Connections: Social media and parents raising children with profound multiple disabilities

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CONNECTIONS: SOCIAL MEDIA AND PARENTS RAISING CHILDREN WITH PROFOUND MULTIPLE DISABILITIES

By

Amy Ann Terra

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CONNECTIONS: SOCIAL MEDIA AND PARENTS RAISING CHILDREN WITH PROFOUND MULTIPLE DISABILITIES

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DEDICATION

Throughout my professional teaching career, I have been drawn to working with people who have profound multiple disabilities. Serving them and their families has been the focus of my 20+ years working in education. These students have been amazing teachers and coaches to me both professionally and personally. I have received far more from them than I have provided in our interactions.

This study was an effort to give back to this amazing population of individuals and their families. They are my favorite people, and I am honored to have heard the voices of these families. It is my genuine hope that this study allows others to truly see them. This study provides a view of their families’ lived experiences and allows them to be heard and supported in a manner larger than I could provide in one-to-one interactions. By documenting these families’ experiences, it is my hope that all those who serve and support them can do so with a greater understanding of the joys and challenges they experience in their lives.
ACKNOWLEDGMENTS

As a single working mom, this dissertation would not have been possible without the love and support of my family. My beloved son, who was 9 when this process started, supported me with a maturity beyond his years. To answer his ongoing question over the last three years: Yes, buddy, mommy is done, and we can go play now. To my parents who took care of my son so many evenings, allowing me to attend classes and complete projects, your undying love and support has been appreciated since I arrived on this earth and will be appreciated until I leave. I am so grateful to be your daughter.

To my committee chair, Dr. Thomas Nelson, who was on my initial doctoral application interview committee, taught many of my doctoral courses, and guided me through the dissertation process, I am truly indebted to you for your patience in facilitating my growth and progress on this journey. I am changed professionally and personally for the better. I could not have chosen a more amazing mentor for this process.

University of Pacific provides several resources for graduate students, two of which have been essential in my dissertation journey. The first is our graduate writing center, led by truly gifted writers and teachers, Molly Rentscher and Melanie Hash. Both Molly and Melanie have supported my writing development and displayed unending patience in providing feedback and gentle writing instruction. They have made me brave in my writing, and for that, I am grateful.

The second essential university resource has been the library and staff members. From midnight online chat sessions with librarians to interlibrary loans and conversations with resourceful librarians, the library’s assistance has been essential to the development of this manuscript.
CONNECTIONS: SOCIAL MEDIA AND PARENTS RAISING CHILDREN WITH PROFOUND MULTIPLE DISABILITIES

Abstract

By Amy Ann Terra

University of the Pacific
2020

Parenting plays an important role in many adult lives. Parenting a child with profound multiple disabilities results in a distinct parenting experience. This qualitative phenomenological study examined the role of social media in the lives of parents raising children with profound multiple disabilities. Five parents raising children with profound multiple disabilities were interviewed, and resulting themes were identified.

Consistent with previous research, parents described the initial adaptation to their child’s disability-related needs as the most challenging period of their parenting to date. Adaptation was followed by an acclimation to a new normal of their parenting experience. Parents described moving from medical crises, feelings of isolation, and unfamiliarity with resource systems to becoming empowered through interactions with other parents raising children with profound multiple disabilities, both in-person and through social media. Parents focused on three areas with their social media efforts: their own social needs, their child’s social needs, and their child’s disability-related needs. To address disability-related needs, parents used a social media bricolage approach to create a composite of social media group memberships that reflected their child’s complex medical, disability and intervention profiles.

Parents described social media use as daily and essential to their functioning both personally and within their parenting. However, parents prioritized in-person social connections
and utilized social media to make and maintain relationships both online and in-person. Parents expressed awareness and deliberate use of privacy settings in using social media. Parents described common pitfalls to social media use and described engaging in disability awareness through social media.

Parents described social media as providing a sense of community through which they became empowered in their parenting. They also networked through in-person and virtual social interactions. Social media provided these parents with a networked community empowerment experience as they parented their child with profound multiple disabilities.
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CHAPTER 1: INTRODUCTION

This study is about connections in the twenty-first century. It sought to examine the role of digital social connections among the lives of a traditionally socially disconnected population—parents raising children with profound multiple disabilities (PMD). Individuals with PMD experience multiple disabilities that impact them globally and profoundly. Because of the intensity of the disabilities they experience, individuals with PMD require constant caretaking, have difficulty communicating, and live with significant motor limitations and complex medical conditions. Profound multiple disability occurs in less than 1% of the population (Profound Multiple Learning Disability [PMLD] Network, 2018) making it an uncommon experience.

As a result, parenting a child with PMD is also an uncommon experience. Parents raising a child with PMD often serve as their primary caretaker and this caretaking role has been shown to have a significant impact upon the parent’s life and well-being (Bellamy et al., 2010; PMLD Network, 2018). The intensity of the child’s care requirements can limit the parent’s ability to work outside of the home as well as have access to social supports in-person. The intensity of care their child requires limits social availability. Children with PMD often require numerous medical appointments and have health issues that are unpredictable. The lack of consistent social contact can result in feelings of isolation and depression (Ambikile & Outwater, 2012; Resch et al., 2010).

Therefore, when the demands of parenting a child with PMD result in social isolation, digital modes of connection may provide the benefits of social interaction through virtual mediums. Research has shown that social media can provide the social support of a community (Parks, 2010). Social media has become embedded within American society with 65% of
American adults using social network sites (Perrin, 2015). Within society as a whole, social media serves as a method of connection for many individuals. It has been shown that mothers seek to share their parenting joys and difficulties online and that this sharing aides in reducing feelings of social isolation (McDaniel et al., 2012). Likewise, social media has the potential to provide social connection for parents raising a child with PMD thus potentially alleviating feelings of social isolation.

**Background**

**Social Media**

As technology has become integrated into American society, digital connections have become a constant option for many through cellular phones and availability of the internet in public and private spaces. It is now common to walk into a room and see people staring into the screen of their cell phones in lieu of talking to the people who are physically present. Personal interactions are replaced by digital connections; people hold their phones in front of themselves at live events with the phone acting as an intermediary to their direct personal experience. While technology can infringe upon direct social interactions between individuals, it can also serve as a conduit for connections across geographical distances (Moorhead et al., 2013). As a result of the dichotomous impact of social media, researchers have looked at the benefits and drawbacks of living in such a digitally connected time (Anderson et al., 2012; Sheldon et al., 2011). Studies have documented the increased opportunities for connectedness as well as the potential disconnection from in-person interaction (Caron & Light, 2015; Dawson, 2015). The increased potential for connectedness across geographical limitations can provide the benefits of community through a virtual format (Blanchard & Markus, 2004; Koh et al., 2003). This study
explored the role of social media in the lives of parents raising children with PMD, focusing on virtual community membership and the potential for personal empowerment.

**Parenting**

Parenting plays a central role in many adult lives. Upon awareness of the existence of a pregnancy, the parent begins imagining what their child will do, who they will be and what parenting will bring to their life. When a child is identified as having a disability, the parents of this child have to process the change of parenting expectation (Green, 2002). The child of the parent’s imagining is abruptly replaced with uncertainty regarding what having a disability will mean for their child and themselves. When the child is diagnosed as having PMD, there are few, if any other children who can serve as a visual example, forcing parents to often operate within an unknown parenting experience.

**Parenting and social media.** Parents raising children who have not been identified as having a disability interact with social media both as a parent and as an individual outside of their parenting experience (Dawson, 2015). Parents raising children with disabilities interact with social media similarly to parents raising children without disabilities although there are some additional uses. These additional uses are related to their redefined parenting experience and their child’s disability-related needs (Blackburn & Read, 2005).

**Society and Disability**

Issues related to disability and parenting a child with a disability involve multiple factors. There are factors that arise from the impact of the disability itself. The diversion from a typical developmental trajectory for the child, the redefined level of the child’s functional skills and the need for assistance and care can represent parenting factors on an individual family level. There are also changes in the parent and child’s access within society. The changes in the parenting
experience for a parent of a child with PMD include social and physical barriers that are due in part to how American society views disability and individuals with disabilities.

Individuals with disabilities have historically been treated as defective. Interventions typically focus on cures and attempts to restore the individual to normalcy. Under this medical model, society seeks to fix the damaged individual, basing their value upon being an able-bodied, contributing and typical member of society (Schlesinger, 2014). This establishes a non-acceptance of the differences that individuals have and places a judgment of diminished value upon parenting a child with a disability. Parenting efforts on behalf of the child with PMD are viewed as less valuable due to the anticipated limited contribution capacity and therefore contributions of the child in adulthood. This view of disability is referred to as the medical model of disability. The medical model of disability focuses all aspects of the disability experience upon the individual with the disability. Societal implications contributing to the experience of the individual with disabilities and their families are not addressed within the medical model of disability.

Since the disability rights movement that followed the civil rights movement in the United States in the 1960s, the medical model view of disability has been slowly impugned by a social model of disability. The social model of disability places the challenges the individual experiences upon the physical and attitudinal constructs of society (Chappell, 2005). More recent disability models recognize the combination of the effect of the disability upon the person as well as the impact of society’s physical barriers and social biases against the disabled (Reid-Cunningham, 2009).

No subgroup of individuals with disabilities has felt the impact from society’s social discrimination and physical access barriers more than individuals with PMD. This low incidence
segment of individuals has historically been perceived as less than human and incapable of understanding or participating in their own lives (Charlton, 1998; Mietola et al., 2017).

Individuals with PMD experience a combination of physical and cognitive factors that limit independence, communication and functioning. Individuals with PMD are dependent upon others for basic self-care and are often unable to communicate basic wants and needs (PMLD Network, 2018). A lack of communication skills and limited physical abilities prevent direct measurement of cognitive functioning using traditional psychological instruments. Typical ability assessments for this population include adaptive scales and measures completed by adult caretakers as individuals with PMD are not considered testable based upon current cognitive functioning tests and measures. This places individuals with PMD in the lowest 3% of the school population for cognitive abilities (Bellamy et al., 2010).

Individuals with PMD have been on the receiving end of controversial medical interventions including, but not limited to, forced sterilization (Seay & Olsen, 2016) and medical procedures to prevent growth and development (Kittay, 2011). However, medical practitioners are not the only professionals to struggle with appropriately serving individuals with PMD.

Public schools are likewise unsure how to best educate children with PMD as they function outside of the standard curriculum and typical educational approaches (Izen & Brown, 1991; Zambone et al., 2010). In 1989, the Rochester School District sought to relieve themselves of the responsibility associated with educating students with PMD. In the first circuit opinion in the *Timothy W. v. Rochester* case, the New Hampshire School District found that “Timothy’s handicaps may be the most severe of any student whose case has reached the courts under EHA-B” (Champagne, 1990, p. 589). Timothy W. was a student with PMD. The court finding concluded that Timothy was not “capable of benefitting” from educational services and
was therefore not included in the protections of the Education for All Handicapped Children Law because his disabilities were too severe. While this finding was reversed in later decisions in the court of appeals, it continues to serve as an example of the assumptions and disregard shown to individuals with PMD, even in our relatively recent social history (Champagne, 1990).

Because of the impacts of their disabilities, individuals with PMD rely upon the advocacy of others to secure and maintain their civil, medical and educational rights. The families of individuals with PMD are often the fiercest advocates for individuals with PMD. Families of individuals with PMD are also often their caregivers. The rewards and demands of parenting a child with PMD comprise an uncommon experience. Families often function in relative geographic isolation from others living a similar parenting experience (Resch et al., 2010).

Parents raising children with PMD often report feelings of isolation, difficulty accessing public spaces and self-report spending significant amounts of time in medical and care procedures on a daily basis (Bellamy et al., 2010; PMLD Network, 2018).

**Problem Statement**

The problem this study addressed is that individuals with PMD and their families are often invisible within society and disconnected from social interactions and supports (Agmon et al., 2016). Their personal challenges are unfamiliar to a majority of people. Parents of children with disabilities often report their own lack of familiarity with disabilities prior to the birth or diagnosis of their own child (Broberg, 2011; Green, 2007). The factors impacting family life when a family member has PMD are outside of a typical parenting experience. Parenting a child with PMD involves combinations of medical interventions, behavioral support approaches, physical access limitations and a multitude of daily care factors not present within typical family dynamics (Green, 2007). These care dynamics do not dissipate over time as care requirements
do in a majority of parenting experiences. Rather, daily care requirements increase in intensity as the child grows with physical access becoming increasingly limited, and formal and informal social support diminishing as the child ages (Hanson & Hanline, 1990).

The particular challenges of raising a child with PMD appear to result in increased social and physical isolation and decreased social support for the parent. A community experience with others who are on a similar parenting journey has the potential to provide social connections to parents raising children with PMD; however, there is the potential that this community membership can provide more than just the social support benefits of community. Social connections can impact decision making processes, ability to function within daily demands and overall perceived quality of life. Individuals that identify as a member of a social community can become empowered to effect positive change including an increased sense of control, identification of desired course of action and development of skills needed to progress in the direction of personal goals.

**Purpose Statement**

The purpose of this study was to explore, document, and understand the role that social media plays in the lives of parents raising children with PMD.

**Research Questions**

The following questions guided this study:

- What are the roles of social media in the lives of parents raising children with PMD?
  - In what ways do parents raising children with PMD engage with social media?
  - In what ways do parents raising children with PMD experience community by engaging with social media?
  - How do parents raising children with PMD describe social media’s influence on their parenting skills?
Significance of the Study

Individuals with PMD exist upon the fringes of society (Blatt & Kaplan, 1966). Individuals with disabilities are defined by society primarily based upon their perceived deficits. This can result in what Longmore and Umansky (2001) describe as “embodying what Americans fear most: loss of independence, of autonomy, of control” (p. 7). Societal response is based upon fear of such an existence and “that which we fear, we shun” (p. 7). As a result, individuals with PMD live lives of invisibility (Carey, 2009).

Families who have members with PMD are also impacted by the aforementioned societal underpinnings and experience. They are devalued by association with their family member with PMD (Green, 2007). The impact of societal judgment has multiple effects upon the family. One effect is the disability itself upon the child with PMD and the associated care needs that impact family functioning. Another impact is society’s treatment of their child, and the devaluing of their child’s life and their parenting (Green, 2007). Parents raising a child with PMD have social support needs, yet the caregiving demands result in a decrease of social connections, personal resources, and accessibility to support over time. Consequently, parents of children with PMD often experience physical and emotional isolation. This limits access to social connections to share their voices and seek support and information about their parenting experience. Social media serves as a potential and available mode of social connection for parents raising children with PMD.

Within our current society, social media has enabled people to experience a level of communication and connection outside of physical presence and real time. Instead of having to physically be in someone’s presence to interact or be in communication at the same time through a telephone call, people can share information and convey messages through internet-based
social media. This access can occur through a cellular phone or computer anywhere internet service is available at any hour of the day. Because of social media accessibility, parents raising children with PMD can access online resources easily.

This study explored the role of social media in the lives of caregivers who are parenting children with PMD. Supporting parents raising children with PMD requires an understanding of the realities of the lived experience of parenting a child with PMD as fully as possible (Redmond & Richardson, 2003). Through exploring this phenomenon of social connection, this study adds to the scholarly research focusing on the needs of this traditionally underserved and understudied population. It does so with a focus to the digitalization of our society by examining the platform of social media. Understanding the role that social media plays in the lives of parents raising children with PMD will provide information regarding parent needs and decision-making processes, identify avenues of available social support that may serve other parents, as well as identify modes to provide potential resources and information in an accessible and timely fashion.

The findings of this study can be used to improve special education practice and procedures as well as special needs resources to support parents raising children with PMD. The findings of this study can be utilized in the development and provision of support resources targeted to this low incidence population across distance and time without being impacted by personal social resource limitations. Policy makers, service providers and special education administration would benefit from access to information about specific family needs when serving children with PMD. Parents themselves, may benefit from understanding that while their parenting journey is outside of what one anticipates as a typical parenting experience, there are other parents who are also on a similar journey. This understanding can provide some sense of
commonality of experience that has the potential to provide a sense of normalcy within an atypical parenting experience.

**Theoretical Framework**

This study sought to examine the ways in which online social connections provide the components of a community for participants. Based upon the theory of sense of community developed in 1976 and published in 1986 by McMillan and Chavis, this theory “sought to explain the dynamics of the sense-of-community force” (McMillan & Chavis, 1986, p. 6). The identified components of sense of community are membership, influence, fulfillment of needs and a shared emotional connection. These are all elements that social media users can experience through digital medium. However, this study examined if the impact social media provides is more than just the benefits of membership in a community. This study explored whether parents raising children with PMD educate and empower each other in their parenting journeys through digital connections. Therefore, the additional lens of the empowerment theory was utilized to focus on the impact of the community membership upon education, awareness and action on behalf of their child and other children with PMD. The combination of these two theories allowed the examination of the role of social media as a virtual community as parents seek to deal with the joys and challenges of raising a child with PMD.

The components of sense of community theory identify the ways in which community members can provide support and a feeling of belonging as well as act as a hub of resources. Community can be both “felt and practiced” (Elliot et al., 2012, p. 3). Membership in a community can increase a person's sense of wellbeing and provide for flow of information (Rovai, 2002). Initially applied to geographically defined neighborhoods, sense of community theory is now applied to both geographical and relational components of community (Elliot et
al., 2012; McMillan & Chavis, 1986). Modern technological innovations have allowed people to connect virtually on a more available level than prior through access to the internet and social media on portable technology devices. Online communities are accessible to anyone with a compatible device and internet access. The benefits of community as described by sense of community theory provides a basis for online connections but does not necessarily empower individuals into action on their own behalf.

Acting on one’s own behalf is representative of empowerment theory. Empowerment theory addresses multilevel conceptions. These include the actions of individuals and groups to work cooperatively in arming participants with knowledge and skill to improve their personal and group lives. The actions of individuals impact not only their lives but also reflect interactions within their social and political environment (Speer et al., 2001). Empowerment theory has been vetted by Rappaport (1981), Sadan (1997) and Zimmerman (2000). Most recently Moran et al. (2017) defined empowerment theory as “a process of giving power or control over one’s own life to an individual or group that has traditionally been marginalized or had control of their own life limited or surrendered” (p. 20). Empowerment is a transformational process in which the power of the individual is increased in order for them to act to improve their life circumstances (Carr, 2003). Empowerment is not a deficit focused approach, nor does it rely upon professional guidance (Moran et al., 2017). Rather, the participants are assumed to be competent individuals who have a need for resources and opportunities to develop skills that they will then apply in their own lives. While often sparked by what Carr (2003) described as a “mobilizing episode” (p. 12), empowerment supports personal development and access to resources, building the skills needed to solve one’s own problems in the present and, as circumstances change, in the future (Carr, 2003; Moran et al., 2017). The implications of
Empowerment theory have been explored in contexts including religious fellowship, mutual help organizations for the severely mentally ill, education programs for urban African Americans grass-roots community and agricultural cooperatives in Nicaragua (Perkins & Zimmerman, 1995).

