where new information needs to be understood, as parents construct their reality based on prior experiences (Jarvis, 2009).

Learning from Experience

While participants described numerous events (e.g., new symptom or diagnosis, acute medical event, hospitalization) as causing disjuncture and leading to questioning (Jarvis, 2009), it was clear across accounts that learning extended beyond documentable occurrences, challenging existing patient education models that focus primarily on information transfer (e.g., Brach, 2024; CDC, 2024). Whereas health care professionals may perceive and even document that caregiver education, and subsequently learning, occurred (e.g., they communicated the diagnosis or

described the dosing and side effects of a new medication), the receipt of this information may actually represent the beginning of a parent’s learning process—during which, they may engage in any combination of the following: “memorizing [the experience], feeling it, thinking about it, or doing something about it” (Jarvis, 2025, p. 86).

Most participants (e.g., Jessica, Kara, Diana, Stephanie) described emotional responses as preceding their rational understanding of acute events and subsequent actions (e.g., information seeking, hypervigilant learning, community building) early in their caregiving journeys. For example, Diana described responding to her son’s bradycardic event by learning everything she could “to prevent [it] from ever happening again.” Diana’s emotional response (i.e., “it felt like it would break me as a person”) followed by cognitive action aligns with Jarvis’s (2009) description of emotion as the key to learning. While coping skills and mental health support have been linked to parents’ ability to provide care (Graaf et al., 2022), a tension exists between positioning emotional intensity as a clinical problem to be addressed and Jarvis’s (2009) position that people learn most from emotionally charged experiences. Data from this study suggests that neither fully accounts for the role of emotion in learning within high-stakes caregiving contexts, aligning with Gengler’s (2020) finding that emotions function as interactional and informational resources for parents making treatment decisions for children with complex medical needs. While parents described emotional learning in varying degrees, their accounts demonstrate that emotion can be a normal (i.e., “it’s okay to be angry, it’s okay to feel disappointed, to be mad,” Stephanie; “there’s no right or wrong way to feel,” Kara), albeit difficult, part of learning in the context of caregiving.

Like Diana’s account, most parents described hypervigilant learning (e.g., noticing “every tiny little trend,” Gwen, “googling everything,” Jane; “reaching for anything,” Raven,

“writing everything down,” Diana) as a condition of their child’s survival. Parents’ accounts revealed a combination of formal (e.g., instruction on sterile technique for administering central line cares, trach training, 24-hour room-in, anticipatory guidance), non-formal (e.g., care conferences, bedside conversations, talking through scenarios), informal or incidental (e.g., protocols, “NEC” and “intestinal rehab,” Diana), and self-directed (“googling everything,”) learning, all of which they processed through their unique biographical lenses.

Parents’ accounts also demonstrate their interpretations of what Jarvis (2009) described as primary experiences (i.e., direct often sensory), such as what they saw (e.g., signs of a stroke she associated with “looking a little like Popeye,” Donna; half of her son’s “body turned red,” Susan), heard (e.g., “he had this funny sound when he was breathing,” Selina; “everything starts dinging, all the things start ringing,” Diana; “hearing parents screaming and crying out for their children,” Jessica), and touched (e.g., “I gave her CPR, so I experienced her not breathing,” Stephanie). Parents also recalled secondary experiences (i.e., mediated), including the receipt of diagnostic, treatment, procedural, and prognostic information needed for immediate decision-making and long-term care provision through multiple channels, sometimes in plain language (e.g., “no butthole,” Carol), through analogies (e.g., “take out his intestines, and it’s just kind of like your appendix,” Diana), and with visuals (e.g., “pictures of his heart,” Donna).