Looking at social media through the framework of sense of community theory with a focus on empowerment theory provides a lens through which one can examine the impact of factors present in support systems that are available through social media and the impact of social media interactions upon personal power. Incorporating sense of community theory with empowerment theory online includes the benefits of community described by Speer et al. (2001): “mutual respect, reflection, caring and participation” with the goal of empowering members who are disenfranchised to gain greater access to resources and increased control over their life in an online format (p. 716). In this online setting, increased community participation leads to increased personal empowerment. Increased personal empowerment has a positive impact upon health and wellness (Cadell et al., 2009).

**Definitions**

*Bricolage* is the process through which someone creates the needed resources by assembling a novel composite from what is available (Duncan, 2011).

*Cluster of meanings* are statements from the data that are collected based upon representation of the identified phenomena. Then repetitive and overlapping statements are delineated. The remaining statements are clustered together into similar meaning units. (Eddles-Hirsch, 2015)

*Coding* is an aspect of data analysis through which the researcher looks through the data, groups it based upon similar ideas and labels it in an effort to make sense of the data. Coding helps identify patterns and connections in an effort to organize and acclimate to the data. (Saldana, 2015)

*Context* is the physical, psychological, social and temporal factors at the time of the study (Heigman & Croker, 2009).
Data is the information collected from the participants in response to the research question (Heigman & Croker, 2009).

Data analysis is the process through which the data that has been collected is examined, organized and prepared for interpretation (Heigman & Croker, 2009).

Data Collection is the process of systematically collecting data (Heigman & Croker, 2009).

Disability is defined by the World Health Organization (2011) as “a part of the human condition” and “complex, dynamic, multidimensional, and contested” (p. 3).

Empowerment addresses multilevel conceptions that include the actions of individuals and groups to work cooperatively to arm participants with knowledge and skill to improve their personal and group lives through interactions with their social and political environment (Speer et al., 2001).

Epoche is the researcher purposefully setting aside any preconceived knowledge or everyday beliefs he or she believes might be used to explain the phenomena being investigated. This allows the researcher to listen and record the participant’s description of an experience in an open and naïve manner. (Eddles-Hirsch, 2015)

Horizontalization is part of the phenomenological reduction process, whereby the researcher gives equal value to all of the participants’ statements. The researcher will remove all repetitive statements as well as those that do not relate to the research questions. (Eddles-Hirsch, 2015)

Interview Guide is a list of topics and questions that are drafted prior to the interview. It helps the researcher prepare for the interview and ensure that areas related to the research questions are considered. (Heigman & Croker, 2009)

Low Incidence Disability is a disability that occurs much less frequently than high-incidence disabilities in a population. Low incidence disabilities are usually more visible than high-incidence disabilities and are often associated with misperceptions that are inaccurate. Teachers tend to have less experience with individuals who have low incidence disabilities. (Zambone et al., 2010)

Natural Setting is the regular environment of the respondent. It can include home, work, and online environments (Heigman & Croker, 2009).

Phenomenon describes something that can be seen or experienced by human senses (Heigman & Croker, 2009).

Positionality refers to the idea that researchers can place themselves either within proximity or far from the respondent’s way of seeing the world (Heigman & Croker, 2009).
Privacy and confidentiality refer to the rights of respondents to have their privacy protected through assurances that their identities and the data collected will be held in confidence (Heigman & Croker, 2009).

Profound Multiple Disabilities refers to severe or profound intellectual disabilities experienced in combination with other complex disabilities and health conditions (Bellamy et al., 2010).

Qualitative research is a study in which the researcher tries to understand the respondent’s experience in a natural setting, using a research approach. The researcher collects words or images. Data collected is analyzed reflexively for common themes to allow for interpretations of the respondents’ experience. (Heigman & Croker, 2009)

Reflexive is to think critically about one’s role in the research process and the process itself (Heigman & Croker, 2009).

Research methodology is the theory of how an inquiry should occur (Heigman & Croker, 2009).

Research question is the question that shapes and directs the research study (Heigman & Croker, 2009).

Respondent is a person participating in the research study (Heigman & Croker, 2009).

Semi-structured interview is an interview based upon an interview guide which provides enough structure to cover essential topics of the study while allowing the interview to develop and topics be explored as they arise (Heigman & Croker, 2009).

Sense of Community is a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members’ needs will be met through their commitment to be together (McMillan, 1996).

Social Media is a particular consumption of digital media or internet that facilitates the user to connect, communicate and interact with other users through instant messaging or social networking sites (Correa, Hinsley, & Zuniga, 2010).

Social Resources are the wealth, status, power and social ties of a person (Lin, Ensel, & Vaughn, 1981).

Transcribe is to convert verbatim the verbal recording to written form (Heigman & Croker, 2009).

Chapter Summary

This chapter shared an overview of the study, providing background information as well as an outline of the study’s purpose, theoretical lens and significance of the study. This study
examined the role of social media in the lives of parents raising children with PMD. This population of parents experiences uncommon dynamics in their parenting lives as a result of their child’s intensive caregiving needs and society’s response to their child’s disabilities. Social factors and caretaking demands often result in social isolation, a lack of available social resources and decreased camaraderie within their parenting experience. This study sought to examine social media as a source of social connection for them personally and as parents raising a child with PMD. Social media is an example of a potential source of sense of community and empowerment in the lives of parents raising children with PMD.

Examining the social media format through the lens of sense of community allowed the researcher to identify whether or not the social media interactions contained the components of community. By incorporating the additional lens of empowerment theory, this study sought to explore whether the membership in the virtual community led to personal and parenting empowerment.

This study is significant because parents raising children with PMD are invisible within society. Parents raising a child with PMD experience limited physical and social access based upon the requirements of care for their child with PMD. Traditionally, parents raising children with PMD have had difficulty accessing resources and information based upon the rarity of their child’s disability and intensity of needs.

**Remainder of the Study**

The remainder of this study is organized with Chapter 2 providing a review of relevant published literature. Chapter 3 delineates the methodology and methods of the study. Chapter 4 discusses the findings of the study. Chapter 5 discusses and explores the implications of the findings of the study. The references are then listed followed by the appendix, which contains
the demographic survey, informed consent form and the Institutional Review Board documentation.
CHAPTER 2: LITERATURE REVIEW

People have various reasons for wanting to become parents (Langdridge et al., 2000; Langdridge et al., 2005) including seeking a sense of fulfilment, pleasing their partner, creating a family unit, biological drive, and feeling that they are capable of providing a good home (Langdridge et al., 2005), as well as the desire to reciprocate love and the ability to enjoy children (Langdridge et al., 2000). The transition to parenthood is a significant life experience. As with any significant life experience, becoming a parent is a major stressor in people’s lives (Kalmuss et al., 1992). Sources of stress continue from pregnancy into the parenting experience.

New parents address the stressors associated with becoming a parent in different ways. One-way new parents respond to stress is through seeking social support. Social media is one avenue of accessing social support that new parents utilize. People interact with social media in a variety of manners in response to entering parenthood (Coyne et al., 2017). The increased demands from parenting decrease their social availability so they use social media to maintain social connections (Baker et al., 2017; Bartholomew et al., 2012). Parents share their parenting experience with family and friends online (Coyne et al., 2017). New parents also seek advice and information through social media before and after the birth of their child (Baker et al., 2017).

Prior to the birth of the child, the parents generally anticipate the arrival of their child with positive expectations (Harwood et al., 2007). However, when a child is identified as having a disability, the expecting parents have to process this change of parenting expectation within the realities of their life (Green, 2007). While parents raising children with disabilities interact with social media much in the same way parents raising children without disabilities interact with social media, there are some additional uses related to their redefined parenting experience.
Parents of children with disabilities seek information about their child’s disability specific to their child’s health or behavioral challenges, as well as to connect with other individuals who are on a similar parenting trajectory (Blackburn & Read, 2005).

The initial diagnosis of their child’s disability is often identified as the most stressful time in the parenting journey (Green, 2007). This may be in part because of the perceptions associated with disability in American society. According to the Americans with Disabilities Act, 2008, "disability" means, “with respect to an individual a physical or mental impairment that substantially limits one or more major life activities of such individual” (Section 3).

According to Hoffman (2011), Congress had found in 1990 that “forty-three million Americans have one or more physical or mental disabilities" (p. 919) and estimates continue to rise as Switzer and Vaughn (2003) estimated 50 million individuals with disabilities in the United States.

Individuals with disabilities have historically been treated as defective by society. Society has focused on cures and attempts to restore the individual to normalcy to alleviate the anxiety caused by interactions with a person who has a disability (Hahn, 1988; Reid-Cunningham, 2009; Switzer & Vaughn, 2003). This medical model focuses all aspects of the disability upon the individual with the disability (Schlesinger, 2014). By focusing the responsibility of the disability upon the individual, society is then relieved of any need to adjust societal practices and attitudes towards individuals with disabilities. This model ignores the role of physical and attitudinal societal barriers that impinge upon the rights of the individual with disabilities as a participating member of society.

This medical model of disability has been impugned by a social model of disability as a result of disability rights activism that began in the 1960s. The social model of disability places
the challenges experienced by the individual with disabilities upon the physical and attitudinal constraints propagated by society (Oliver, 1990; Rieser & Mason, 1990). Most recent disability models recognize the combination of the effect of the disability upon the person as well as the impact of society’s physical and social biases against the disabled (Reid-Cunningham, 2009). Within this combined view, what society labels as disability is described as variability within the human experience. The impacts of this variability upon the individual are one aspect of the lived experience. An additional aspect of this lived experience is the response from society through social and physical barriers limiting access, participation and membership (Green, 2007).

No subgroup of individuals with disabilities has felt the impact from society’s presuppositions more than individuals with profound multiple disabilities (PMD) (PMLD Network, 2018). Individuals with PMD experience a combination of disabilities in which the impact is global and lifelong. Individuals with PMD require constant care and often have accompanying medical and communication needs (PMLD Network, 2018). The lives of individuals with PMD are marked by inability to communicate, limitations of physical control and, oftentimes, complex medical issues.

Society treats individuals with PMD as less than human and incapable of understanding or participating in their own lives. Often denied the rights and protections of full citizens, individuals with PMD are treated as less than fully participating members of society (Charlton, 1998; Mietola et al., 2017) even though our laws reinforce the right of individuals with disabilities to “fully participate in all aspects of society” (Hoffman, 2011, p. 923). Individuals with PMD have been on the receiving end of controversial medical interventions (Kittay, 2011). Until recently, public schools often denied the responsibility to include students with PMD under the protective umbrella of equal education access laws. The court decision in the 1989 case of
*Timothy W. v. Rochester* represents the formal inclusion of students with PMD under the umbrella of the Education for All Handicapped Children Act of 1975 by establishing a zero-reject application regardless of disability intensity (Champagne, 1990). It is important to note that public schools continue to struggle with how to best educate students with PMD (Izen & Brown, 1991).

Care of individuals with PMD is often provided by their family members. Family members of individuals with PMD are often the fiercest advocates for children with PMD (Watermeyer & McKenzie, 2014). Raising a child with PMD is a parenting experience with distinct characteristics when compared to raising a child who follows a typical developmental trajectory. The child’s development milestones remain under that displayed by a typical 3-year-old and often follows a non-traditional pathway. Parenting a child with PMD often incorporates high demand care involving medical interventions, behavioral challenges and limited communication skills for the child with PMD. The parenting of a child with PMD is uncommon as children with PMD are estimated to comprise less than 1% of the population (PMLD Network, 2018).

Because PMD occurs with such low prevalence, the rewards and demands of raising a child with PMD comprise a low incidence experience not shared by many parents. The odds of families living in proximity to each other is unlikely and this means that families raising a child with PMD often function in relative geographical isolation from each other. This geographical isolation combined with the extreme diversion from a typical parenting experience can impact parental social connectedness. As a result, parents raising children with PMD often report feelings of social isolation, increased incidences of depression and physical ailments (Resch et al., 2010). The challenges of parenting a child with PMD often preclude traditional person-to-
person social interactions (Heiman, 2002). This can be attributed to the intense care needs of the child, the challenges of physical access, societal barriers and the behavioral and sensory needs of the child. Additionally, parents raising children with PMD often feel that few people within geographically available physical social circles understand their life and parenting experience (Davis et al., 2010). This can limit access to social support and connections for parents raising children with PMD.

Parents raising children with PMD may benefit from alternative opportunities for social connectedness. Social media has the capacity to provide a medium for social support and connections beyond immediacy of geography (Anderson et al., 2012; Dawson, 2015). Social media has been shown to provide the potential for online communities in which people are able to find commonalities and exchange resources (Mano, 2014; Whiting & Williams, 2013). As a result, individuals can be empowered to meet life challenges (Barak et al., 2008; Mano, 2014). This study sought to explore the role of social media in the lives of parents raising children with PMD through McMillan and Chavis’ (1986) sense of community theory with the focus on Zimmerman’s (2000) empowerment theory within the virtual context. The study sought to explore whether interactions through social media meet the social support needs of parents raising children with PMD. Do parents raising children with PMD experience the elements of community when interacting on social media? Do their interactions online empower them in their lives as individuals and as parents raising a child with PMD?

Through the lens of sense of community theory, the factors that comprise community and their influence upon its members are examined in relation to social media and parenting a child with PMD. Social media has the potential to provide the benefits of community membership to its users (Mamonov et al., 2016). Membership, influence, fulfillment of needs and a shared
emotional connection are all elements that social media users can experience through a digital medium (Koh et al., 2003). The connections to this community have the potential to impact parents in their sense of self power. Therefore, the additional focus of the empowerment theory examined the impact of the sense of community in the parents’ lives by exploring the changes in their personal power and parenting as a result of the community connections. Does the online community membership empower the parents in their lives raising a child with PMD? Do parents gain control over their life, gain knowledge and confidence through the online interactions and effect action and advocacy (Moran et al., 2017; Speer et al., 2001) as a result of the virtual community membership? Social media can be a resource for gaining information, exploring resources, and receiving support while developing advocacy skills, and this can have a positive impact upon adjustment and coping for its users who are seeking support in their uncommon parenting journey.

**Research Questions**

The following questions guided this study:

- What are the roles of social media in the lives of parents raising children with PMD?
  - In what ways do parents raising children with PMD engage with social media?
  - In what ways do parents raising children with PMD experience community by engaging with social media?
  - How do parents raising children with PMD describe social media’s influence on their parenting skills?

**Disability in America**

Disability has been defined in a variety of ways over time based upon cultural and societal factors (Reid-Cunningham, 2009). The World Health Organization (2011) describes disability as “a part of the human condition” and “complex, dynamic, multidimensional, and
contested” (p. 3). Disability can be thought of as a “decreased functioning associated with disease, disorder, injury or other health conditions” (Leonardi et al., 2006, p. 1220). Disability is additionally defined by the duality of the limitation of the impact of the condition the person experiences in addition to the societal stigma and construction of isolation and inaccessibility within the lived experience (Hahn, 1988). Disability can be sensory (visual, hearing, neurological impairment), physical (cerebral palsy, spina bifida, amputation, paralysis), a temporary or long-term illness, visible or invisible, encompass mental health, cognition or a myriad of other states of human existence. It is likely that every person is going to experience disability at some time in their life (World Health Organization, 2011). Congress found in 1990 that “forty-three million Americans have one or more physical or mental disabilities” (Hoffman, 2011, p. 919). According to the U.S. Census Bureau (2012), about 56.7 million people, 19% of the population, had a disability in 2010.

The term “disability” is clearly pejorative. The status of individuals with disabilities within American society is described as marginalized at best (Charlton, 1998). Historically, society has adopted a binary conception of disability: there are the disabled (them-us) and the able-bodied (us-them) (Devlin & Pothier, 2006). As a result, the able-bodied assume a role of benevolent caretaker. Because of this assumption of roles, society has established a relationship of dependence through welfare and perceived charity in lieu of true access and civil rights (Charlton, 1998). Devlin and Pothier (2006) described the status of the disabled in society as being denied formal and substantive citizenship. Rather, individuals with disabilities are assigned to the status of dis-citizens, a form of citizenship minus, a disabling citizenship.

The modern era of disability has relied heavily upon the use of the medical model. Disabilities are diagnosed, treated as abnormalities with potential cures and interventions
are applied to remove the defect. Welfare is provided to ease the impact of disabilities (Reid-Cunningham, 2009). Schlesinger (2014) described that under this model, incapacity and the resulting barriers to "normal" societal participation are considered exclusively the products of the disabled individual's impairments without any meaningful influence from external forces. Within the postmodern era, the medical model has begun to be slowly overtaken by the social model of disability. The medical model faced significant deconstruction in response to disability rights efforts post the civil rights movement in the United States. According to Oliver (1990) and Rieser and Mason (1990), the most significant example of this deconstruction has been in the rejection of a medical model of disability and the establishment of a social model to replace it.

Chappell (2005) described the social model as emphasizing social and economic structures; in particular, the nature of work in a capitalist economy as the root cause of the disadvantage and discrimination encountered by disabled people. Within the social model, individuals with disabilities are not the source of societal conflict, but rather society’s reaction to them and society’s treatment of them creates the societal imbalances. Kudlick (2003) drew comparisons to other disenfranchised groups of society when he wrote that just like women, people of color, Jews, and sexual minorities, many with disabilities have come to equate breaking free of medical definitions as a form of liberation and a way to contest historically contingent ideas of normality.

Historically, disability has been used by society to subjugate groups through metanarratives associating those populations with the disabled. During slavery, African Americans were described as intellectually inferior and incapable of survival without the support of their masters. Prior to suffrage, women were described as too emotionally fragile to participate in politics without adverse psychological impact. Baynton (2001) showed how in the
United States opponents of suffragists, abolitionists, and immigration all used disability to discredit undesirable groups' claims to citizenship.

Consequently, women, African Americans, and immigrants bristled at being associated with disability. Groups experiencing this metanarrative association with the disabled attempted to emerge from oppression by disassociating from the demarcation of “being disabled” while disregarding the impact of this metanarrative upon individuals with disabilities. By associating the label of disability with that of a sub-citizen, having a disability becomes an inferior social status by default. Using this label in a derogatory manner with other disenfranchised groups causes these groups to struggle against the label of being disabled instead of struggling against the larger social factors causing their disenfranchisement (Vaughn et al., 2015). Therefore, minorities, feminists and other groups in society labeled as disabled have systematically stated, “We are not disabled, we are ‘abled.’” The focus of their pursuit of rights becomes disassociating themselves from the disabled other and associating themselves with the oppressive culture resulting in an example of Paulo Freire’s (2000) concept of pseudo-liberation in which the oppressed seek the role of oppressor instead of true liberation for both the oppressed and the oppressor.

This leaves individuals with disabilities disenfranchised as the ultimate example of the necessary other used in comparison to define normal. Individuals with disabilities became the unseen societal group to be pitied and taken care of through handouts and welfare. According to Kudlick (2003), the disabled are different from other groups including racial, ethnic, and sexual minorities in that people with disabilities experience attacks cloaked in pity accompanied by a widely held perception that no one wishes them ill.
This differentiation from the other oppressed groups has resulted in the disabled being perceived as *excused* from active participation in society without their consent. Individuals with disabilities continue to be oppressed within society’s metanarrative defining who they are and what they lack. This metanarrative is accepted and reinforced by other oppressed groups which further reinforces their excluded status within society. Lazarsfield-Jenkins (2014) found that disability as a modern institution is defined through nuances of language and silence so that power constructs are hidden and continue to evolve through social collusion.

This effort to distance oneself from the label of disabled may prove to be a mute exercise for most people as having a disability in some form, whether temporary or long term, is a likely experience for most individuals across the course of their lifetime. There is the reality that disability impacts 19% of the population of the United States (Mont, 2007). Many people will experience temporary effects of disability due to illness or physical decline associated with aging. Within the disabled population, there is a multitude of life experiences based upon the individual disability and its subsequent impact upon the person’s life activities. A segment of this population includes individuals with PMD. This low incidence segment of the population experiences complex combinations of conditions that may include physical, medical, cognitive and communicative challenges (Sontag et al., 1977).

**Profound Multiple Disability**

Within the disability community, there remains massive heterogeneity (World Health Organization, 2011). There are disabilities that are invisible to the public observer. There are also highly visible disabilities. Some disabilities impact specific parts of a person’s life. Some disabilities impact a person’s life globally and intensely. Within the segment of those globally affected, individuals can be identified as having PMD. While definitions of individuals with
PMD vary and these definitions do not represent a diagnostic criterion (Mietola et al., 2017), the definitions do reflect the complexities of PMD as a descriptor that indicates a significant intensity of disability that impacts every aspect of the individual’s life. One definition includes:

Children and adults with profound and multiple learning disabilities have more than one disability, the most significant of which is a profound learning disability. All people who have profound and multiple learning disabilities will have great difficulty communicating. Many people will have additional sensory or physical disabilities, complex health needs or mental health difficulties. The combination of these needs and/or the lack of the right support may also affect behaviour. (PMLD Network, 2018, p. 3)

Intelligence quotients of individuals identified as having PMD are estimated to be below 20 representing less than 3% of the population. Functional skills remain below the 3-year-old developmental level (Bellamy et al., 2010). Definitions of PMD address severe cognitive impairment, communication and social challenges, more than one disability present, sensory and behavioral or medical challenges (Bellamy et al., 2010). For the purposes of this study, individuals with PMD will be identified by the documented presence of an estimated IQ below 20, global developmental profile below 36 months in combination with at least one other health, orthopedic or sensory disability.

The intensity of needs for individuals with PMD necessitates constant care and support (National Health Services Midlands and East, 2018; PMLD Network, 2018). Individuals with PMD are unique, forming a very heterogeneous subgroup (Sontag et al., 1977). “The diagnostic trajectory in these disorders is usually complicated and long-lasting and may be burdensome to the patients and their parents” (van Nimwegen et al., 2016). Because of the intensity of their disabilities, individuals with PMD have difficulty advocating for themselves. Without an audible voice for self-advocacy, individuals with PMD are frequently neglected in society (PMLD Network, 2018).
Estimated rates of incidence suggest that children with PMD are a very low incidence population. Kurth et al. (2016) describe this population as “1% to 2% of students with intellectual disability, who complete an alternate assessment and have support needs across domains” (p. 227). Students with PMD require extensive supports and services within an educational environment. Even with significant investments of educational supports and services, individuals with PMD rarely access or make measurable progress in traditional core curriculum. Hence, the investment of educational resources on behalf of students with PMD is often challenged. One noteworthy example of this is the 1989 court case of Timothy W. v. Rochester. This court case represents a school district legally questioning the fundamental benefit for including children with PMD in public education. The school district testified that Timothy W. was too disabled to benefit from public education. Because of Timothy W.’s lack of educational capacity, the school district argued that they should be excused from the legal responsibility of educating Timothy. Initial rulings agreed with the school district argument. In a reversal of this initial court finding, the appellate court ruled that all children must be included in public education thus formally legally establishing the expectation of educating children with PMD (Champagne, 1990).

While inclusion in legal protections for students with PMD has been established within public education, there remains relatively little evidence in the way of an agreed upon way to educate students with PMD and there lacks developed evidence-based practices or sufficient teacher training targeted at serving students with PMD (Izen & Brown, 1991; Shurr & Hollingshead, 2017). Credentialed teachers trained to serve the needs of learners with disabilities often feel unprepared to address the complexity of needs of learners with PMD (Izen & Brown, 1991). Students with PMD are complex and unique and even the most experienced
teacher will encounter situations that are unfamiliar when working with students who have PMD (Lang & Fox, 2004). In terms of inclusion into school site citizenship, students with PMD have minimal experience in general classrooms and are most often educated in segregated classrooms or separate school sites (de Boer & Munde, 2015).

The challenges experienced within education for students with PMD are also evident within society as a whole. Within modern debates, individuals with PMD are often characterized as less than human and often are described as animalistic or subhuman in nature (Mietola et al., 2017). At other times individuals with PMD are described as forever infantile (Kittay, 2011). Individuals with PMD are often excluded from disability studies and positive impacts of research or activism are unintended byproducts of social change geared for the benefit of other disabled subgroups (Mietola et al., 2017). This results in a lack of research addressing the specific needs of this population (Shurr & Hollingshead, 2017). There has been a long history of disregard, institutionalization and justification of invasive medical procedures performed based upon the assumption that individuals with PMD are incapable of understanding what is happening and therefore controversial decisions can just be made about them by others. It is assumed by society that others know what is best for their quality of life without regard to who the person with PMD is as an individual (Kittay, 2011).

While society treats individuals with PMD as sub-citizens, those who know individuals with PMD recognize their humanity (Kittay, 2011). When one cannot know for certain how much a person understands, how can anyone treat a human being as anything but a full citizen endowed with the rights of humanity? “The uncertainty of us not knowing what they know is a great risk” (Kittay, 2011, p. 625). While our laws and judicial decisions indicate that as a
society, we hold true that every person is endowed with inalienable rights, our societal practices render individuals with PMD as partial holders of the true experience of full citizenship.

**Social Media in American Society**

According to Pew Research Center (2018), three-quarters of Americans own a smartphone. A similar percentage has broadband internet available in their home. Seven-in-ten Americans use social media. Popular social media applications at this time include Facebook, Instagram, Pinterest, LinkedIn, Twitter, YouTube and Snapchat. YouTube and Facebook are the two most popular applications with 70% of American social media users saying they use these applications. Facebook, introduced in 2004, and other social media have moved from a novel entertainment activity to a functional and purposeful activity having desired outcomes for its users (Anderson et al., 2012).

Social media provides a method for its users to seek attention and connect online. It allows friends and families to share life experiences across distances, maintaining and establishing connections with a variety of people in the user’s life (Anderson et al., 2012; Dawson, 2015). Social media networks are valued for their ease of access, their user friendliness, and the fact that many are free (Anderson et al., 2012; Russell et al., 2016).

A user’s activity on online social networks are indicative of that individual’s sense of self. The creation of one’s own identity or profile provides a sense of control over the self that is presented online (Pitts, 2004). People have indicated that the control over one’s own identity can result in a liberating feeling during online interactions (Anderson et al., 2012). Through this online persona, people engage with social media to ease feelings of disconnection and, in doing so, they gain a sense of connection (Sheldon et al., 2011). Sheldon et al. (2011) go on to suggest that online activity can serve as a distraction from real world challenges potentially providing a
method of coping. Individuals are allowed to participate in either an active or passive manner depending upon their own interests and needs. Passive participation, described as “lurking,” entails information gathering without contributing actions or information (Anderson et al., 2012, p. 25). Social media provides avenues of interaction outside of traditional face-to-face social settings. In developing the social media usage construct, Hu and Zhang (2016) identified and validated four dimensions to social media usage including relationship developing, information sharing, self-presenting and entertaining. These dimensions correlate to the components of the theory of sense of community used within this study as a theoretical framework.

**Theoretical Framework**

This study utilizes sense of community theory in combination with empowerment theory as a framework to explore the role of social media in the lives of parents raising children with PMD. The theory of sense of community was developed in 1976 and published in 1986 (McMillan, 1996). This theory “sought to explain the dynamics of the sense-of-community force.” (McMillan & Chavis, 1986, p. 6). Sense of community can provide support, a feeling of belonging and can act as a hub of resources. Community can be both “felt and practiced” (Elliot et al., 2012, p. 3). Membership in a community can increase a person's sense of well-being and provide for flow of information (Rovai, 2002). Initially applied to geographically defined neighborhoods, the theory is now applied to both geographically and relational components of community (Elliot et al., 2012; McMillian & Chavis, 1986).

Empowerment theory addresses multilevel conceptions that include the actions of individuals and groups to work cooperatively to arm participants with knowledge and skill to improve their personal and group lives through interactions with their social and political environment (Speer et al., 2001). Empowerment theory primarily focuses on disenfranchised
groups within society (Barack et al., 2008; Bayes, 2015). Based upon a common experience, these groups seek to empower their members in order to improve their personal resources and confidence (Speer et al., 2001). In turn, these members can affect positive change in their life where they previously felt overwhelmed or powerless (Moran et al., 2017).

The theoretical lens of this study combines the sense of community theory with empowerment theory in order to view the role of social media in the lives of parents raising children with PMD. It examines online space as a virtual community in which parents raising children with PMD may experience the components of sense of community and, through this community membership, may become personally empowered as parents of a child with a low incidence disability living a highly demanding parenting experience.

**Components of Sense of Community**

McMillan and Chavis (1986) initially identified four components of sense of community. These included membership, influence, fulfillment of needs and a shared emotional connection. McMillan (1996) later described these components as “spirit, trust, trade and art” (p. 315). In his examination of online learning communities, Rovai (2002) labelled similar concepts of community as spirit, trust, interaction and commonality of goals (p. 2). In 2008, Peterson et al. identified a similar cadre of components of the community experience as including “needs fulfillment, group membership, influence and emotional connection” (p. 62). Sense of community parameters included in this study are membership, influence, fulfillment of needs and shared emotional connection thus incorporating the more recent contributions to the original theory.

Membership is the first component of sense of community to be examined. Membership comprises “boundaries, emotional safety, a sense of belonging and identification, personal
investment, and a common symbol system” (McMillan & Chavis, 1986, p. 11). McMillan and Chavis (1986) describe membership parameters as evidence of the boundaries of the community. While Westheimer and Kahne (1993) struggle with the exclusionary nature of community membership because of the creation of a them vs. us dyad, this distinction creates a sense of belonging for members. This sense of belonging allows participants to personally invest in the community. At times, the investment may include sharing of personal information. This requires that the community act as a safe space for members to participate. This safe space permits participants to engage in personal disclosure which is key to the development of connections between members and the maintenance and strengthening of the community connections (Rovai, 2002). This level of intimacy within interactions supports the discovery of similarities and allows for bonding between community members (Cummings et al., 2002; McMillan, 1996).

Community members must feel safe to be honest, feel accepted, and receive empathy and support from the community (McMillan, 1996). Individuals who are members of disfranchised groups often do not feel this safety within larger diverse groups of people. As a result, disenfranchised populations form communities by grouping together on social media. Examples of such communities include migrants, cancer patients, political organizations and unions (Dekker & Engbersen, 2014; Liu & Lu, 2018; Panagiotopoulos & Barnett, 2015; Sugawara et al., 2012).

Community can reflect a group of social outcasts who understand each other based upon a common experience. This community of outcasts can be powerfully bonded within disenfranchised populations. McMillan (1996) describes this connection as the ability to perceive “ourselves mirrored in others” (p. 315). Connecting to someone with a similar life
experience when there was a previous sense of isolation results in pride of association. This sense of pride as a member of a community can be a fundamental benefit of community membership (Rovai, 2002). For individuals with disabilities and their families, this sense of pride of membership can serve as a significant departure from the typical negative societal response to disability.

The second aspect of sense of community is influence. Influence reflects the capacity of the system to be both acted upon by and act upon its participants. This results in a back and forth flow between participant and group. For community members, the concept of consensual validation, the mutual understanding of a common life experience and similar life views contributes to the idea that one’s experiences and perceptions are seen by the other members of the group. McMillan (1996) describes the “search for similarities as an essential dynamic of community development” (p. 320). Community is the “fundamental human phenomenon of collective experience” (Peterson et al., 2008, p. 62).

The third component of sense of community is fulfillment of needs. In the original 1986 presentation regarding the theory of sense of community, fulfillment of needs of community members was described as “reinforcement” (McMillan & Chavis, 1986, p. 12). Fulfillment of needs represents the benefits of being a community member. This positive experience provides the motivation for further investment of personal time and energy into the community. People seek what serves their needs in terms of social connection and interaction (McMillan & Chavis, 1986). Satisfying personal needs for support, information and connection to others are driving forces behind development of communities (Rovai, 2002). The challenge of maintaining communities over time involves maintenance of efforts towards the community and fulfilling the needs of community members (Westheimer & Kahne, 1993).
The time and energy put into community are key to community stability because people do not have unlimited time and energy in their lives. Caretakers of individuals with PMD experience further limitations in available personal resources to put forth in initiating and maintaining social networks. The application of personal resources reflects the values and priorities that people have in combination with the resources they can access to meet their personal and social needs (Elliot et al., 2012). When people experience limited social resources, the investment in community has to have benefits commensurate with or in excess of the perceived personal value of their investment. This necessitates that a community consists of individuals matched in such a way that their individual needs are being met simultaneously. McMillan (1996) later used the term “trade” to describe the commodities that the community has to offer its members. This “continuous bargaining process” seeks to match needs and resources within its community members (p. 320). This requires elements of diversity within the community membership. There must be enough difference to provide a variety of resources while the commonalities are consistent enough to support bonding and group cohesiveness (Graves, 1992). This becomes the basis of a social economy of personal disclosure in a safe environment in which members can experience growth and needs fulfillment.

The final component of sense of community is emotional connection. Shared emotional connection, according to McMillan and Chavis (1986), is based upon a “shared history” (p. 13). This shared history is supplemented by frequency of interaction, quality of interaction, intensity of experiences shared, intimacy, and bond. Shared emotional connection is key for the development of true community. McMillan used the term “art” to describe this concept in 1996. This art is a manifestation of the community and its values. This manifestation can be a tradition
or common practice such as a song, dance or story. It can also be a shared event or moment. The basis of this shared history is a shared experience (McMillan, 1996).

In summary, the theory of sense of community identifies these four components as being present in a community. This sense of community was originally applied to physical and geographical communities but has more recently moved into virtual communities separated by distance but connected by a common life experience (Blanchard & Markus, 2004). Strong communities are those that offer members positive ways to interact, important events to share and ways to resolve issues positively, opportunities to honor members, opportunities to invest in the community, and opportunities to experience a spiritual bond among members (McMillan & Chavis, 1986, p. 14).

**Social Media and Sense of Community**

Virtual communities have been shown to comprise essential elements of sense of community (Căciulan, 2017; Koh et al., 2003; Mamonov et al., 2016; Wang et al., 2017). Modern technological innovations have allowed people to connect virtually on a more available level than previously through access to the internet and social media on portable technology devices (Boyd, 2010). Online communities are accessible to anyone with a compatible device and internet access. Membership in social media communities such as Facebook, Instagram and Twitter require downloading the application, registering and agreeing to the application’s policies.

Once online, the user is able to present their own digital persona. Through this digital persona, the user is able to explore the digital presentation of other individuals and collections of individuals through online groups based upon topic, experience or interest. These interactions allow the user to gain information and keep abreast of events or activities. Donath and Boyd
(2004) describe the need for a common “focus” to serve as the commonality for online connection (p. 77). Once an area of interest is found, online connections snowball as the user is exposed to increasing resources based upon previous online activity.

Online interactions provide the components of Sense of Community including membership, influence, needs fulfillment and shared emotional connection (Parks, 2010). Online membership and friendships are based upon familiarity and commonality and, depending upon user settings, can be exclusive resulting in a “membership” in an online community.

The second component of sense of community, influence, is provided by the software application itself. The application dictates the structure and rules of participation described by McMillan (1996) as key to the influence component of sense of community. The user influences the group and the user is also influenced by the group. Online forums allow for this back and forth interaction between users.

Fulfillment of needs through resource and information acquisition is available online. Online forums serve as hubs of information and resources. While the quality and accuracy of the resource and information is not formally vetted, participants are able to seek specific resources as simply as performing an online search (Moorhead et al., 2013). Participants are able to interact in real time or in delayed time allowing them to seek fulfillment of needs and to fulfill the needs of others.

Online forums also allow for aggregation of participants into groups that have some shared interest or experience. This provides an available forum for a shared emotional connection. These virtual communities can comprise components similar to those found in the theory of sense of community. Similar to the theory of sense of community, Koh et al. (2003) found virtual communities as being tri-dimensional including membership, influence and
immersion. Parks (2010) goes on to describe the components of virtual community to include “collective action, shared rituals, a variety of relational linkages, and emotional bonding” (p. 118) which bears striking resemblance to the components of theory of sense of community. Căciulan (2017) found similar community experiences and topics of interest in virtual communities that transcend geographical location. The benefits of virtual community contribute to its sustainability (Mamonov et al., 2016). If online members feel the components of sense of community, the community members are more likely to continue to participate in the online forum. Sustained interaction online suggests in itself that the user is benefitting from the online experience.

**Empowerment Theory**

Through this sense of community, members can gain knowledge and build confidence in areas of personal challenge. When a group self identifies needs and seeks to meet those needs, they develop support systems that can empower its members (Bayes, 2015). This correlates with empowerment theory. Most recent contributions to empowerment theory include Moran et al. (2017) defining empowerment as “a process of giving power or control over one’s own life to an individual or group that has traditionally been marginalized or had control of their own life limited or surrendered” (p. 20). Empowerment is a transformational process in which the power of the individual is increased in order for them to act to improve their life circumstances (Carr, 2003). Empowerment is not a deficit focused approach, nor does it rely upon professional guidance (Barack et al., 2008; Moran et al., 2017). Rather, the participants are assumed to be competent individuals who have a need for resources and opportunities to develop skills that they will then apply in their own lives. While often sparked by what Carr (2003) described as a mobilizing event, empowerment supports skill development and access to resources building the
skills needed to solve one’s own problems in the present and, as circumstance change, in the future (Carr, 2003; Moran et al., 2017). Empowerment creates social connections for individuals to positively influence their own coping and help others in an interactive community (Perkins & Zimmerman, 1995). However, empowerment does not consist solely of disseminating information and providing support. Given the same resources, some people become empowered and others do not utilize the information to attempt to better their personal circumstances (Bayes, 2015).