Parents were not always privy to primary and secondary experiences at the same time, a finding that applied to parents understanding of diagnostic information, discharge instructions, and medical technologies. While Carol could immediately unswaddle her son to see firsthand that “his bottom is completely smooth,” for example, secondary information (i.e., “the long list... of things to look for”) became actionable for Donna through a later primary experience (i.e., observing her son was “looking a little like Popeye”). When primary experience of new

information was impossible (e.g., genetic diagnoses, chromosomal variations), parents were dependent on secondary experiences (e.g., test results delivered via MyChart, provider explanations, internet resources). While parents may be able to access this information, their understanding of what it means may be significantly limited (e.g., “it's nothing, and then I thought, oh, that can be fixed, and then I realized, like, oh shit, no, it can't,” Raven), and the goal of health literacy may shift to what it means practically (e.g., what to expect, and what his needs were,” Raven) rather than biologically. These findings suggest limitations in “discharge instructions” (spoken or written) as the primary means for parent education (i.e., banking model of education, Freire, 1970), highlighting an opportunity for longitudinal and individualized learning supports. A unified wraparound infrastructure—like Jarvis’s (2025) suggestion for learning therapists—may better equip families to navigate these complex, interrelated systems.

While parents may lack a frame of references for new experiences, their accounts demonstrate that each arrived at the caregiving role as capable adult learners. Most parents (e.g., Jane, Diana, Jean, Zoey) recalled actively seeking information regarding their child’s condition from electronic and print resources to supplement direct observations and information mediated by providers, aligning with what Lloyd et al. (2014) called “orienting” (p. 211). Like in Lloyd’s study, orienting involved peer-to-peer information sharing. The present study extends the authors’ exploration of how patients with chronic kidney disease and HIV activate the health information landscape to parents’ experiences in the context of caregiving. Notably, the experiential learning and ecological systems lens used in this study centered parents’ learning processes over time while drawing attention to the structure of the broader caregiving ecosystem. This framework helps to account for both the differential experiences of individual learners and the structural differences they encountered.

Aligning with existing scholarship on ventilator training (e.g., Graf, 2008; Tearl, 2007; Truitt et al., 2025), parents described varied experiences with patient education before discharge. Some parents (e.g., Gwen, Kara) recalled feeling confident at discharge and others (e.g., Felicia, Selina) identified gaps in their training. Parents accounts demonstrate what Jarvis (2009) differentiated as *knowledge how* (e.g., articulating “if there's any difficulty, always look at her first, always look at her, go from her to the trach, to the tubing, to the vent,” Gwen) and *being able to* (e.g., “after three and a half weeks of being with her and caring for her with her trach 24-7... there really wasn't much more to know,” Gwen). Here, Gwen’s account suggests that she was nearing the “taken for grantedness” or “flow” phase Jarvis (2009) posited to be the starting point and anticipated end point of a learning process. In this case, Gwen and her husband were able to be present “24-7” which was not possible for all participants (e.g., Felicia). Parents’ descriptions across this context suggest a combination of memorization, imitation, adaptation, and experimentation (Jarvis, 2009). Like it did for other parents (e.g., Donna, Kara, Diana), taking on independent responsibility for their child’s care generated another disjuncture, although, as Jarvis (2009) discussed, for some parents, the gap may not have been nearly as wide (e.g., It was “absolutely terrifying... joyful... but it also kind of helped... instill that confidence in our abilities to take care of him,” Kara). For several parents (e.g., Gwen, Carol) the change in context created another, related disjuncture (“everything was very disjointed... the pediatrician was separate from the pulmonologist was separate from the DME company... there was no cohesion, there was no communication... it was really all on me,” Gwen), exposing new gaps between expectations and new experiences.

Consistent with Zhang et al.’s (2025) findings with Chinese parents, this study suggests that a significant amount of learning takes place outside of the caregiver-provider relationship.