Empowerment theory has intrapersonal, interactional and behavioral domains (Moran et al., 2017; Speer et al., 2001). The interpersonal domain encompasses the internal locus of control over one’s own life. The interactional domain consists of how a person thinks about and relates to their environment. This includes their awareness of social and political forces that help or hinder their progress towards personal goals. The behavioral domain includes taking action by collaborating with others who are like-minded (Moran et al., 2017; Speer et al., 2001). With some overlapping components with sense of community, empowerment theory is comprised of a safe participatory environment, membership based upon participation, sharing of power, focus on both the individual and community, as well as a larger focus upon activism within society and a reflective evaluation of the process (Bayes, 2015).

Social Media and Empowerment

Empowerment examined in the realm of social media was described by Li (2016) as an “emerging area” that has been investigated in a very limited manner (p. 56). Active use of social media has been shown to have a positive correlation with feelings of well-being (Verduyn et al., 2017) while online support groups have been shown to have varied effectiveness (Barack et al., 2008).
Social media has changed the manner in which people interact and some suggest it has devalued traditional friendship (Anderson et al., 2012). Pierson (2012) examines the positive potential for empowerment online as well as the potential for issues related to online vulnerability. Social media provides a forum for the exchange of resources and information across distance with the investment of minimal financial cost and social resources (Barack et al., 2008). This makes social media a promising resource for geographically or socially isolated and disenfranchised populations. Individuals are able to access the online community and their resources, receive support in gaining information, and seek guidance specific to their needs thus developing skills in a supportive environment with individuals experiencing similar life phenomenon. By utilizing ongoing feedback, they can address the challenges in their own life without excessive demands on their social resources. Online communities that support empowerment are based upon interpersonal connections and voluntary participation. Participants both give and receive help from each other without the formal involvement of professionals in the field (Barack et al., 2008). Online activity levels have been shown to positively correlate with feelings of personal empowerment (Li, 2015; Verduyn et al., 2017). The online community provides a forum of common experience, reducing the sense of living an anomalous and isolated life (Barack et al., 2008).

Looking at social media through the framework of sense of community with a focus on personal empowerment theory provides a lens through which one can examine the impact of factors present in support systems available online through social media and its impact upon personal power. By incorporating sense of community with empowerment theory, community not only includes “mutual respect, reflection, caring and participation” but is combined with the goal of empowering members who are disenfranchised to gain greater access to resources and
increased control over their life (Speer et al., 2001, p. 716). Within this community setting, increased community participation can lead to increased personal empowerment. Increased personal empowerment has a positive impact upon health and wellness (Cadell et al., 2009). This study examined the social media experiences of parents raising children with PMD through the theoretical lenses of sense of community theory and empowerment theory.

**Parenting**

**Parenting expectations.** The months of anticipation before the arrival of a child are filled with positive expectations (Harwood et al., 2007). Will my son play for a major league baseball team? Will my daughter become the President? Parents often transfer their personal dreams onto their unborn children. This exhibition of “positive illusions” may be essential to healthy psychological functioning, particularly in times of stress and change (Taylor & Brown, 1994, p. 21). While this optimism about their child’s future may be less than realistic, having these hopes and dreams contributes to successful coping and better outcomes for new parents (Taylor & Brown, 1994).

The transition to parenthood is described by Kalmuss et al. (1992) as a “major life event with long-term consequences” (p. 516). When a child is born and meets expected developmental milestones, the dreams of the parents are slowly replaced by the real existence of the child as he or she grows and develops. Dreams of major league ball are replaced with the joys of first steps. Hopes of a presidency are shifted towards the attainment of skills and joys of observing life experiences. Within the typical parenting experience, social connections provide avenues of support and sharing. Parents bond and socially connect over shared experiences and activities. This social connection can take place in-person or through virtual means. One method of facilitating these connections is through social media.
**Parenting and social media.** Parents utilize social media for a variety of reasons. Social media users seek attention and connect across distance to interact with family and friends (Dawson, 2015). Anderson et al. (2012) described numerous motivations for Facebook use including “information, friendship, communication...keeping up to date with old and new friends, organizing, studying, dating” (p. 26). Parents use the internet and social media to maintain connections with established family and friends (Coyne et al., 2015). Because of increased demands in response to the arrival of their child, there is a negative impact on social accessibility and available social resources. Online methods of connection allow new parents to share their parenting experiences across geographical boundaries with reasonable investment on their expended social resources. Social media allows users to receive social support while at home or while doing other tasks (Bartholomew et al., 2012). One post can inform multiple online connections simultaneously. This also allows the parent to maintain awareness of the activities of those family and friends through bidirectional online exchanges (McDaniel et al., 2012). Additional benefits include the potential to anonymously post when addressing sensitive topics. The amount of rich, relevant and timely information available online and access to experience-based information from other parents is described as a valuable resource by parents (Walker et al., 2017).

Entering parenthood, new parents are dealing with the stress of a major life transition. While social support has been shown to increase parental well-being and buffer stress (McDaniel et al., 2011), parenthood reduces access to traditional sources of person-to-person support because of new parenting demands. Increased risk and stress have shown to result in decreased social accessibility (Baker et al., 2017). This social isolation lends itself towards the use of online support as web-based resources are available through cell phones, tablets and home-based
computers at any time and any place that internet is available. The availability, flexibility and timeliness of social media creates a resource for social support that meets the needs of a life in transition and this gains in significance as access to the internet becomes more ubiquitous within society (Baker et al., 2017; Walker et al., 2017). Social support and positive adjustment have been shown to have a positive correlation (Bartholomew et al., 2012).

Parents, especially new parents look to the internet for web-based resources on parenting topics. Mothers have actually shown a preference for web-based information (Baker et al., 2017; Walker et al., 2017). Parents raising developmentally typical children use social media to “build, rekindle or maintain relationships” with whom they experience a “common offline element” (Anderson et al., 2012, p. 29). Social media can provide information as well as emotional support (Anderson et al., 2012; Haslam et al., 2017). The range of topics, immediacy of access and availability of experience-based information are all positive aspects of online information (Haslam et al., 2017). Haslam et al. (2017) postulate that the use of social media is a self-reinforcing dynamic. Participating in social media results in reinforcement which, in turn, drives additional participation on social media. The positive results received from social media support the output of personal resources in future online social media participation.

However, not all social media experiences are positive. Potential issues for parents include privacy concerns for themselves and their children (McDaniel et al., 2011). Parental postings leave a digital footprint for their child resulting in potential impacts upon the child’s future. Concerns regarding the impact of parental postings and their potential to violate a child’s privacy have been voiced (Dawson, 2015). The mere act of engaging in social media has been suggested as an issue. The dedication of personal resources of time, energy and focus towards social media can be seen as an infringement upon the quality and quantity of time that could be
spend with family engagement. “Where it becomes worrisome is when parents are pulling away from family life, lost in their smartphones and their screens, leaving their children feeling neglected and lonely” (Dawson, 2015, p. 116). Social media pressure to keep up with the virtual Jones’s can place undue pressure on parents (Coyne et al., 2015). Additionally, there are few control standards for information presented to parents through the internet (Haslam et al., 2017). This results in potential misinformation with varying negative impacts.

**Violated expectations: When your child is diagnosed with a disability.** When a child with a disability is born, the hopes and dreams of the parents are abruptly displaced as the family begins travelling an uncertain path. The dreams of great achievement for their new child are superseded with the loss of the expectation of normalcy. Green (2007) describes this as the loss of the “child of their imagining” (p. 155). The time immediately following diagnosis has been reported by parents of children with disabilities as the most stressful period of their parenting (Green, 2002). If the child is diagnosed with a disability, the family experience often becomes highly uncommon and unfamiliar to most parents who raise children that meet expected developmental timelines. If the child has PMD including medical conditions, this experience moves further into unfamiliar territory. Doctor appointments fill the days as the search for answers ensues (Green, 2007). Families are often filled with uncertainty. What will my child be able to do? What will our future be? Will my child be able to walk or talk? Will my child ever smile? This challenging situation, being a less positive experience than was anticipated, will result in a more difficult adjustment (Kalmuss et al., 1992).

**Parents raising children with disabilities and social media.** When a parent is raising a child with a disability, the parenting needs expand to encompass the disability and its impact upon the child and the family. Provision of relevant and timely information provided to parents
of children with disabilities has been a historical challenge (Blackburn & Read, 2005). Not having access to relevant resources and information increases disempowerment (Bayes, 2015). Miller (2017) described technology as facilitating connections with people in similar life experiences across distances providing a potential resource for information dissemination.

To date, the use of the internet as a mode of delivery of information from professional to consumer has primarily been through the medical field. Much of this online support addresses specific diagnosis or life characteristic. Examples include the hearing aid community (Choudhury et al., 2017), the use of social media for individuals with ALS (Caron & Light, 2015), the LGBTQ disability population (Miller, 2017), the disabled population (Shpigelman & Gill, 2014) and individuals with breast cancer (Pitts, 2004). The ability to access medical information has the potential to empower parents in a traditionally stratified relationship with medical professionals (Pitts, 2004). However, online information is not mediated for quality or medical accuracy and this may prove problematic and potentially dangerous (Moorhead et al., 2013).

Not all online information originates from professional entities. Online support can be peer-to-peer rendered on an informal basis. An examination of the use of informal peer support on social media resulted in four themes relevant to support and social media targeted to a specific audience. These themes included emotional support, trust and safety, connectedness and informal consultation (Gandy-Guedes et al., 2016). These themes correspond to the sense of community theory attributes of emotional connection, membership, influence and needs fulfillment. Online communities of parents use social media to obtain information, keep in contact with others, pursue entertainment and improve quality of life through online activities.
Parents of children with disabilities report using social media for similar purposes as well as for reasons related to having a child with disabilities (Blackburn & Read, 2005).

As a parent of a child with a disability on social media, online activity can present hazards specific to having a child with a disability. There have been examples of social media being used to subjugate individuals with disabilities. Images of individuals with disabilities are used to generate social media “clicks” and “likes” from other social media users. These images are used without permission and at times in a derogatory manner. The internet can be used as a method to maintain the status quo of an ableist society through the propagation of oppressive social norms (Pitts, 2004). Images of individuals with disabilities are used to maintain the social outlooks that reinforce pity and secondhand citizenship.

Paradoxically, social media contributes to the creation of “super crip.” Super crips are individuals who overcome their disability through hard work and perseverance. This places negative societal impacts of disability square on the shoulders of others who have disabilities but do not rise to the same level to overcome their disabilities. These often unrealistic representations of individuals overcoming illness or disability places the blame for not overcoming disability unfairly on the individual or their family (Pitts, 2004). The characterization of the super crip reinforces negative societal stereotypes regarding disability by presenting successful individuals with disabilities as “in spite of stories” indicating an assumption that individuals with disabilities are not expected to succeed. This places individuals with disabilities as objects of pity. Society no longer permits this brand of stereotyping for race or gender. While it is no longer acceptable to call someone a “credit to their race” or describe a women’s achievements as outstanding “for a woman”, it is permissible to characterize individuals with disabilities in this sensationalized manner. This relieves society of any
responsibility in the circumstances contributing to the societal subjugation of individuals with disabilities (Liddiard, 2014, p. 96).

It is important to recognize that the internet and social media are fundamentally a commercial space designed to make money from its users (Liddiard, 2014). The use of images of individuals with disabilities without their permission to make money is one example of commodification of disability. Liddiard (2014) shared examples of companies using images of individuals with disabilities as marketing tools without the knowledge or consent of the individual or their family. Families posting pictures of children with disabilities also places them at risk for this online abuse. This potential for abuse should be acknowledged in any examination of social media involving individuals with disabilities and their families.

Positive impacts of social media can be seen through the potential connections it can provide. Online forums provide the opportunity to share experiences in an effort to support others going through a similar experience contributing to the process of empowerment of individuals and online communities. When participants band together through social media, this can result in a form of activism (Pitts, 2004).

**Parenting a child with profound multiple disabilities.** Health related quality of life measures have found that when compared to the general population, parents raising children with neurologic disabilities score lower on health and quality of life measures (Nimwegen et al., 2016) with the complexity of the disability correlating to decreased measures of quality of life (Isa et al., 2016). Stressors include gaining information regarding services, navigating the financial impact due to their child’s needs as well as managing the limited ability of caregiver to work, addressing school and community access challenges while accessing needed formal and informal supports (Resch et al., 2010). Children with PMD often experience disrupted sleep
patterns negatively impacting their caregiver’s ability to get consistent rest (Isa et al., 2016). Children with PMD have substantial health and social care needs (Blackburn & Read, 2005) and children with PMD require around-the-clock assistance (Bellamy et al., 2010; PMLD Network, 2018). This can significantly disrupt parental access to social interactions and supports (Heiman, 2002; Resch et al., 2010). Parents raising a child with PMD are at risk for depression, physical health problems of their own and, due to increased levels of stress, higher levels of conflict in their personal lives (Resch et al., 2010). If not appropriately supported, the demands of parenting can outweigh the parents’ perception of their ability and personal resources leaving them in a coping deficit (Resch et al., 2010).

Parents raising children with disabilities experience a variety of emotions depending upon their situation. Parents struggle with the realities of their child’s disability, the unknown that the future holds as well as society’s judgement and prejudice towards individuals with disabilities (Watermeyer & McKenzie, 2014). Parental processing and ongoing coping are very individualized. While Kittay (2011) found that parents overwhelmingly desire that their children live happy and healthy lives, their day to day emotional response varies widely. There is often a projection of judgement towards parents if outsiders deem their emotional response to their child and their life circumstances inappropriate. This externally restricts certain feelings and responses as inappropriate and off limits for parents to express. Parents can feel guilty for negative feelings they may have about their child, their child’s disability or the difficulties associated with raising a child with PMD (Watermeyer & McKenzie, 2014).

Exploring the complex dynamics of this parenting situation is key to ensuring that potential supports are available to address the realities of the parent and the child as they exist and not as we envision or assume they should feel and respond to this dynamic parenting
situation (Resch et al., 2010). Some parents report disturbing thoughts, emotional challenges, struggles with their child’s limited communication, and worries about the future (Ambikile & Outwater, 2012). The availability of social support can impact the coping abilities of the family (Walker et al., 2016). Research has shown that families raising children with PMD report feelings of social isolation (Walker et al., 2016) and this has a negative impact upon personal empowerment (Speer et al., 2001).

However, many parents quickly develop coping strategies (Watermeyer & McKenzie, 2014). Parents have been described as using a variety of coping mechanisms, both constructive and avoidant. These strategies include “disengagement and distraction” as well as “engagement and cognitive reframing” (Isa et al., 2016, p. 75). Parents describe the importance of having someone listen to them (Ambikile & Outwater, 2012). This emotional support correlates with “better cognitive and social functioning” (Isa et al., 2016, p. 75). Parents also report the positive impact of meeting new people through their children (Isa et al., 2016). These specific connections have the potential to provide targeted resources and information relevant to parenting a child with PMD which is of particular importance as access to information has been described as a major challenge for parents (Resch et al., 2010).

Parenting itself brings great joys and challenges that impact parental health and quality of life. When complex disabilities, medical challenges and communication challenges are added to the family dynamic, the intensity of joys and challenges is magnified within the family unit (Green, 2007; Magill-Evans et al., 2011). Parents of children with disabilities express feeling a deep love for their child (Kittay, 2011). In fact, there is often a very strong bond between a parent and their child with PMD (Walker et al., 2016). Factors contributing to parental resilience include a sense of mastery, positive outlook and religion (Heiman, 2002). More than three-
quarters of parents report that their initial negative reactions to their child’s diagnosis turn into “feelings of love, joy and acceptance as well as the satisfaction and strength that accompany success in rearing their special child” (Heiman, 2002, p. 167).

Parents love and care for their child despite society’s message that individuals with PMD lack characteristics of citizenship and human value within society. Given that parenting a child with PMD is a rare experience, parents are asked to foresee the future with an unknown trajectory. Within the PMD parenting experience, parents have to navigate their journey, balancing their hopes with the known realities and the unknowns, all while finding the strength and resolve to face the daily challenges.

Parents have to tread a delicate line between refusing resignation and accepting the child as she is and will become. When there is no way to ‘normalcy’ or increased function, a change in perspective is more than just ‘settling’- it is positively transformative.” (Kittay, 2011, p. 627)

Some parents describe advocating for the needs, rights and humanity of their child as a “war” (Watermeyer & McKenzie, 2014, p. 406). Service provision often involves accessing a variety of resources, governmental agencies and systems that can prove challenging (Heiman, 2002). The creation of public perceptions of “super parents” who heroically and often publicly deal with the stresses of raising a child with PMD can create unattainable idealization of parenting expectations. Support in this situation can be key to positive and realistic parenting functioning.

Available supports can include respite care, house modifications for physical access, medical resources, orthopedic and equipment resources, access to specialists, vehicle modifications, specialized daycare and education. Social supports include family, friends, other special needs parents, support groups, and social media-based interactions. Resiliency factors include aspects of community such as a safe space to share and consult with others, social bonds
between caregivers, and ongoing support for family members as their personal dynamic evolves and changes (Heiman, 2002).

**Chapter Summary**

Parents raising children with PMD have a parenting experience that results in compromised person-to-person social access and reduced social resources (Barack et al., 2008). They also have uncommon stressors and experiences in their parenting (Resch et al., 2010). Social media has been shown to provide a forum for connections that requires minimal social resources and access that is available beyond geography (Barack et al., 2008). Parks (2010) described social media connection as a way to satisfy the “hunger for community” (p. 107) which is particularly important when life circumstances reduce in-person social access. Social media connections serve as online support systems when the participants have connected based upon a specific common need. The social media format, acting as an online support system, provides a mode to transmit resources, share emotional support, develop friendships, and “reduce their perceived anomaly” (Barack et al., 2008, p. 1868). Social networking sites have been shown to have the potential for increase in social resources (Ellison et al., 2010). Donath and Boyd (2004) suggest that the value of the online connection is commensurate with the benefits it brings to the user.

While research specific to parents raising children with PMD and the role of social media is relatively unexplored, disenfranchised populations have been shown to benefit from the access to information, social reciprocity and sense of community through online social networks (Dekker & Engbersen, 2014; Liu & Lu, 2018; Panagiotopoulos & Barnett, 2015; Sugawara et al., 2012). This study sought to examine if social media can create a virtual sense of community for
parents raising children with PMD resulting in empowerment within their life as an individual and as a parent raising a child with PMD.

Social media has transformed the way people interact in-person and online. Social media users are able to become community members, participate in a back and forth interaction, gain resources and forge emotional connections online. These factors comprise the components of community as described in the theory of sense of community. Membership in online communities can provide resources and needed support to develop personal empowerment. This is especially poignant when the online community member is also a member of an isolated and disenfranchised population within society at large. This study examined the role of social media in the lives of parents raising children with PMD through the theoretical lens of sense of community with a focus on empowerment theory in an effort to document their social experiences online. These online experiences may be a source of accessible support that could mitigate the isolation and stressors associated with raising a child with PMD.

Parents report benefits from having a safe space to openly and honestly express the myriad of feelings involved in parenting a child with PMD without feeling as though they are being judged or deemed “pathological” (Watermeyer & McKenzie, 2014, p. 412).

Emotional support from formal and informal sources of support tended to be a major concern for caregivers ... Families could help in enhancing the sense of self-perception such as self-efficacy and self-esteem, educating positive coping strategies, and building social support networks (Isa et al., 2016, p. 76).

It is an ethical and professional mandate to support parents on their individual journeys in a manner that is respectful and non-judgmental of their life as they cope within a society that maintains barriers to participation for their child and subsequently themselves (Watermeyer & McKenzie, 2014).
Remainder of the Study

Chapter 3 delineates the methodology and methods of the study. Chapter 4 documents the findings of the study. Chapter 5 discusses the study findings and conclusions and documents recommendations for future research. The references are then listed followed by the appendix containing the demographic survey, informed consent form and Institutional Review Board documentation.
CHAPTER 3: METHODS AND METHODOLOGY

Introduction

Society is designed for the able bodied and most people expect a life of normalcy for themselves and their children. When a child has profound multiple disabilities (PMD), the extreme diversion from the expected creates a reality outside of most peoples’ conception of parenting, much less experience of parenting (Green, 2007). This can result in a lack of understanding of, and connection to families with members who have PMD. Individuals with PMD and their families are invisible within our society (Agmon et al., 2016). Because PMD occurs at low prevalence, parents tend to be geographically isolated from each other. The factors impacting family life when a child has PMD are uncommon and often involve combinations of medical interventions, behavioral support approaches, physical access limitations and a multitude of daily care factors not present within typical family dynamics (Green, 2006). This intensity of caretaking requirements limits parental social access to other parents. As a result, parents raising children with PMD tend to live disconnected from typical social supports and from each other.

Because of the caretaking demands related to raising a child with PMD, parents need a method of social connection that requires minimal social resources to make and maintain social connections. Social media is an accessible, free and easy to use resource for virtual social connections. Social media is also commonly used with 65% of American adults reported using social media applications (Perrin, 2015).

Virtual communities established through social media have been shown to provide similar benefits to geographically connected communities (Burrows et al., 2000). Membership in a community provides benefits according to the theory of sense of community. Sense of
community theory identifies four components of community including membership, influence, fulfillment of needs and a shared emotional connection (McMillan & Chavis, 1986). Parents raising children with PMD struggle to physically access community because of the social and physical barriers within society for individuals with disabilities (Chappell, 2005). However, social media provides an accessible avenue to connect to virtual communities and reap the benefits of community membership (Nettleton et al, 2000). Because parents raising children with PMD live physically and socially disconnected (Ambikile & Outwater, 2012; Resch et al., 2010), the virtual community connections have the potential to empower parents into action on their own behalf, on behalf of their child and on behalf of other members of the PMD community. This empowerment is reflective of the theory of empowerment (Moran, 2017). The theory of empowerment describes the impact of social support as including increased topic-specific knowledge, increased sense of personal control and progress towards personal goals. By combining the theoretical lens of sense of community and theory of empowerment, social media participation by parents raising a child with PMD was explored to identify factors of community experienced online and their impact upon this physically and socially isolated population.

In this study, I explored and documented the role that social media plays in the lives of parents raising children with PMD by answering the following questions: What are the roles of social media in the lives of parents raising children with PMD? In what ways do parents raising children with PMD engage with social media? In what ways do parents raising children with PMD experience community by engaging with social media? How do parents raising children with PMD describe social media’s influence on their parenting skills in raising a child with disabilities?
Research Design

Qualitative Design

Qualitative research is used to document complex world dynamics. Qualitative research does this by exploring a lived experience. Data collection entails gathering accounts and formulating complex representations of this experience (Marshall & Rossman, 2015). The data that is collected is subsequently interpreted by the researcher. Through these interpretations the researcher gives voice to participants of the study (Denzin & Lincoln, 2011). From the researcher, qualitative research involves inductive and deductive reasoning and a focus on participants’ meanings. Qualitative research engages a dynamic and evolving research design and acknowledges the researcher’s background (Marshall & Rossman, 2015). Carcary (2009) describes qualitative inquiry as “the researcher being actively involved in attempting to understand and explain social phenomena” (p. 12).

Qualitative research takes into consideration the social and political factors present at the time of the study (Creswell & Poth, 2018). By incorporating the social and political setting, qualitative research findings represent a specific lived experience unique to the time and place it occurred. Qualitative research approaches are “flexible, context sensitive and largely concerned with understanding complex issues” (Carcary, 2009, p. 11).

This study was designed as a qualitative study. The purpose of this study was to explore complex dynamics appropriate to qualitative inquiry methods. Exploring this topic required in-depth data collection and analysis. According to Denzin and Lincoln (2011), qualitative research includes practices that “make the world visible” (p. 3). This study sought to give voice to a disenfranchised population of parents raising children with PMD by documenting the complexity of their experiences with social media.
Phenomenological Research Approach

According to Creswell and Poth (2018), phenomenological studies seek “to describe common meaning for several individuals of a common lived experience of a phenomenon” (p. 75). By examining these individual experiences of the same phenomenon, common themes and components can be identified providing a description of the experience’s “essence” (van Manen, 1990, p. 177).

In this study, the lived experiences on social media for parents raising children with PMD was the common phenomenon under examination. This study sought to understand the essence of social media in the lives of parents raising a child with PMD by creating a composite description (Moustakas, 1994, p. 104) that articulates the phenomenon of navigating online resources for social support. Wolcott (2010) described the importance of the what and the how when examining a lived experience. This study sought to identify what families raising children with PMD experience through social media and how they navigate life systems in relation to social media within the realities of their experiences.

This study identified what aspects of community parents of children with PMD share with each other on social media as they function within the systems of virtual support. Parents raising children with PMD may not share the same geographical space of living, but their life contexts provide a similar experience and reality. The identification and exploration of this common experience had the potential to provide insights, critically explore resource needs and provision, identify community member empowerment factors and improve effectiveness of resource identification and provision through virtual connections.

A qualitative phenomenological research approach was appropriate to this study because the rich complexities of this lived experience required complex data gathering and examination
to capture the context of the experience as well as identify the themes evident across respondents. The respondents of the study represent a specific lived experience replete with emotion and unique perspectives of parenting and social media, which Leung (2015) described as essential elements to qualitative research. Leung went on to describe the individual’s perspectives and complexities as “extra dimensions and colors that enrich the corpus of findings” (Leung, 2015, p. 324).

**Respondent Selection Strategy**

Respondents were identified through purposeful sampling (Creswell & Poth, 2018) based upon their use of social media and parenting of a child identified as having PMD. Purposeful sampling identifies potential respondents based upon specific criteria present at the time of the study (Padilla-Diaz, 2015). According to Padilla-Diaz (2015) using specific criteria ensures that the identified respondents have “common experiences regarding the studied phenomenon” (p. 104).

The social media platform that was the focus of this study is Facebook. Facebook hosts several public and closed groups specific to parents raising children with PMD. The researcher was a member of several disability support groups on Facebook. Respondents were solicited from Facebook through a recruitment post describing the study posted by myself on these disability support group pages. Solicitation post read, “I am conducting a doctoral research study examining the experiences involved in parenting a child with profound multiple disabilities and social media use. Participation includes an hour-long interview that can be conducted in-person, through Skype or Facetime at a time of your convenience and involves some follow up activities. If you are interested in participating in this study, please send me a message in Messenger to find out more.”
Interested potential participants were asked to contact the researcher through a message using Facebook messenger. Interested participants were vetted to determine if they meet the research participant requirements and it was verified that they were willing to participate in the study. If the potential respondent was willing to participate in the study and met the participant criteria, they were included as a respondent. Five research participants were identified through this post. If fewer than five participants were identified for the interviews, additional participants would have been identified through snowball sampling from previous participants. Snowball sampling involves respondents identifying people they know as potential study participants from their acquaintances (Creswell & Poth, 2018).

Criteria for participant selection required that the respondent was over 20 years old but less than 60 years old. Respondent must have a child that was registered in public school and the child must be at least 4 years old. The parent’s child must also be served under an active individualized education plan that identified the child as having multiple disabilities conjointly with communication, health or physical impairments with a severe global impact upon adaptive skills according to school psychological report corresponding to this study’s criteria of PMD. For the purposes of this study, individuals with PMD were identified by the documented presence of an estimated IQ below 20, global developmental profile below 24 months in combination with at least one other health, orthopedic or sensory disability per parent report. If the potential respondent was willing to participate in the study and met the participant criteria, they were included as a respondent.

Sampling continued until five interviews were completed. While Creswell and Poth (2018) describe phenomenological sample sizes ranging from 1 to 325, Mason (2010) describes sufficient sample size for phenomenological research as the “point of diminishing return” (p. 1).
Because this study is an exploration of a phenomenon, the occurrence of data is critical for inclusion in study results. Therefore, the anticipated sample size is based upon exploration of the experienced phenomenon and exploring its meaning for participants rather than making generalizable statements to be applied across a population. As a result, this study included five respondents who are both social media users and primary caregivers raising children with PMD. This sample size allowed for exploration of the experience of raising a child with PMD and interactions on social media without the data providing unnecessary repetitive information that does not provide further insight into the dynamics of the lived experience (Mason, 2010). Because social media and technology resources such as video phone calls transcends geographic boundaries, there were no theoretical geographical limitations for respondent selection. However, respondents were limited to residents of the United States. Interviews could have been conducted through digital means across geographic distances within the United States as necessary.

**Data Collection Strategies**

The identified respondents who were social media users and parents of children with PMD participated in one initial semi structured interview per participant designed to identify experiences with parenting their child with PMD and their social media use. The semi-structured interview allows “the researcher to address the phenomenon profoundly, providing a space of aperture for the informants to express their experiences in detail, approaching reality as faithfully as possible” (Padilla-Diaz, 2015, p.104). Initial interviews were anticipated to last an hour. Follow up interviews were completed as needed to verify information, expand on specific topics and for the respondent to approve the accuracy of data (Padilla-Diaz, 2015). The interview took place at a location and time of the respondents choosing. If respondents were geographically
distant from the researcher, interviews could have been completed by phone or video conferencing allowing for removal of geographical limitations to participation. With the respondent’s permission, all interviews were recorded with the researcher’s password protected phone. If the respondent declined recording, detailed notes would have been taken throughout the interview.

Respondents were asked to read and sign a participation consent form prior to the interview. An understanding of the voluntary nature of this study and contact resources for concerns or questions were verified with each participant. The demographic survey and consent form are included in Appendixes A and B. The researcher protected the anonymity of study respondents through the use of pseudonyms, the storage of interview recordings through password protection on a digital recording device, and the storage of paperwork in a locked and secure location.

The interview format was semi-structured and open-ended with guiding questions (Moustakas, 1994). Participants were asked two broad questions about the phenomenon of the role of social media in their lives to “focus attention and gather data that will lead to a textual and structural description of the experiences” (Creswell & Poth, 2018, p. 79). Additional prompts addressing topics included social media use, exploration of the components of community and empowerment. Particular attention was focused upon describing the experiential aspects of the phenomenon of parenting a child with PMD and navigating systems of social media as a potential resource and support system. Interviews were semi structured to allow the respondent to openly share the complexities of their experience (Wengraf, 2001).

Using the semi-structured construct instead of a standardized format was deemed appropriate for this study. With a standardized format, the prompts are delivered in exactly the
same wording to each respondent in an effort to provide the same stimuli to each respondent. The intention of the standardized process is to attribute variance in response to the differences of the respondents’ experiences and not the variation of the stimuli (Barriball & While, 1994). However, the respondents may not have the same interpretation of the vocabulary in a standardized interview format. Utilizing a semi-structured interview allows the researcher to adjust the stimuli to ensure the respondent understands the meaning of the interview probe (Barriball & While, 1994). Additionally, the semi-structured interview format utilizes a list of topics and probes that will be covered during the interview but allows for topics that arise to be explored as the interview progresses (Cohen & Crabtree, 2006).

The semi-structured format contributes to relative standardization. According to Morse (2015) utilizing a semi-structured interview format supports consistent coding systems that can contribute to validity and findings. After Institutional Review Board approval, the interview format was pilot tested with one individual fitting the respondent selection guidelines prior to initiation of data collection. No data was collected until Institutional Review Board approval of the study proposal.

**Data Analysis Procedures**

Data analysis was based upon the phenomenological data analysis research guidelines established by Moustakas (1994) and Polkinghorne (1989). Interviews were transcribed verbatim by the researcher. Member checking was utilized by providing transcripts to respondents for verification of accuracy of content. The transcribed interview was reviewed by the researcher repeatedly for familiarity. Phenomenological reduction was implemented. Through bracketing, everything that incorporated the focus of the research was placed in brackets and non-topical data was set aside. Through horizontalization, every statement was
treated with equal value. Then statements that were not related to the research topic, repetitive or overlapping were deleted. What was left were the horizons. Moustakas (1994) describes these as the “textural meanings and invariant constituents of the phenomena” (p. 95). From these statements, themes were developed.

These themes were used to write a description of the “context that influenced how the participant experienced the phenomenon” (Creswell & Poth, 2018, p. 80) creating a structural description of the phenomenon. The composite description of the phenomenon must reflect the common underlying structure across respondents (Creswell & Poth, 2018). This common essence will then be presented in a format that is complex enough to represent the entirety of the lived experience of the participants while still being represented by “plain words” (van Manen, 2014, p. 370).

The lens of sense of community and empowerment theory was utilized to explore the resulting themes from the data. This comparison of the data outcomes with the components of sense of community and empowerment theory provided the structure to explore the role of social media in the lives of parents raising children with PMD. By comparing the themes evident in the data analysis within the theoretical framework, the essential components of community and empowerment were evaluated for presence and potential significance within this lived experience as documented by this study.

**Role of the Researcher**

As I prepared to undertake this study that is focused on a population of people that, while marginalized by society, has taken a primary role in my own life, I was eager to facilitate their voices being heard. Through our interviews and interactions, my focus was to document their lived experience in forging social connections with each other. By reflexively participating in
the exploration of the roles of social media in the lives of parents raising children with PMD, I hoped to be respectful and representative of the study participants by giving voice to their connections and not my presumptions. To do so, I needed to focus on the participants by bracketing myself outside of the study as much as possible by following the participants’ exploration of the phenomenon and developing an accurate representation of the essence by utilizing epoche.

Through epoche, the suspension of assumptions, an accurate representation of the participants’ lived experience can be documented. It is important to recognize that we are all products of our experiences and that this impacts our views and interpretations of what we perceive, making truly value-free and objective interpretation impossible. As Carcary (2009) stated, “a single objective reality does not exist” (p. 12). It is requisite upon the researcher to recognize this and engage in reflexive thinking throughout the research and data analysis. This is key to ensuring that the data drives the results. The focus of the research was to develop an understanding of the experience of the families, not serve as a delivery vehicle for preconceived expectations by the researcher. The role of the researcher includes facilitation of data collection in a manner respectful of respondents’ life experiences and representative of their experienced phenomena. I used a journal to track my reflexive process throughout data analysis. The written process of reflexive thought allowed me to track and document self-awareness and ensure that the self-reflexive process was active throughout analysis. Study outcomes were outside of my prior, self-identified preconceptions, indicating that I was able to explore the data outside of my personal assumptions.
Researcher Positionality

I have been involved in special education for over a quarter of a century now. I have always been drawn to working with individuals who have PMD. I find individuals with PMD to be humanity in its most honest form. The individuals with PMD with whom I have worked have taught me to communicate beyond spoken words, be honest and open and helped me understand that the joys in life can be found even when some aspects of living must be endured.

Working with individuals with PMD means that I have also worked closely with their families and caregivers. Individuals with PMD are reliant upon others for their care and well-being. Parents and caregivers have entrusted me with that responsibility and have had to trust my intentions and efforts because their child with PMD is unable to communicate with them fully. This has resulted in close bonds between myself and parents of children with PMD over the years.

Through this experience, I have been a connected outsider in the lives of these families. Through this connection, many parents raising children with PMD have shared their feelings of isolation and sense of being inundated by the care of their child with PMD. They have also shared their joys and pride. I have seen parents rise to demands that they never knew existed and never believed they could handle. I have also seen incredibly strong parents bend and even emotionally break under the challenges. Most often, I have seen them deal with these challenges in isolation.

The isolation of the experience of parenting a child with PMD can exist within a supportive environment. Family units and extended family often try to help the primary caretaker. Yet, I have heard over and over from caretakers, primarily mothers, that no one except other primary caretakers truly understand what is involved in raising a child with PMD.
They share that while their families try to support them and the child with PMD, not even those who live in the same house truly understand- not even their spouses or their other children.

Over the years, I have tried many approaches to connect parents raising children with PMD. I have facilitated parent support groups, offered meals and childcare for all of the family’s children during gatherings. Parents have tried to attend and feel that these activities are important but continued to struggle to attend because it was just too challenging to physically get to the meetings.

More recently, I have begun to try to connect parents using technology, initially through phone number exchanges. Phone calls proved difficult and parents moved their contact to digital formats including texting and social media. It has been my observation that this method of contact and support has proven valuable and sustainable in a way that other forms of contact have not. For example, I introduced two mothers of children with PMD over three years ago. They connect almost daily via text or social media. They have attempted to meet in-person for the duration of their three-year friendship but have not been able to because of the instability of their children’s health, intensity of care needs and limited time. They live a 20-minute drive from each other.

These experiences have led me to this study. I wanted to explore the connections that parents raising children with PMD have forged for themselves through social media. I believe that in documenting what they are doing for themselves, we can explore the components and potential benefits of social media in connecting parents raising children with PMD.

It is my belief that individuals with PMD, while often treated as less than human, should be afforded the rights we purport for all human beings. It is also my belief that the parents raising children with PMD would benefit from meaningful social support from other individuals
with the same life experience. Disability is experienced not only in the physical manifestations of the variability of human experience, but also within the societal context that creates social and physical barriers to true membership. Not only are individuals with PMD subject to these realities, but so are their families and caregivers.

The concept of realities is delineated by one’s epistemological beliefs regarding the very concept of reality. My personal epistemological beliefs reflect a subjectivist perspective. Hanly and Fitzpatrick Hanly (2001) describe subjectivity as including the existence of a reality outside of human perception. Hanly and Fitzpatrick Hanly (2001) further cite subjectivists including Plato, Berkeley and Kant espousing an existence independent of human interpretation and perception. As self-aware humans who are dependent upon our limited senses to gain information about ourselves and our environment, we are also dependent upon our ability to process the information provided by our senses. We are limited in our ability to comprehend and perceive the very complexities in which we exist. Therefore, we rely upon the individual interpretations of our realities based upon the sensory information as filtered by our perception and experience of it (Hanly & Fitzpatrick Hanly, 2001).