Parents used terms such as “experiential” (Zoey), “trial and error” (Carol), “trial by fire” (Diana), and “baptized in fire” (Felicia) to describe this type of learning. While these accounts align with what Jarvis (2009) described as trial and error learning, a tension exists between the idea of “discovering how to behave” (p. 149) and the potential consequences (e.g., “if I fail... my baby could die,” Diana). Parents referenced using ChatGPT to interpret lab results and identify potential medication interactions, respectively. Carol noted: “I mean, there's absolutely no doctors helping us, we're just figuring it out ourselves.” Parents’ accounts suggest that becoming an expert in their child’s care (Ainbinder et al., 1998; Glick et al., 2024) is an ongoing process of experiential learning, one that is more often than not “born out of necessity” (Diana).

An Ecological Systems and Experiential Learning Lens

Examining parents’ accounts through an ecological systems (Bronfenbrenner, 1977; 1994) and experiential learning lens (Jarvis, 2009) demonstrates that health literacy is a dynamic, contextual, and social process (Office of Disease Prevention and Health Promotion, n.d.; Tschamper et al., 2023). This study extends existing health literacy (e.g., Nutbeam, 2008) and adult learning literature (e.g., Jarvis, 2009) and challenges health care professionals and adult learning scholars to expand our thinking about health literacy development and adult learning in high-stakes contexts. Whereas recent decades have seen efforts to transform health systems to more readily align with population health literacy (Altin et al., 2014); minimal scholarship has explored the learning processes within these interrelated systems.

The data from this study reveals that parents are active participants across their complex, often unstable web of systems (e.g., “so much ambiguity,” Gwen) extending both Bronfenbrenner’s (1977) and Jarvis’s (2009) model beyond gradual change and transitions. Parents of children with significant disabilities cannot escape the patterned changes the authors’

posited as occurring in their environment and themselves, but they must simultaneously respond to the unpredictability of their day-to-day lives. For many parents, the persistent potential for acute crisis, rather than the return of “flow,” Jarvis (2011) posited, has been constitutive of transformation (e.g., “I’m strong as fuck,... and I’m able to... slow things down and just enjoy, like, literally just enjoy everything about life now,” Raven; “it’s not just him, like, it’s now kind of evolved into, this is important to me, and how do I make that, you know, more, broad than just my kid,” Donna); however, that does not negate the challenges (e.g., “the dream was never to be a stay-at-home mom for me... I have to stay home,” Felicia; “getting to a place of not only focusing on what a good life means and looks like but also... navigating through what it means to have a good death,” Selina; “as hard as this is... I’m really thankful that I’m her mom... even amidst all of the... trauma and... horror of that time, it also was very clear to me, like... I’m her mom, and like... that’s a good thing,” Gwen). Notably, two parents’ journeys included adoption of a child with a history of medical complexity or significant disabilities since their initial caregiving experience.

Implications

The multi-theoretical framework applied to this study reveals significant implications for health care professionals and adult educators alike. Through the lens of Bronfenbrenner’s (1994) ecological systems model, the data corpus reveals the complex web of systems in which parents must engage. These findings challenge organizations to curate learning environments as well as individualized and group-based learning opportunities that intentionally cut across systems (e.g., health care, education). Examining the data through an experiential learning lens (Jarvis, 2011) demonstrates that parents are capable adult learners, each bringing rich biographies to the caregiving role. As AI transforms health care, organizations may benefit from preparing

professionals to recognize and leverage parent experience as a learning resource (Jarvis, 2025) and to scaffold learning to support the development of critical evaluation skills parents need for navigating complex systems. Examining the data through a combined lens of ecological systems and experiential learning challenges decision-makers across the care continuum to expand their focus beyond individual behavior and knowledge transmission toward the development of health care organizations as places of mutual learning.

Future research should explore the potential of adult learning-informed approaches that leverage the experiential nature of learning in this context as well as peer-to-peer support and emerging artificial intelligence (AI) tools to support families across the caregiving trajectory. For example, parents described varying levels of perceived preparedness for delivering technology-dependent care following discharge. Data from this study suggest that a gap may exist between the outcomes of competency-based training (e.g., checklists, teach-back methods, rooming-in) and how learning in the context of caregiving occurs. Rather than treating discharge training and instructions as an endpoint, health care organizations might reframe it as part of parents' ongoing learning journey, with follow-up support planned at regular intervals.