There are often commonalities of this perceived reality based upon common experiences and personal filters. These commonalities result in interpreted “truths” held by groups or individuals. These truths are often closely tied to social norms of the time and are subject to change, reinterpretation and revision when viewed from different perspectives and times. Regardless of mass agreement of these common realities, as humans I believe we depend and operate through our subjective interpretations of the world around us.
Assumptions

In undertaking this study, I assumed that the participants were sharing information openly and honestly during the interview. This study was exploratory in nature and sought to examine the role of social media in the lives of parents raising children with PMD. As such, the results are not intended to serve as generalizable findings. Rather, they serve as introductory insight into the phenomenon of social media in the lives of parents raising children with PMD. Future research is needed to assess generalizable findings regarding social media usage of parents raising children with PMD. This will require a larger scale, numerically based study that is outside of the scope of this endeavor. This study is a contribution to the ongoing discussion on the topic of social media and parents raising children with PMD. This discussion will continue well after this study as the nature of the topic is not only complex but also subject to rapid technology and social changes over time.

Chapter Summary

This chapter describes the methodology for this qualitative phenomenological study. An open-ended interview protocol was utilized with the selected population of five respondents. Potential participants were purposefully identified from Facebook groups specific to parents raising children with PMD. The parents must have had a school age child being served under an active individualized education plan having been identified as PMD by school psychological assessment.

Interviews were recorded and transcribed. Transcriptions were reviewed and coded for themes according to Moustakas (1994). Coded themes were explored across all data. The resulting themes were compared with the identified study framework of sense of community and empowerment theory components.
Remainder of the Study

After review and approval by Institutional Review Board, the research protocol was followed. Findings are discussed in Chapter 4. Discussion and implication of findings are discussed in Chapter 5.
CHAPTER 4: FINDINGS

Introduction

Parenting plays a central role in many adult lives. The typical parenting journey serves as an experience of camaraderie shared across a similar experience. When a child has profound multiple disabilities (PMD), parenting often begins as a highly isolated experience. This is due in part to the marginalization of individuals with disabilities in American society. Parents raising a child with PMD experience this marginalization in conjunction with their child. A result of this marginalization is decreased social support and opportunities for social interaction with other parents on a similar journey. However, virtual social interaction is available through social media.

Social media serves as a means for application users to connect virtually without requiring high levels of social resources. This study explores the lived experiences of the respondents as parents raising children with PMD and the role of social media in their lives. This chapter explores the findings of the data. The respondents and their families are introduced. Themes found within the data that reflect the lived PMD parenting experience are documented in this chapter. Major themes include adaptation to changed parenting expectations, acclimation to PMD parenting, social connections and social media.

Data Collection

This study was conducted as a qualitative phenomenological examination of the role of social media in the lives of parents raising school age children with PMD. The study proposal was reviewed and approved by the doctoral committee. Institutional Review Board approval of the study proposal was obtained. An initial parent was identified and interviewed to pilot the
interview protocol format. Interview prompts were refined as a result of this pre-interview. Study respondents were solicited from a Facebook post on the researcher’s Facebook timeline. Five respondents were identified based upon responses to the Facebook post and snowball sampling that resulted from referrals of other Facebook users who forwarded the initial post. Each respondent reviewed the consent form and agreed to participate in the study prior to being interviewed.

Each of the five respondents participated in a one-hour interview. Interview location and method was based upon respondent preference. One interview was conducted face to face and four via phone conversation. All interviews were recorded with the permission of respondents. Interviews were transcribed and member checked. Basic demographic information was obtained as a part of the interview process. Respondent description included in this chapter was reviewed by each corresponding parent to ensure acceptability of personal information provided in this manuscript.

Meet the Families

Demographic Information

All of the respondents were female. Mean age of respondents was 46 years old with a range of 35 to 52 years. Four respondents were Caucasian with one respondent being Hispanic. All respondents were high school graduates with four having attended college and two having obtained master’s degrees. Two respondents were single. One respondent was divorced. Two respondents were married or in a domestic partnership. All respondents currently work in their home providing care for their child with PMD fulltime. Two respondents are retired and also now provide full time care to their child with PMD. Household incomes ranged from $35,000 to
over $100,000 per year with one household in the $35,000 bracket, two households between $50,000 and $75,000 and two households with incomes over $100,000.

Table 1
Demographic Information of Respondents

<table>
<thead>
<tr>
<th>Age (in years)</th>
<th>Number</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>35-44</td>
<td>3</td>
<td>60%</td>
</tr>
<tr>
<td>45-54</td>
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</tr>
<tr>
<td>Mean age: 46.2</td>
<td>Mode: 44</td>
<td>Median: 44</td>
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<table>
<thead>
<tr>
<th>Gender</th>
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<th></th>
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</thead>
<tbody>
<tr>
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<td>100%</td>
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</table>

<table>
<thead>
<tr>
<th>Ethnic Origin</th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>4</td>
<td>80%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>1</td>
<td>20%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>High School Diploma</td>
<td>1</td>
<td>20%</td>
</tr>
<tr>
<td>Some college, no degree</td>
<td>2</td>
<td>40%</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>2</td>
<td>40%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital Status</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>2</td>
<td>40%</td>
</tr>
<tr>
<td>Married, Domestic Partnership</td>
<td>2</td>
<td>40%</td>
</tr>
<tr>
<td>Divorced</td>
<td>1</td>
<td>20%</td>
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<table>
<thead>
<tr>
<th>Employment Status</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Work at home, subsidized care for family</td>
<td>4</td>
<td>60%</td>
</tr>
<tr>
<td>Retired</td>
<td>2</td>
<td>40%</td>
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</table>

<table>
<thead>
<tr>
<th>Household Income</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>35,000-49,999</td>
<td>1</td>
<td>20%</td>
</tr>
<tr>
<td>50,000-74,999</td>
<td>2</td>
<td>40%</td>
</tr>
<tr>
<td>Over 100,000</td>
<td>2</td>
<td>40%</td>
</tr>
</tbody>
</table>

The respondents’ children with PMD included one female and five males. The ages of children with PMD ranged from 4 years to 20 years. Diagnosis of the children with PMD included significant developmental delay, hemiplegia, cerebral palsy, rheumatoid arthritis, brain injury, stroke, meningitis, rare genetic diagnosis, hypoxic ischemic encephalopathy (HIE), septic infection, infantile spasms and epilepsy. Medical interventions and treatments included gastronomy tube, total parenteral nutrition (TPN), alternative communication strategies for
nonverbal individuals, alternative mobility for non-ambulation, trachea and ventilator dependency. Parents reported large medical teams with up to 16 specialists. One child takes 21 medications daily. All of the children with PMD rely on others for all self-care needs. Those that take nutrition orally require modified food presentation such as pureed food. All of the children with PMD require constant supervision and multiple daily interventions in addition to periodic large-scale surgical and medical interventions.

The Parent Respondents

Anne. Anne is a 44-year-old single mom with extensive experience working in the field of special education and residential services for children with disabilities. With initial intentions of pursuing teaching or nursing, Anne began fostering children with disabilities and eventually adopted three children that were foster children placed in her home. Anne’s sons include biological brothers Adam and Nate who have PMD and middle child, Jack who experienced in utero drug exposure.

Anne shared that she has always had a passion for working with children who have PMD:

I like to try to figure out the best way to help them learn and have a better life and I also want everyone to see that special kids are just like every other kid. I don’t want them treated differently. I want them to be treated the same. You just have to give them a little extra help.

Her oldest son Adam (11) and youngest son Nate (7) are diagnosed with a rare genetic condition, Coffin-Lowry Syndrome. Both boys experience severe cognitive impairment, are nonverbal communicators and, while ambulatory, experience atypical limb and skeletal abnormalities, altered gait and balance, heart problems and hearing and vision impairments. Both boys experience scoliosis that will require major corrective surgeries throughout their lives. Anne shared that Nate additionally experienced a stroke shortly after birth and Adam was born prematurely at 32 weeks. When Adam was placed with her as a foster child, Anne was told by
doctors, previous foster parents and social workers that Adam would be a “vegetable” that would be bedridden and would “never do anything.” Anne was told that it was unlikely that he would live past eight months of age. Later, when Nate was placed with her, doctors told her that Nate would be deaf and blind. Both boys are currently active walkers and have functional hearing and vision. Anne describes them as “busy” and functioning developmentally as young toddlers.

Anne described her previous experience in special education and at care homes for individuals with PMD as beneficial in meeting the parenting requirements she needs in raising Nate and Adam. “I think it is different for me because I had a background and support which is different than a parent that has a child born and then they find out they have special needs.” Anne described having an understanding of what parenting children with special needs and PMD involved when she adopted Nate and Adam. She also felt she has had in place from the beginning, knowledge and connections that have aided her in her parenting journey.

Anne self describes her social media use as publicly a “lurker.” Although she accesses Facebook multiple times throughout the day, she generates posts on her public page infrequently. She described her social media use as “Often. All day.” Social media is her little de-stressor that she uses “when she needs a break from the kids.” Anne maintains a page for herself that has privacy settings set for Facebook friends only. She posts on this page infrequently, including only significant life events. She posts to let friends and family know how Adam and Nate are doing and how far they have come from those initial expectations. “I was told that Adam would be a vegetable and bedridden. That he wouldn’t be able to do anything, and that boy does so much. He does everything a 3-year-old would do. I just want people to see that.” Adam and Nate’s biological relatives maintain contact and gather information about Adam and Nate through this Facebook page. Anne is an active member of private Facebook groups related to the
syndrome of Nate and Adam’s rare genetic diagnosis. Anne is also a member of a support page for parents raising a child with PMD.

Anne shares items and information that have helped with Adam and Nate with other parents on the private, disability-focused Facebook pages because she has not found many resources for parents raising children with PMD available. She shares items that have helped with behavioral challenges and items she is familiar with because of her special education experiences. “Because I have worked so long in the field, for me it’s about putting stuff out there that can be helpful to others that haven’t had the same access to resources and information.” Anne shared that it is helpful to know through virtual life experiences on Facebook that other parents are going through the same things she is experiencing with Nate and Adam. Helping other parents makes her feel useful and of service to others, especially as what she describes as a “stay at home mom.”

Serving as a source of support and resources transfers into Anne’s in-person experiences with Adam and Nate. When they are in their community, she often encounters other parents of children with special needs or their relatives. These in-person connections are often transferred over to virtual life through ongoing contact via Facebook and texting.

Anne described going out into the community as something that she does but is really a challenge. When describing routine errands like grocery shopping, Anne shared some of her experiences:

I take them all the time. I don’t want to. I don’t want to at all, but they like going to Costco. Adam likes getting the samples. Nate- I call him my little monkey because he is always reaching and grabbing on people and their carts. Luckily, he is really cute, so people tend not to get mad and just kind of put up with it. If they weren’t cute, it would be harder.
When Anne encounters a challenging situation for Adam and Nate, her first source of assistance is the special educators at the boys’ school. She also contacts the boys’ physician as the physician also has a patient who is a little older than Adam and Nate with the same diagnosis. Anne describes posting on the Coffin-Lowry Facebook page as comfortable because it is a private group that requires members to be a doctor, parent or therapist to access the group page. Through the Coffin-Lowry page, she has been able to identify what is normal for the boys’ syndrome. This helps her in determining her response to unfamiliar situations. She shared an example of this.

Without the Coffin-Lowry page I would have a lot of moments I wasn’t sure what was normal. For instance, the boys lose their teeth early- like at age two. When they fall out, the whole tooth falls out- root and all. Their teeth will fall out and it would be like an inch long. It was so scary. The first time it happened I went on the Facebook syndrome page and I asked if this was normal. I got like 20 responses that that had happened to other people. They told me that was normal and that the teeth don’t come in for years…So, it freaked me out at first and now I know its normal. If I see a tooth laying around the house- a big old giant tooth with the root and everything I just go- whatever. It is normal for us. It’s no big deal but the first time it was like, oh my goodness. What should I do? I asked the doctor and she wasn’t sure. I asked the dentist and he wasn’t sure either. If I didn’t have social media, I wouldn’t have known until it happened to Nate too.

Anne will look at the stories on Facebook and look for the commonalities amongst different children with the same diagnosis to vet information. She has also had online contact with the founder of the boys’ syndrome. However, much of the information she is seeking for parenting decisions is not in the diagnostic description or within medical knowledge of the syndrome. What she is seeking is available from other parents and involves the day-to-day caretaking and non-traditional developmental pathway that Adam and Nate are following as a result of their diagnosis. She has heard of another child living near her who has the same diagnosis as Adam and Nate but has not yet met anyone in-person with their diagnosis. “It is really rare what they have. So, you don’t just come across other people with it very often.”
Anne balances her parenting demands by carving time out of her day to explore her own interests and decompress. Up until recently, she utilized the time that all three of her sons were in school to enjoy her hobbies and interests. Anne has recently hired babysitters to help her at home with the boys. She enjoys gardening and going to the gym to do spin classes.

Social support for Anne includes her mom, family members, babysitter and support providers for all three boys. When asked if she identifies herself as a member of any communities, Anne shared that previously her middle child had been able to participate in youth sports, but parenting demands have limited their ability to participate in the youth sport community. She feels like a member of her sons’ school community but acknowledges that it has been harder for her to maintain social connections in-person. Anne described a tapering off of in-person gatherings with friends since the boys were little.

It used to be that my friends would always come over. I think because a lot of my friends don’t have kids of their own it has dwindled off. I still talk to them occasionally but it’s not like it used to be…I do miss that…I do understand because we don’t have anything in common anymore. It’s totally different. That’s the one thing I didn’t think would be so different. I thought it would stay the same.

This decline in personal social connections has prompted Anne to incorporate additional help through her babysitters. “Babysitting is a big piece. I did this by myself for a long time… I hire the aides from their school classrooms because they know the boys and they are trained. It helps where I didn’t have help before.”

**Lilli.** Lilli is married to Kyle and they have a 4-year-old daughter together named Lila, a 14-year-old daughter and adult children including a daughter and two sons. They are also active grandparents. Lilli and Kyle’s daughter, Lila, was born prematurely at 33 weeks. Her diagnosis includes cerebral palsy and a rare disorder called West Syndrome that is characterized by infantile spasms, regression of skills and intellectual disabilities. Lila obtains nutrition through a
gastronomy tube and utilizes a wheelchair pushed by others for her mobility. Lila was diagnosed at 6 months of age with this rare disorder, but Lilli shared that she knew something was different from typical developmental expectations with Lila from birth.

Lilli has had extensive exposure to parenting and childrearing through growing up in her mother’s daycare throughout her childhood. “Growing up in a daycare and as the youngest of eight children, you end up taking care of kids all the time. You just learn to be a nurturer.” She describes her parenting style as “treating Lila the same as everyone else. We are just as fun-loving and sarcastic with Lila as we are with anybody else.”

Lilli uses social media applications including Snapchat, Facebook, Instagram and YouTube multiple times daily. She describes her social media use as being mood dependent. If she is feeling depressed, she does not post but will look at other peoples’ posts daily. If she is feeling good and Lila is doing well, she posts what she describes as a “Lila-palooza” of pictures. She does not tend to post pictures of herself but focuses on Lila. She also tags her posts with relevant hashtags for cerebral palsy awareness and epilepsy awareness.

I just try to build up these pages. It is always about Lila doing something or smiling or looking cute or being beautiful or whatever. But that is usually what I post. Lila doing something that you wouldn’t typically see- whether its swimming or just laughing or one of us tossing her up in the air or playing on a blanket. Something fun. She is the cutest kid. She is absolutely adorable.

Lilli did join Facebook groups but found the virtual interactions laden with negativity. “I joined Facebook groups, but it was just people ranting, raving, moaning and groaning. Trust me, I don’t think it is wrong to moan and groan and vent about things. But literally, that’s all it was… it’s so depressing.”

Having had adverse experiences in disability specific Facebook groups, Lilli concentrates her social media use on Instagram, Snapchat and YouTube.
I have tons of people that either follow me or are friends with me on Instagram, Snapchat or Facebook that are all over the world and are very like-minded. I just can’t find anybody like that in a neighboring city to connect with. But, across the world I can through Facebook or Instagram.

Lilli prefers to try to focus on what she describes as the “positive” within her life and parenting experience with Lila. Lilli shared that she locates resources including toys and equipment for Lila through social media posts. Lilli stated that sharing resources with other parents makes her feel good.

That’s another way I have found some really cool toys and really cool equipment for Lila. People have liked my post and I have looked at theirs and by looking at their stuff I’ve been like ‘Oh, this is so cool. What is she playing with?’ And then they tell me and then I will find it online and I can get it for Lila.

Accessing the community in-person has specific challenges for Lilli. Lilli is unable to drive due to a disability. She shared that this limits her ability to access her geographical community. She goes places with family and friends and will use transportation services for herself. She had previously used transportation services such as Uber and Lyft with Lila but after a disturbing experience, no longer takes her when utilizing those services. Lilli described the increasing challenges of caring for Lila as she grows in size.

When she was little, there was no difference. Now there is a big difference. The older she gets, the bigger she gets. But mentally, or should I say cognitively, she is still younger, and she wants to be treated like a little girl- like a baby. She still wants to be held and cradled. I can’t provide those things when she is 39 pounds and 3½ feet tall.

Lilli referred to using her “mommy gut” when making decisions about Lila’s care and medical needs. She accesses resources including doctors, nurses and regional center service coordinators, friends and family but ultimately relies upon her own maternal intuition for her final decision making. “You know, I have found that 85 to 90% of the time, mommy gut is the best thing to follow… We’ve all tried to figure out solutions when we felt stuck between a rock
and a hard place.” When exploring options for challenging situations, Lilli describes her resources as coming “from anywhere and everywhere.”

You have to be like cut and paste. Doctors will tell you one thing. A nurse will tell you another. You have to figure out what is best for your kiddo because the doctor may tell you to do one thing, but your kid hates it. Then the nurse gives you an idea and the whole world changes.

Other resources for Lilli include her regional center service coordinator and a nurse assigned to her through the family’s private insurance. She also accesses physicians and specialists through phone calls.

When asked the most challenging aspect of parenting Lila, Lilli shared that the hardest part is finding friends for her young daughter and meeting people in-person. Lilli seeks to provide Lila with a semblance of social normalcy by actively seeking friendships and in-person activities for Lila.

I actively try to find friends for Lila with her school now that she is going to preschool. I do anything to try. It is just so hard. I mean Lila is four years old and I still haven’t found a single friend for her.

Lilli emphasized how important having a friend for Lila was to her.

I want Lila to have friends. I want Lila to experience having a best friend. I want her to go over to other people’s house and play. I want that for her even though she has these things. I want her to have a best friend and for me to feel comfortable enough to say to her best friend’s mom, ‘OK, this is Lila and this is how you take care of her because she is your child’s best friend and she wants to spend the night and when your child comes over, I will do the same. So what she has a feeding tube? That means she doesn’t get to have a sleepover? So she doesn’t get to experience those things?

Lilli describes her social support as great connections with family and friends. She has had a hard time connecting with other moms since Lila’s birth. Lilli shared that she had briefly forged an in-person friendship with another mother and child with a similar diagnosis who lived near her that she had met through Lila’s therapist. They briefly met in-person for playdates but as caregiving stressors and depression increased for the other parent, their meetings tapered off.
“I understood because we all go through that. I gave her some time and reached out and didn’t hear anything. I got busy and started doing my own thing…time has gone by and now we are just Facebook friends.” Lilli describes using online apps such as Meetup in an effort to connect with moms of children for playdates but had little success with these approaches. She described herself as a member of her family community. “It’s my family and my dog and, I don’t know, my best friend and YouTube.”

**Alma.** Alma is a retired single parent of two children. She has a 20-year-old daughter named Cassie and a 16-year-old son named Corbin. Cassie attends college and lives at home. Alma describes her daughter as having been always independent and content doing things on her own. “Cassie has always been happy and comfortable with herself.” Alma shares that growing up, Cassie was receptive to discussions about her brother Corbin and his special needs within the family.

Corbin was born with a cephalic condition that caused constant seizures from birth. At 5 months of age, he had a hemispherectomy to disconnect the damaged half of his brain. His diagnosis includes developmental delay, hemiplegia, ankylosing spondylitis, esophagitis and cerebral palsy. Corbin relies upon a gastronomy tube for nutrition and uses a wheelchair pushed by another person for mobility. Corbin does not communicate verbally. At the time of Corbin’s birth, Alma had a circle of friends but none of those friends had children with disabilities and she felt very alone in her parenting experience.

When Corbin showed up, I had no exposure whatsoever to the world of the disabled. When people ask me now what it is like to parent a disabled child, I answer that we are like wizards. We live right alongside the typical world, but no one ever sees us. They have no idea what our world is like even though they pass right by us in Target. This was true of me until I had a child with special needs.
That initial solitude has been replaced by a sense of community in-person and within social media. “To have built that community that I need for emotional support has been vital to keeping me functioning. You know? And not giving up and being able to share and support other people through my expertise.” For Alma, the process of developing her PMD parenting skills over the past 16 years has involved unanticipated realizations.

You know, when I gave birth to a child with a catastrophic brain abnormality, if anyone had said to me that I would spend most of his life worrying about whether he pooped or not I would have laughed and then cried in their face. But the reality is that it is the ongoing day to day maintenance of keeping him alive and keeping him medicated and keeping him fed and, you know, making sure he is comfortable that takes up the bulk of my time.

Alma describes Corbin’s life as getting more involved as he ages. She describes his early years as being focused on acute medical issues. There were seizures, brain surgery, nine months of infection and “everything was an emergency and we didn’t know him yet. We didn’t know what his normal was.” As Corbin has aged, the family has developed a better understanding of “where we exist in the world and what is normal for him and what’s not normal for him.”

Because Corbin is a nonverbal communicator, Alma had to learn to read him and understand his communication. She describes it as “being immersed in an entirely different country where you don’t speak the language and trying to figure it out as you go. The longer you are there, the more the patterns start to make sense.” Corbin’s daily care requires a great deal of physical effort. “He can’t walk, and he can’t eat, and he can’t be, so I have to do a lot of things for him.” Even with all of the medical and physical parenting requirements, Alma describes Corbin as an emotionally easy child to raise and connect with.

You know, Corbin is a clown and he likes to make me laugh and he’ll give you hugs and I feel like I am parenting a kid- I am raising a child and we have a relationship that helps nurture my soul along when I am getting tired and changing diapers on my 16-year-old. Then he does something to make me laugh and it makes it all better. Worth it. Easier.
Corbin’s condition is very rare. Alma has not met another child in-person with the diagnosis and treatments that Corbin has. However, she has connected through disability-specific Facebook groups to other parents raising children with some of Corbin’s diagnosis and treatments.

I can be connected to the hemimegalencephaly group on Facebook. There, parents are trying to decide whether or not to have surgeries. Or trying to decide which medications to try or not try. We share what we have done and it’s this concentration of expertise that I don’t think you could find anywhere else prior to the existence of Facebook.

Alma uses social media applications of Instagram and Facebook multiple times daily. Alma maintains a Facebook profile for herself that includes parenting joys and challenges. She maintains a social media presence for Corbin on this page. Her Instagram page is dedicated to her personal interests and activities including running which is her primary hobby. She actively posts on all of her pages. Her use of Instagram also includes organizing running activities with her running friends. Alma and Corbin are connected online with national disabled running organizations. Alma describes social media as “a very important link in our lives.” Because they are not able to get out physically as much as other families, Alma utilizes social media as a link to the outside world and as a link to the special needs’ world. “To be able to get into peoples’ in-person experience parenting children with profound disabilities has been more valuable than anything else I could have found.”

Corbin attends a pediatric daycare for children with disabilities and medical needs. Alma describes a circle of friends at the daycare for herself and Corbin. These friendships are also explored through online and virtual connections of texting, Facebook and Facebook Messenger. “We are all connected online. I can’t tell you the number of times I have gotten a text at 3 o’clock in the morning with pictures from a parent asking me for advice.” Alma has a
background in biology and pathology and is often the source of information in that area for other parents.

I am often the go-to for when someone’s child is sick or broken. But we have other friends who are experts in the medical system or the regional center or the IHSS program. We belong to a Facebook group for that sort of information. You always know someone who is going to have an answer for you and if they don’t, they know someone who will...Having ready access to that network and that hive mind through social media is really, really important.

As Corbin has grown, getting out into the community has become more of a challenge for Alma and Corbin. Alma describes Corbin as her physical trainer. He is able to help with weight bearing during transitions, but she facilitates all of his movements. The valet seat in her vehicle aides in transfers in and out but he weighs 110 pounds and at times she is lowering him and lifting him from ground level. “I grin and bear it and lift with my legs.” Because of the amount of energy required to get Corbin and his wheelchair in and out of the vehicle, Alma says that she takes him on fewer errands than when he was smaller and younger.

When he was a baby it was just like carting around any baby in a carrier or stroller. But now he weighs 110 pounds and his wheelchair over 50 pounds, so hoisting things in and out of the car takes a great deal of effort.

Instead of putting her energy into taking Corbin on errands, she focuses on taking him for social activities. “We still get out and do things. We go to movies. We go to amusement parks every two weeks. We run together.” Alma seeks social connections for Corbin. Corbin is a member of his high school cross country team and Alma pushes him in his special racing wheelchair for his team races. Alma utilized online resources to Crowd Fund equipment for Corbin to participate in running. When Alma sought to purchase the special racing wheelchair for Corbin, she raised the $4,500 online. “Corbin has a fan club amongst our friends and so we raised the money pretty quickly. He loves to be in it and loves to be out racing.”
Alma describes a deep circle of online connections ranging from people who have followed Corbin since he was young: family friends, other parents, running friends and people who just enjoy her son. She has close relationships with her son’s physicians and specialists. While they do not have family living close by, the connections she has made in-person and through social media has been a key factor for Alma. When describing her membership in the running community, she said it is what “keeps her alive and going.”

Maggie. Maggie is a single mom of her adopted son Brandon. Maggie had previous experience in special education while working at a private school for medically complex children with PMD as well as taking some college special education courses prior to becoming a mother. This gave her not only hands on experience but also access to professionals in the field prior to starting her parenting journey with Brandon.

I knew where to look. I kind of knew who to talk to and how to go about it. Even when I hit roadblocks with the medical world, or at times with the school district, I had other people that were therapists. I had a friend that was an OT. I had a friend that was a PT. So, I had people that I could call and ask, “What do I do next?” and they would help me do this. I can’t get help from the system- but they helped me figure it out.

Maggie’s son Brandon is the oldest individual with PMD included in this study. At 20 years of age, he will soon age out of the school system. Brandon has been on home instruction for his entire schooling experience due to the intensity of his medical needs. On home instruction, Brandon has a teacher that comes to his house several hours each week instead of him going to school. Maggie shared that Brandon is “very sharp” but that people most often assume that he is not cognitively responsive. She attributes this to his physical appearance, the presence of a trachea, dependence upon a ventilator and the fact that he does not respond quickly or through traditional verbal communication modes. Brandon uses his eyes to answer questions and makes choices by looking at what he wants or in a specific direction to answer yes and no.
questions. Brandon will also opt to not communicate when he “is not in the mood” or if he does not care for the person he is communicating with. Brandon is very particular about who he interacts with according to Maggie. She shared a circumstance when a specialist came to their home to see Brandon and Brandon transitioned from active use of his alternative communication eye gaze system to just staring up at the ceiling in a nonresponsive manner while the specialist was at the house. As soon as the specialist left the house, Brandon went back to communicating actively. Maggie described Brandon as having perfected “the art of nonverbal sarcasm.” Maggie shared that in order for Brandon to benefit from activities, education and therapies, “You had to find people that he clicked with.”

Maggie described Brandon as having specific interests. Brandon loves *Star Wars* and scary movies and the show, *Bones*. He loves anything “medical and gross” according to Maggie. Brandon has a service dog and Maggie, Brandon and his dog, Rex enjoy going for walks near where they live. Maggie shares the modifications she makes to toys and activities to make them accessible to Brandon on a Facebook page dedicated to accessibility for individuals with severe orthopedic impairments. Through her modifications, Brandon is able to interact with toys and activities incorporating his interests.

Maggie was told to “not get attached” to Brandon when he was placed with her as a foster child at the age of two. The doctors did not think he would survive long due to his complex medical issues.

He can’t see. He can’t hear. He can’t communicate. He can’t do anything. We were given a whole list and it was basically that he was a vegetable. And, you know, anybody could look at him and see that wasn’t the case.

By utilizing her background in special education, Maggie was able to build Brandon’s communication skills. Once they established basic communication through eye gaze, Brandon
was able to engage and participate and this reduced some of what Maggie describes as his tantrums. “It got us through a lot of, you know, really difficult moments. It also let us know where we were going and that his brain was definitely working.”

Maggie describes Brandon’s younger years as “having many bumps in the road” but that Brandon is resilient. Maggie described a particularly traumatic hospital stay when Brandon coded prior to his tracheostomy.

He had a long seizure and we went to the ER. They did an MRI. They did all the tests because he had had such a long seizure there was concern that he had further damage. But, when they finished the MRI and got him back to the ER, he crashed. His airway started to go. Needless to say, he started to crash. His blood pressure was dropping. Everything. They rushed into the big trauma room all of a sudden and you know, I am staying calm but only on the outside.

As Brandon has aged and he has medically settled, as a family, they have established their “normal.” As Maggie has developed her medical and systemic competencies, they have come to exist within an equilibrium- balancing complex medical care and personal interests.

While Brandon has a circle of friends, Maggie says that the people capable of caring for his medical and physical needs are few. Because Brandon has a trachea and is ventilator dependent, the medical care aspect of his life can be particularly stressful.

Because of the trach and all the stuff that he has, there is usually some point in each day that we have some kind of mini crisis…if people knew what our real life was, they would be really scared. But for us, it is just part of our normal life. People don’t realize that. We’ve had nurses walk out of the house and never come back because we scare them but to us it is absolutely normal life. We scare people. Sometimes we even scare the doctors.

The intensity of their daily medical routine can be off-putting to people. Maggie shared, “You know, this life is lonely anyway with medical conditions and being stuck at home most of the time and you can really feel isolated.”

Maggie has nursing support that allows her to go out and have face-to-face social connections a few times each month. Additionally, the nurse has also become a social
connection within the home. “She’s more like family. She has been for a really long time.”

Having another person in the home has proven beneficial for Maggie. Maggie also described social media as helping with social connectedness. She shared that she prefers face-to-face social interactions but struggles to meet people in-person a few times each month.

Another addition to the household that has aided Maggie and Brandon socially has been their service dog Rex.

I know it sounds totally weird, but Rex has really helped. He really helped with emotional health I would say. You know, when you are having a rough day and there’s this furry face and he comes and plops in your lap- it really just helps. It doesn’t just help Brandon. It helps me as well.

The addition of Rex has increased Brandon’s willingness to go into the community. Brandon attends church with his mom and they love to go shopping and on walks. Maggie shared that this is a new development for Brandon as he previously refused to leave the house.

Brandon had gotten to where he just didn’t like going out. When he was little, we could tell him that people were staring because he had a cool wheelchair or this or that. I could fake it. But as he has gotten older, he wasn’t buying it anymore. He got to where he just didn’t want to go out into public anymore. He didn’t want to be around people. The dog changed that. Now he loves to go out. People see the dog instead of seeing the chair and stuff which has really changed things for him. People don’t focus on the chair or the ventilator. Before it was always ‘What’s this?’ and ‘What’s wrong with him?’ and now people ask about Rex and what he does. It really has shifted the entire conversation and allowed him to interact with people.

Maggie observed that prior to Rex, people seemed intimidated by Brandon’s appearance and his trachea and ventilator. They would not say anything to him instead of running the risk of saying the wrong thing. “When we would go before we got Rex, people didn’t know what to say so they said nothing... hardly anyone would say hello because people seemed so scared to say the wrong thing that they don’t say anything. It’s a catch 22.”

Maggie and Brandon attend a camp for individuals with disabilities every year for a week. She describes camp as being a great deal of work but has been pivotal in their social
connectedness over the decade they have attended. “Camp is only five days, but you are 24/7 with people who get it and that makes a big difference.” Maggie describes camp “as a huge outlet to help Brandon get socialization and make friends.”

Brandon also has a friend that comes over occasionally for sleepovers at his house. His friend also has PMD and Maggie cares for both boys when they have their sleepovers.

It’s a lot of fun when they have a sleepover, but it is a lot of work. The kids have a ball. For them it is a big slumber party. But for me, it is a bit of a challenge when you have two of everything.

Family connections and support are pivotal in Maggie and Brandon’s lives. Brandon and Maggie have support from his grandmother, his aunt and his niece. He has had the same home instruction teacher come into the home weekly for 14 years. When faced with a challenging situation for Brandon, Maggie calls her mother and they work through an action plan together.

Oftentimes it is just the ear because she is really good. She’ll just kind of say, “What do you need to do first?” and half the time, after I get off the phone I realize that I just needed someone to say, “You’ve got this and you are going to be fine”… You just have to deal with the challenges as they come.

Maggie enjoys sewing and cooking. When discussing her own social interests and activities, Maggie shared, “I can’t really go out and do these kinds of things, so I do it through social media.” Maggie describes her social media use as being concentrated on Facebook. Maggie leaves the Facebook application open on her computer when they are home and checks it frequently throughout the day and when she is awake at night. She maintains a “friends only” privacy setting on her own social media page. She is also a member of several disability and activity specific Facebook groups. Maggie has created online connections with a mom in another state who has a child with similar medical issues as Brandon and that they often connect through social media to discuss situations.
I message her and can send her a picture or video and ask if she has seen this before. She helps me figure it out and will tell me to relax and that he is fine or reinforce my concerns and support my judgement in being concerned about it and acting on it.

Maggie and Brandon maintain a blog about his educational activities and how they make his studies accessible for him cognitively and physically. She also facilitates Brandon’s use of Facebook, Facebook messenger, emails and texts. Brandon’s biological family also maintains contact through Facebook. Maggie and Brandon maintain social connections for Brandon through social media. “He has a lot of friends, but he doesn’t have a lot of friends we see.” The challenge for them is getting friends that they can actually see in-person.

He may not see his friends much, but he knows he has friends. He knows that we can see stuff on Facebook, and he can see his buddies doing stuff. We may only see them in-person once a year but with Facebook and social media, we can stay in contact through the year even when we can’t see them face to face.

With Maggie’s help, Brandon maintains a private Facebook group that facilitates his contact with his social connections. Brandon’s Facebook activity has provided motivation for using communication tools and resources and developing his own skills in this area of his education.

He is motivated to use his iPad to make his posts, but it also helps him feel connected because he reads what people write to him. They comment on stuff and I think it gives him a little more feeling that he has connections when he isn’t able to be around people. I think it is the same as we all feel when we are stuck at home and we are on Facebook because it gives us some human connection.

Maggie has a reliable vehicle for transportation and community access, but it is not wheelchair accessible. She describes any trip that she drives Brandon as requiring significant coordination and planning to get Brandon and all of his equipment safely transported.

We go out less because it is a huge effort. He’s got the trach. We’ve got the ventilator. We’ve got different machines and I don’t have a van, so it is a challenge. We do get out. We do our best, but it takes a lot of planning before we go in the car.

Maggie and Brandon prefer to go for walks to local neighborhood locations when weather permits. Brandon especially enjoys taking Rex out and having him bark upon command.
Maggie shared, “It’s a good life. Being disabled doesn’t make you somehow less worthy or not capable of having a good life- it is just different.”

**Diana.** Diana and her domestic partner, Linda are raising their 17-year-old son, Clark. They have an adult son who is in the military and lives in a different state. Diana describes Clark as a superhero. “My kid is super cute, and he never meets a stranger and you just can’t help but love him.” Clark has a delightful and engaging personality but because of his complex medical conditions, he requires significant daily medical interventions to obtain nutrition and stay alive. Clark utilizes a manual wheelchair pushed by another person for his mobility. Clark receives various therapies such as occupational therapy, physical therapy and speech therapy. Clark sees over a dozen doctors and specialists near his home and outside of his hometown. Diana describes Clark’s education as being home schooled in lieu of attending public school but that it is facilitated through an off-campus private school. Diana has had Clark involved in a special needs social skills group for the past 6 years.

Diana shared that Clark had his initial brain injury at birth and then at the age of 3, he had an infection that resulted in a hospital stay where he contracted a further infection that resulted in sepsis. As a result of this, Clark went from using a walker for aided ambulation to non-ambulation and use of a manual wheelchair. After the secondary infection he also had more complex cognitive disabilities and medical interventions related to damage to his digestive system. Diana describes their parenting experience those first 3 years as entirely different from the parenting experience after his second infection at the age of 3.

We got the rug pulled out from under us when he got the second injury. Then it was- he will never walk. So, the hope that we had for independence for him was changed too because before that he was walking with a walker and we thought that he would be able to go to school. But that hope for independence was gone and now he’ll always need somebody to take care of him.
While Diana recognized the shift in their lives, particularly from the second injury, she also noted that who Clark is was a source of great joy in their lives.

I mean I’ve got the best kid forever. I’m going to have a kid forever. I have a kid that fully believes in Santa Claus and the Tooth Fairy even though he isn’t losing any more teeth. I have a full-on kid that believes in the Easter Bunny. Man- I got stuck at the best years. So, you know, there are trade-offs.