Parents' accounts demonstrated that learning in the context of caregiving is continuous, and it does not always occur during regular office hours. Further, parents described when and where to seek subsequent medical care as often being a carefully calculated decision, one that included evaluation of perceived risks (e.g., being seen as noncompliant, cost of treatment). Reconceptualizing discharge training and instructions and expanding post-discharge support to ensure families can access the information they need when they need it may reduce cognitive load and stress. Future research should involve the development and assessment of curated, regularly updated just-in-time electronic resources—including clinician-approved AI tools that

can respond to parents' non-emergency inquiries in real time. At the same time, systems should explore opportunities for fostering mutual learning between parents and clinicians and supporting connections among caregiving families.

The findings from this study highlight the importance of extending this line of research, as the data suggest that health literacy, even at advanced levels, may be insufficient for navigating existing structures. Federal, state, and institutional policy barriers must be addressed to better support families of children with significant disabilities—work that should be co-created with individuals with lived experience, whose expertise uniquely positions them to inform policy change.

Limitations

Limitations represent constraints beyond the researcher's control (Terrell, 2022). Parents who participated in this study came from diverse backgrounds with experience supporting children with different conditions and unique needs; thus, experiences may have been heavily influenced by specific institutions or systems, potentially limiting the transferability of the findings. Eighteen mothers responded to recruitment efforts and were interviewed for this qualitative study. The absence of paternal accounts is a limitation of these findings, one that should be addressed in future research. Additionally, this qualitative study relied on participants' conscious memories of their experiences navigating complex, interrelated systems in the context of caregiving, which research suggests may be stressful for parents (Holmes et al., 2024). Some parents acknowledged the impact of this stress in the clarity of their memories (e.g., "coping mechanisms is making history a little blurry sometimes," Susan), particularly those with older children. Because caregiving expertise develops over time, parents drew on current knowledge to describe past experiences, which may have also influenced how those experiences were

represented. Future research designed to follow families longitudinally would offer rich insight into parents' learning processes.

Recommendations for Future Research

The present study challenges health literacy and adult learning researchers to further examine learning in high-stakes contexts such as health care. Ethnographic research should be conducted to better understand the hospital as a learning environment—both from the perspective of parents and health care professionals. Future research should also be conducted to explore how fathers make meaning from engaging with these interrelated systems. Future research should also explore the potential of adult learning-informed approaches that leverage experiential learning, peer-to-peer support, and emerging artificial intelligence (AI) tools to support families across the caregiving trajectory. Specifically, research is needed to develop and evaluate AI tools for parents' non-emergency inquiries, including those that cross systems (e.g., health care, education). The data from this study also suggests a need to better understand the relationship between emotion, hypervigilance, and learning in high-stakes context, supplementing existing scholarship on coping skills and mental health supports.

Conclusion

The purpose of this study was to explore how parents of children with significant disabilities perceive learning from encounters within complex systems in the context of caregiving. Specifically, it explored how parents of children with significant disabilities make meaning from engaging with these interrelated systems, asking: How do parents of children with significant disabilities describe learning from their experiences in the context of caregiving? This study was grounded in a multi-theoretical framework, layering Bronfenbrenner's (1977) ecological systems model and Jarvis' (2009) experiential learning theory to examine parents'

interactions with systems (the “what”) and the internal processes of learning from those caregiving experiences (the “how”).

Applying an ecological systems and experiential learning framework to explore how parents of children with significant disabilities learn in the context of caregiving challenges health care professionals and adult learning scholars to expand our thinking about health literacy development and adult learning in high-stakes contexts. Specifically, they become tools for meeting parents within their developing story and supporting them with reconstructing a future narrative. “The sooner that we learn the job of caregiving, the sooner that we get to be a person, in addition to being a caregiver” (Jean).

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Appendix A - Advertisement

Figure A.1 illustrates the digital advertisement shared with my professional network and online social networks.

Appendix Figure A.1. Digital Advertisement

Parents of children with disabilities
or complex medical conditions:

SHARE YOUR STORY.

Seeking parents of children with
disabilities or complex medical
conditions to share your
experiences related to
caregiving. Stipends available.

To learn more, please email
mmfiala@ksu.edu.
To see if you qualify for
participation, visit
<http://tinyurl.com/4vzs6y>.

**KANSAS STATE
UNIVERSITY**

IRB# TBD



Note: The image included in the advertisement is owned by me.

Appendix B - Screening Questions

The following questions will be used to screen potential participants:

1. Are you the parent or legal guardian of a child, age 18 or younger, with a health condition or disability? If yes, move to question 2. If no, the potential participant does not qualify for this study.
2. Has your child's health condition or disability lasted for 12 months or longer or is it expected to last for 12 months or longer? If yes, move to question 3. If no, the potential participant does not qualify for this study.
3. Does your child's health condition or disability limit their ability to do things their peers can do? If yes, skip to question 5. If no, move to question 4.
4. Are your child's daily activities substantially affected by their health condition or disability? If no, the potential participant does not qualify for this study.
5. Do you provide regular, unpaid care and support for this child related to their health condition or disability? If yes, move to question 5. If no, the potential participant does not qualify for this study.
6. Were you a health care professional (e.g., nurse, doctor, speech-language pathologist) prior to your child's diagnosis? If yes, the potential participant does not qualify for this study. If no, conduct the informed consent procedure (Appendix E -).

Appendix C - Consent Form

PROJECT TITLE:

What can parents of children with significant disabilities teach us about developing health literacy?

**PROJECT
APPROVAL DATE:****PROJECT
EXPIRATION
DATE:****LENGTH OF
STUDY:**

6
months

**PRINCIPAL
INVESTIGATOR:**

Dr. Susan Yelich Biniecki

CO-INVESTIGATOR(S):

Maryjan Fiala, M.S.

**CONTACT DETAILS FOR
PROBLEMS/QUESTIONS:**

Maryjan Fiala
Email: mmfiala@ksu.edu
Phone: (402)326-5604

**IRB CHAIR CONTACT
INFORMATION:**

Lisa Rubin, IRB Chair
(785) 532-3224
comply@ksu.edu

Brad Woods, Associate Vice President for Research,
Compliance
(785) 532-3224
comply@ksu.edu

PROJECT SPONSOR:

Institute of Humane Studies

PURPOSE OF THE RESEARCH:

Parents of children with significant disabilities often take on responsibilities beyond what is typically associated with parenting. These responsibilities may require and lead to advanced levels of health literacy (i.e., the ability to access, understand, and use health-related information to make decisions). This research study will explore parents' learning experiences in the context of caregiving.

PROCEDURES OR METHODS TO BE USED:

1. I have volunteered for participation in this Zoom *or* in-person interview based on my lived experience as a parent or legal guardian of a child with significant disabilities.

2. I acknowledge that I must provide electronic or verbal consent to the interviewer prior to data collection.
3. I acknowledge that I will be asked to complete an information checklist and two semi-structured interviews. Data for the information checklist will be collected via Microsoft Forms. Interviews will be recorded and transcribed using Zoom web conferencing software.
4. I consent to audio and video *or* audio only recording.
5. During the initial interview, open-ended questions will encourage me to describe my experiences as a caregiver for a child with significant disabilities. Probing questions will be used to encourage me to provide additional detail.
6. After the initial interview, data will be transcribed, cleaned up to remove identifiable information, and analyzed for qualitative and descriptive research purposes.
7. During the second interview, open-ended questions will encourage me to describe my experiences prior to my child's birth or diagnosis. Probing questions will be used to encourage me to provide additional detail.
8. After the second interview, data will be transcribed, cleaned up to remove identifiable information, and analyzed for qualitative and descriptive research purposes.
9. I may be contacted to review the study results as part of a member check.
10. Research results may be submitted for publication, presentation, and/or contribute to the development of future research studies. Recordings and transcripts that are collected as part of this study may be used for further research relating to the learning experiences of parent caregivers.
11. All electronic communication and file storage, including video recordings and transcriptions, will be managed confidentially using Kansas State University's encrypted and password-protected information technology systems. These files will be deleted permanently after 7 years.
12. I am free to withdraw from the study at any time.

RISKS OR DISCOMFORTS ANTICIPATED:

Participating in the study comes with risks associated with examination of my personal or sensitive information in a recorded interview. Because the interviews will be recorded, there is a potential for loss of confidentiality. There may also be risk of an emotional reaction when recalling my lived experience.

BENEFITS ANTICIPATED:

Participants are eligible for a stipend upon completion of each phase of the research study. Participants will be eligible for a \$20 electronic gift card after completion of the initial interview. Participants will be eligible for a \$20 electronic gift card after completion of the second interview. Participants will be eligible for a \$10 electronic gift card after completion of the data validation process. There are no other immediate benefits available or any of the research participants. The information gathered may contribute to the advancement of knowledge on the core experiences of parents learning in the context of caregiving.

EXTENT OF CONFIDENTIALITY:

My interview will be electronically recorded and transcribed. Recordings and transcripts will be stored in Kansas State, password protected cloud storage sites (OneDrive, SharePoint, etc.). Access will be restricted to research personnel and regularly monitored. Recordings and transcripts will be permanently deleted after 7 years.

The information or biospecimens that will be collected as part of this research could be used for future research studies or distributed to other investigators for future research studies without additional informed consent.

Terms of participation: I understand this project is research, and that my participation is voluntary. I also understand that if I decide to participate in this study, I may withdraw my consent at any time, and stop participating at any time without explanation, penalty, or loss of benefits, or academic standing to which I may otherwise be entitled.

I verify that my signature below indicates that I have read and understand this consent form and willingly agree to participate in this study under the terms described, and that my signature acknowledges that I have received a signed and dated copy of this consent form.

(Remember that it is a requirement for the P.I. to maintain a signed and dated copy of the same consent form signed and kept by the participant).

PARTICIPANT NAME:

**PARTICIPANT
SIGNATURE:**

DATE:

--

Appendix D - Screening and Consent Form (Microsoft Forms)

* Required

Screening

Thank you for your interest in my study.

- This study seeks to understand parents' learning experiences related to caring for a child with significant disabilities.
- The following questions will ask you about your relationship with a child with significant disabilities. Your responses will be used to determine your eligibility for participation in the study.
- If you have questions or prefer to be screened over the phone, please contact Maryjan Fiala at mmfiala@ksu.edu.

1. Are you the parent or legal guardian of a child, age 18 or younger, with a health condition or disability? *

☐ Yes

☐ No

2. Has your child's health condition or disability lasted for 12 months or longer or is it expected to last for 12 months or longer? *

☐ Yes

☐ No

3. Does your child's health condition or disability limit their ability to do things their peers can do? *

☐ Yes

☐ No

4. Are your child's daily activities substantially affected by their health condition or disability?

☐ Yes

☐ No

5. Do you provide regular, unpaid care and support for this child related to their health condition or disability? *

☐ Yes

☐ No

6. Were you a health care professional (e.g., nurse, doctor, speech-language pathologist) prior to your child's diagnosis? *

☐ Yes

☐ No

Thank you for your interest in my study.

Based on your responses, you are not eligible for participation in this study. If you believe you have received this message in error, please contact Maryjan Fiala at mmfiala@ksu.edu. Thank you for your time.

Informed Consent

Thank you for your interest in my study. Based on your responses, you are eligible for participation in this study. In this section, I will collect your name and contact information and introduce the study protocol. You will be asked to give consent for participation.

7. Full Name *

Enter your answer

8. Preferred Contact Method *

☐ Phone

☐ Email

9. Phone Number *

Enter your answer

10. Email Address (must be provided for delivery of electronic gift card) *

Enter your answer

11. Have you reviewed the informed consent form?

- The informed consent form can be downloaded from the following web address: [URL]*

☐ I acknowledge that I have reviewed the informed consent form.

☐ I have not reviewed the informed consent form.

12. Do you have questions about the informed consent form?

- The informed consent form can be downloaded from the following web address: [URL]*

- ☐ I acknowledge that I understand the informed consent form and my rights as a research participant.
- ☐ I have questions about the informed consent form.

...

13. Do you consent to participate in this study?

- The informed consent form can be downloaded from the following web address: [URL]*

- ☐ Yes, I consent to participate in this study.
- ☐ No, I do not consent to participate in this study.

14. Electronic Signature (full name) *

Enter your answer

15. Today's Date *

Thank you for completing the screening and consent form. Upon review of your responses, I will send you a link to begin Phase 1 of the study. During this phase, you will complete an information checklist (i.e., basic demographic information) and the initial interview. Please contact Maryjan Fiala at mmfiala@ksu.edu with questions.

This content is neither created nor endorsed by Microsoft. The data you submit will be sent to the form owner.

 Microsoft Forms

Appendix E - Information Checklist

Thank you for your interest in the “What can parents teach us about health literacy?” study. Please complete the following information checklist to help me prepare for our discussion.

Name

Email Address

Relationship to Child with Medical Complexity or Significant Disabilities

How are you related to this child?

- ☐ Biological or Adoptive Parent
- ☐ Stepparent
- ☐ Grandparent
- ☐ Foster Parent
- ☐ Other:

Age Range

What is your *current* age?

- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-64
- ☐ 65+

What is your child's *current* age?

How old were you *at the time of your child's diagnosis*?

- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-64
- ☐ 65+

How old was your child at the time of their diagnosis (at birth or before birth, enter 0)?

Nationality

Where were *you* born?

- ☐ In the United States
- ☐ Outside of the United States

Where was your *child* born?

- ☐ In the United States
- ☐ Outside of the United States

Education

Which of the following best describes your *current* educational attainment (highest degree completed)?

- ☐ Less than a high school diploma
- ☐ A High School Diploma or GED
- ☐ Some College Credit, but No Degree
- ☐ Associate degree (AS, AA, AAS, ADN)
- ☐ Bachelor's Degree (BA, BS)

- ☐ Master's Degree (MS, MA, MSN, MSW, MBA)
☐ Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)

Which of the following best describes your educational attainment *at the time of your child's diagnosis* (highest degree completed)?

- ☐ Less than a high school diploma
☐ A High School Diploma or GED
☐ Some College Credit, but No Degree
☐ Associate degree (AS, AA, AAS, ADN)
☐ Bachelor's Degree (BA, BS)
☐ Master's Degree (MS, MA, MSN, MSW, MBA)
☐ Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)

Family Status

What is your *current* marital status?

- ☐ Married
☐ Not married, but living with a partner
☐ Single
☐ Divorced
☐ Separated

How many children do you *currently* have?

- ☐ 1
☐ 2
☐ 3
☐ 4+

What was your marital status *at the time of your child's diagnosis*?

- ☐ Married
☐ Not married, but living with a partner
☐ Single
☐ Divorced
☐ Separated

How many children did you have *at the time of your child's diagnosis*?

- ☐ 1
☐ 2
☐ 3
☐ 4+

Military Experience

Have you *ever* served in the U.S. Armed Forces, Reserves, or the National Guard?

- ☐ Yes
☐ No

Employment

Which of the following best describes your *current* employment status?

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Working WITHOUT pay
- ☐ Not employed but looking for work
- ☐ Not employed and not looking for work

Which of the following best describes your employment status *at the time of your child's diagnosis*?

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Working WITHOUT pay
- ☐ Not employed but looking for work
- ☐ Not employed and not looking for work

Social Supports

Do you or anyone in your household *currently* receive any of the following social supports?

Please check all that apply.

- ☐ Health care programs (i.e., Medicaid, Medicare)
- ☐ Income support (i.e., TANF, SSI)
- ☐ Home and Community-Based Services (i.e., waiver services)
- ☐ Housing support (i.e., Section 8, public housing, energy assistance)
- ☐ Food and nutrition support (i.e., SNAP, WIC, National School Lunch Program)
- ☐ Other:

Did you or anyone in your household receive any of the following social supports *prior to your child's diagnosis*? Please check all that apply.

- ☐ Health care programs (i.e., Medicaid, Medicare)
- ☐ Income support (i.e., TANF, SSI)
- ☐ Home and Community-Based Services (i.e., waiver services)
- ☐ Housing support (i.e., Section 8, public housing, energy assistance)
- ☐ Food and nutrition support (i.e., SNAP, WIC, National School Lunch Program)
- ☐ Other:

Timeline

Please provide a chronological timeline of notable events in your life. You can 1) handwrite a timeline, 2) create a digital timeline, or 3) record a 3–4-minute video timeline.

I am interested in learning more about your experiences with your child and those prior to their birth/diagnoses. The following questions are included for your consideration as you document your experiences.

- What personal health care experiences have you had before or after your child's diagnosis (e.g., surgery, hospital stay, diagnosis of chronic illness, birth of children)?
- When was your child born, and when did you receive your child's diagnosis?
- What health experiences has your child had (e.g., surgery, hospital stay, discharge, new providers, therapies, etc.)?
- Please feel free to document other experiences.

Appendix F - Interview Guide (Initial Interview)

The following list includes the proposed interview questions for the initial interview and potential prompts. Questions may be adjusted based on the participant's timeline.

1. In as much detail as possible, tell me about [when your child was born OR when you received your child's diagnosis].
 - What are the first things you remember being told?
 - What were you thinking about?
 - What were you feeling?
 - Tell me about the support you received in understanding your child's diagnosis.
 - How did you process the news of your child's diagnosis?
2. Think about the skills and knowledge you use most frequently caring for your child. Describe how you learned these things.
 - What kinds of information or skills related to your child's condition have you sought out?
 - What routines have you developed in supporting your child? How did these routines come about?
 - Tell me about the things that you just know about your child's condition. How did you come to that understanding?
 - How does this knowledge support you in making health-related decisions for your child.
3. In as much detail as possible, describe how you learned to be the caregiver you are today.
 - How has your understanding of your child's needs changed over time?

- What does being your child’s caregiver mean to you? What, if anything, have you learned about yourself?
 - How do you approach new recommendations from health care professionals?
 - What advice might you offer a parent beginning a similar journey?
4. In as much detail as possible, describe the services your child receives and how you went about identifying and securing these services for your child.
- What do these services mean to your family?
 - What have you learned about support systems for children with disabilities?
 - When you a new need arises, how do you know what to do?

Appendix G - Interview Guide (Second Interview)

The following list includes the proposed interview questions for the second interview and potential prompts. Questions may be adjusted based on the participant's timeline and their initial interview.

1. In as much detail as possible tell me about your life before receiving your child's diagnosis.
 - Tell me about any memorable experiences you or your family had with the health care system.
 - What, if any, messages did you grow up with related to chronic illness or disability. How have people close to you spoken about these topics?
 - What were your thoughts about chronic illness/disability before your child's diagnosis?
2. Thinking back on your life before your child's diagnosis, what, if anything, do you think most prepared you for the caregiving role?
 - Prompts will be based on digital timeline.
3. Follow-up questions from Initial Interview