Diana likewise shared that as Clark has gotten older things change. “As your kid gets older and things get tougher, their demands are more. You can’t just leave them with someone else because people can’t physically handle them. So, your support starts to fall off.”

Diana shared that taking Clark out into the community takes two people. “Everything we do with him we do together. It takes two people. We don’t take him to do errands. Linda does the errands. We could never grocery shop with him. He can’t handle that kind of stuff.” Diana shared that the demands of parenting a child with PMD can stress a relationship and that she and Linda divide the responsibilities up to get things done to circumvent overstressing their partnership.

She [Linda] does all the post office, banking, grocery shopping because when you have a kid in a wheelchair it isn’t easy to haul. He’s 100 pounds. To haul him in and out of the van and with bad weather on top of that is really hard, so more of those things have fallen on her. I am the one who usually takes him to all of his therapies. We both go to doctor’s appointments because he has a really hard time with that. Any of his social activities take two people.

In addition to in-person activities, Diana is active on social media. She maintains a Facebook account for herself and Clark. She also maintains an Instagram account for Clark. She is a member of multiple private Facebook groups that focus on aspects of Clark’s multiple disabilities and interventions. She carefully and deliberately posts information about Clark on these different platforms. She utilizes the Instagram profile to promote Clark’s social life and disability related activities and causes. She posts her interests and parenting joys on her
Facebook profile. She generally maintains disability related concerns and questions for the private disability groups. Diana seeks to convey this message through Clark’s Instagram page.

You can have a life. You can have friends. You can get out and do it. You can also sit at home and feel sorry for yourself but you’re never going to find anybody to love your kid that way. You have to market your kid. Like we just went to a restaurant and this girl came up to us and asked if he was Super Clark. I told her yeah and she said she had seen his Instagram account. She said she had never met a kid in a wheelchair before and that he lives a better life than she does.

For Diana, her online closed support group is where she goes to gather and vet information about Clark’s disability. It is the first place she goes. This Facebook group includes health professionals, but she is often seeking information that only other parents will have.

When the doctor prescribes a new medication, I go on my group and ask about it. If like 25 of the kids have a specific side effect, I know it’s real. My doctors will say that they have never heard of that side effect, but you have all these moms from all over the world who have firsthand seen it. My doctor will even tell me to ask my moms when something comes up because they (doctors) understand that actual experience is a wealth of information.

Diana uses Clark’s social media account to advocate for children with PMD and inform parents of activities and resource possibilities for themselves and their child with PMD. She shares equipment and activities- especially activities related to Clark’s education. She described it as showing people what they can do because other parents have shared with her that they struggle figuring out what to do and how to go about addressing some of the environmental barriers involved in community activities. She described sometimes receiving feedback that she presents an unrealistic representation of their PMD parenting experience.

People would tell me that I wasn’t showing the real world. I responded by saying that I choose to see the joy- the happiness in each day. If people knew that we had a medical crisis just about every day and if I focused on that in our lives- nobody wants to hear that every day and frankly I don’t want to focus on that every day.

Diana described social media as “lifesaving” for her.
When you have the other mothers, you don’t feel like you’re alone. I see other mothers who think that they are bad moms and that they can’t do this and that maybe they should give their kids to foster care. But we can go online and tell them that they are doing a great job. It is just hard! And we can get them hooked up with resources. It’s just lifesaving. I’m 110% better parent because I have these other moms.

Diana has weekly gatherings at her house with parents who are also raising children with PMD. She met these parents that live locally through social media and subsequently met them face to face. They share information and equipment but mostly their gatherings are a chance to make in-person social connections. Diana has also found similar in-person experiences through an annual parents’ retreat she attends. The retreat is for women who met and follow each other on social media in a brain injury Facebook group. They meet in-person once a year.

Some of the moms meet in-person and that is huge. I mean huge. You know, you’re not getting judged. You really have a high for a long time after that because then you follow them on social media and you are still connected.

When describing the moment she entered the room at the parent retreat for the first time, Diana shared her experience.

It was like having a little minute in heaven. It was like these people are my people. Imagine you are the only white person or gay person or black person and then you get to be around someone else like you. It is like going to gay pride. You just know that these are your people. Everyone felt that way. We just sat in this room, looking around and everyone was crying.

**Themes**

The data produced four major themes related to the phenomenon of parenting a child with PMD within a digital age. The major themes are adaptation, acclimation, social connection and social media use. Each theme consists of additional subthemes.

Adaptation is the initial shift in parenting expectations in response to the arrival of the child with PMD, diagnosis or the occurrence of the disabling condition. For two of the parents in this study, this occurred at the placement of their adopted child with PMD. For two of the
parents in the study, this occurred at birth or shortly after the birth upon diagnosis of their child. For one parent this occurred after their child, who was born with mild disabilities experienced a septic infection resulting in PMD. Adaptation subthemes include: focus upon the moment, understanding systems of resources, and lack of accessible parent role models.

Acclimation occurs as the parent develops skills in navigating the requirements of parenting a child with PMD. Acclimation subthemes include: living a new normal, accessing systems of resources, and accessing parent peers.

Throughout interviews, parent respondents spoke in depth about social connections. Social connections subthemes include: inter-relatedness of in-person and virtual-life connections, a triad of social effort focus, and the use of social media bricolage to meet disability related needs.

The theme of social media use is comprised of benefits of use, online privacy, pitfalls and collective power.

**Adaptation to Changed Parenting Expectations**

The parent respondents described their initial PMD parenting experience as a time of adaptation from the expectations associated with parenting a neurotypical child to parenting a child with PMD. The parents in the study described being immediately immersed into a world of medical crisis, unclear and complicated resource systems with no in-person parent role models available for guidance and advice.

**Focus upon the moment.** Upon the arrival of their child with PMD, parenting concerns for all of the respondents were focused upon immediate medical stability. Initially, all of the children had been given grim predictions of their futures in terms of survival and developmental outcome. Anna was told her boys, Adam and Nate would be “vegetables”, unable to walk or
respond in any functional manner. Maggie was told that Brandon’s stay in her home when he arrived at the age of 2 would be short lived as the medical professionals and social workers didn’t expect him to live past the age of 3. Parents focused on the survival of their child. They described this as the hardest part of their parenting journey to date. The thought processes the parents described were of an immediate focus with little consideration of long-term issues. Alma recounted Corbin’s early years as being consumed with acute medical issues. “We were dealing with seizures- uncontrollable seizures. Then we were dealing with brain surgery to try and control the seizures. Then after that was nine months of fighting infection and recovering from surgeries. Everything felt like a crisis.”

Like all parents, parents of children with PMD initially get to know their child’s personality through caregiving. The presence of complex medical conditions complicated this process for respondents. Lengthy hospital stays and ill children interfered with traditional bonding experiences for the parents and their children. Their children with PMD often responded in non-traditional ways to interactions because of physical discomfort or cognitive variability.

Understanding system resources. The study’s parents seek medical stability and manage complex medical issues throughout their child’s life. While there are educational, systemic and medical resources available to families, this study’s respondents described receiving little guidance in navigating these systems during the initial period of adaptation. The parents found that even medical information was often unclear. Lilli shared, “Doctors tell you one thing. A nurse tells you another. You have to figure out what’s best.” Diana described sitting in the doctor’s office discussing treatment options for Clark and having the doctor ask her what she thought they should do.
I told him that I am not a doctor. I have no idea what treatment is best. This was all new to me. Apparently, neither did he and he was the leading expert in the field. At that moment I knew that we were pretty alone in this because even the experts didn’t know what to do with us.

Diana said, “Early on no one tells you anything about resources. I found out more once I got connected to other parents on social media.”

The two parents that adopted their children with PMD had previous experience with individuals with disabilities and systems of resources. Both of these parents shared that the familiarity with disability-related information and access to resources aided them in adjusting to their parenting journey but they also experienced roadblocks. Maggie shared her experiences of working with individuals with disabilities prior to adopting Brandon.

I had worked at a private school that served multiply complex kids. Basically, it was a special school for kids that couldn’t be managed in typical public school because they were so complex. So, I had a lot of exposure while I was in college. I had a lot of exposure to different communication strategies...all of the exposure that I got just rolled over to Brandon. It was really perfect for ending up with us here together as a family.

Having an understanding of available resources and individuals to contact for information helped Maggie and Anna adjust to their PMD parenting experience. The parents in the study each developed their own resources and understanding of complex medical, educational and resource systems over time as they acclimated to PMD parenting but described the period of adaptation as overwhelming, disorienting and without access to in-person peer parent resources.

**Lack of accessible role models.** The parents described adapting to an unfamiliar parenting experience with minimal guidance, role models or understanding of how to navigate the systems of support available. The parents in this study shared that they were unable to find in-person accessibility to other PMD parenting peers early in their child’s life during adaptation. Parents described feelings of isolation. Parents who gave birth to their child with PMD shared
that they did not personally have interactions with another parent raising a child with PMD when their child entered their life. Alma recounted,

When Corbin was little, things were hard, and it stressed our marriage. We went through a divorce and I don’t have family living near here. All of my friends had children but none of them were raising a child with a disability. I felt very alone.

Several parent respondents shared that they struggled off and on with depression. Parents did not just feel alone emotionally, they also struggled to find other parents raising a child with their child’s conditions in-person. Because each child with PMD represents a particular collection of rare diagnosis, conditions and treatments, none of the parent respondents have been able to interact with someone raising a child with the same diagnosis, combination of disabilities, interventions, skills and needs in-person.

The parents in this study reported turning to social media for assistance in connecting with geographically distant parents raising children with PMD. Parent respondents shared that they were often faced with major medical decisions with few in-person resources guiding their decision-making. Dana recounted trying to decide if Clark should have a rare surgery.

We sat down with the doctor and he told us that the surgery should help with the pain Clark was having. He had done the surgery with about 10 kids like Clark and felt they all had positive outcomes. It was a huge surgery. Once it was done it couldn’t be reversed. The doctor said it was up to us. How are we supposed to make a decision like that? He thinks it helped the other kids? He wants to cut my child open and he thinks it will help? I need more than that. I went online to my other parents and tried to find kids that had had this surgery. All the parents I talked to online said the surgery did more damage than good. I couldn’t find one good outcome in real life. I needed more information than the doctor gave me to make a decision like that.

Parents reported seeking other parents and children with PMD through social media to locate in-person experiences of these rare interventions that are more common within the lives of children with PMD. Parents reported finding relevant information from other caretakers regarding surgeries, medications and therapies through social media groups that focused on the needs and
diagnosis of their child. Online, parents shared resources and services available to them creating
a virtual resource hub for these geographically isolated parents. This virtually sourced
information aided them in navigating resource systems in-person.

**Acclimation to PMD Parenting**

**Living a new normal.** As the children with PMD medically stabilized and parents
developed skill sets according to their child’s needs, they begin to acclimate to their “new
normal.” Families incorporated complex medical and care procedures as familiar daily tasks.
The parent respondents reported being able to focus on getting to know their child.

Corbin is nonverbal so I had learned to speak ‘Corbin’. Over time I have developed a
better understanding in being able to read him and understand if he is hurting or if he is
stressed or if he is mad at his sister or just annoyed at the dog barking.

Within this new normal, parent respondents had to develop an understanding of not only
who their child is, but also develop an understanding of the implications of their child’s medical
conditions and diagnosis. During acclimation, the parents begin understanding the long-term
implications of their child’s PMD and reorient to this changed parenting expectation. When the
children were young, parents sought therapies, interventions and pursued resources in what
Maggie described as a “frenzy of effort to try to fix everything.” As their children aged, parents
described an acceptance of their child that resulted in a more relaxed enjoyment of their life and
parenting. Alma shared, “As Corbin has gotten older, we have a better sense of what he needs
physically and physiologically and emotionally. There’s more balance.” Maggie shared a
similar sentiment:

I’ve gotten more relaxed. That’s huge. When he was little, I wanted to try everything.
Do everything. Every possible therapy. Anything that had any potential to help him. I
was pushing us way too hard. As he has grown, I have had to slow down because he is
bigger, and I am older. I can’t keep up the speed and I think we are both doing better
because I am more relaxed. I am not so intent on changing him or fixing him. I realize
that this is where we are and we’re good. He’s much more relaxed and we actually accomplish more this way.

For parents of neurotypical children, the physical requirements of parenting decrease over time as the child becomes more independent. For parents raising a child with PMD, the physical care requirements increase as the child ages. Houses and vehicles need to be modified for physical access and to support care routines. Their daily care becomes more physically intensive. Alma describes Corbin as her personal trainer.

I have pretty good biceps on me and a really strong back. He can bear weight to some extent so that helps in getting in and out of the car… I only really have to pick him up when he gets in and out of the tub. He weighs 110 pounds now.

Parent respondents voiced the impact of the physical toll of caretaking upon their health. They also shared the impact of the increased size of their child and that the weight of their equipment limits their ability to access the community. Diana shared:

People just don’t understand. There are no quick trips to the store. You just need one thing? You just have a minute? It doesn’t matter how much time you have or how little you need to pick up. Every time we get to a store or stop somewhere, it’s drag the wheelchair out of the trunk and put it together. Then I have to get Clark out of the car and into his chair. Then I have to figure out how to take this kid that gets overstimulated so easily through a store while I push or pull a cart. Then reverse it all and lift him into the car, break down the wheelchair and put it in the trunk. Then I get to figure out where to put all the things I bought because Clark will mess with them if I put them with him and there is no room in the trunk because of the wheelchair. An accessible van changed our life, but it is still a whole lot of work to get in and out every stop we need to make. It just isn’t worth our energy. Instead we focus on the social stuff that we think benefits Clark— not picking up a grocery item or mailing a letter.

Lilli also echoed these difficulties as Lila grows. “It makes it exponentially more difficult.

Lugging a cart behind me. Pushing Lilli in front of me—especially when she gets upset. Most of the time she is great but if she gets upset, the world will know it.”
Within the realities of their new normal, each of the parent respondents described the effort required to go into the community as forcing them to focus their resources by prioritizing their outings. Medical appointments were listed as a priority by all respondents. Social outings were also a high priority. Parents found ways to meet household needs such as shopping and errands through delivery, curbside pick-up shopping services and division of household responsibilities with spouses. Parents also utilized nursing services, specialized daycare and babysitting to allow for errands to be run without having to transport their child with PMD into and out of vehicles at every stop. However, finding qualified childcare proves a significant challenge for some of the parents, particularly if there are complex medical supports required. Because of Brandon’s trachea and ventilator, Maggie shared, “There’s not a lot of people that know Brandon well enough to take care of him.” Anna hires babysitters from the boys’ school and utilizes curbside pickup.

I needed more help, so I hired one of the aides from the boys’ school. He knows them and I feel comfortable leaving him with them while I run errands. The other thing I do is the Walmart or Target grocery pick up. I can keep the boys in the car, and I don’t have to run them through the stores.

In addition to the amount of physical effort increasing as the child with PMD ages, the barriers to community access and societal response to their child’s presence often resulted in adverse experiences. Maggie shared a particularly disturbing experience with a nurse:

We had a nurse come out to our house to work with and take care of Brandon. She said in front of him, ‘Nobody should have to live like that.’ I was afraid to leave him alone with her. She wasn’t allowed back in our home. It is hard to imagine that taking care of people is her job.

Parent respondents described stares and derogatory comments when in the community outside of disability focused activities. Parents also described a sense of invisibility when in the community.
Even within educational and medical systems designed to serve their child with PMD, parents described having to force people to see their child as a human being. Parent respondents described educators treating them as if they overestimate their child’s skills and communication. Maggie shared her experiences with school district personnel when they were working with Brandon.

It was kind of a challenge. I felt like I was battling with people who only saw him for a half an hour each semester. They didn’t see him—how capable he is. His teacher saw it because she spent more time with him. The school district people treated both his teacher and I like we were only seeing what we wanted to see.

Similarly, parents reported experiences of medical professionals dismissing their child’s humanness during treatment and interactions. Maggie shared that Brandon has to feel comfortable with his medical professionals. “If he isn’t comfortable or if they don’t talk to him like a person, I just know it isn’t going to work. We don’t even try at that point. We move on and find a better fit.”

One aspect of their new normal included parent respondents having to interpret their child to the world within service systems designed to meet their child’s needs as well as in the community in general. Parents described trying to make their child visible to others through social media posts. Social media presented a format to share their child in what the parents describe as a “positive light” to multiple individuals with minimal effort. Alma shared.

My friends have developed an appreciation for who Corbin is through all these years of following him on Facebook. He has basically grown up on Facebook. People were with us in the early days when he was tiny, and I would celebrate that he was 2 ½ years old and could finally hold his head up. Any parent wants to celebrate those milestones. Facebook allows me to celebrate who he is and what he is doing. I guess it is a way for Corbin to express himself through me through Facebook. He has quite an online fan club because of it.

**Accessing systems of resources.** As they acclimate to PMD parenting, the parent respondents describe an increase in their understanding systems of resources and how to
effectively negotiate these systems to meet their child’s needs. Maggie shared that over Brandon’s life she has gained confidence, skill and knowledge in meeting his needs. “We have these hiccups, but we just deal with them as they come now.” Parents described finding out from other parents what resources were available through social media and virtual messaging. The parents developed relationships with service providers including service coordinators, nurses, doctors, social workers and teachers that aided in the access and understanding of systems.

As the parents acclimated to navigating resource systems, meeting their child’s particular needs and developing their own skills in meeting caretaking requirements, they developed an increased sense of competency over time. This competency was not just in specific knowledge, but also in developing the connections and familiarity with resource systems to get what they needed for their child. They developed the personal resources to persevere through these processes. Diana described everything as a “battle.” Anna described the amount of time that it takes to navigate systems.

The systems are supposedly designed for my child’s needs but getting those needs met is not easy. I spend hours on the phone. It is a fulltime job just getting to the right person about something we need, and this isn’t just one call and done. I am on the phone constantly. You would think things would just fall into place over time, but they don’t. Medical supply orders that we have gotten for years all of a sudden aren’t approved or they send the wrong thing. Every month I struggle to get his prescriptions filled correctly. Every month. Like we haven’t been doing this for years.

While the parents describe experiencing stretches of medical stability for their child, life continues to present challenges medically, systemically and educationally over time. A particular challenge was significant system-based life transitions. At the age of 3, the children transition to school services from early intervention. Then, at 22, they transition from school services to adult services. These transitions prove to be challenges as they involve transfer to new systems of resources. However, the parents describe an understanding of how to facilitate
the transition process for their child because they have developed a sense of their own competency at navigating systemic resources. At the time of the interview, Maggie and Brandon were facing a significant life transition as he prepares to enter adult programs from school-based programs. This transition forces changes of several significant service providers in Brandon’s life. Maggie described her approach to this transition and its challenges for their family.

We were told things were going to work one way and then as his birthday is approaching, we are being told they can’t happen that way. So, we just have to switch gears and figure out how to approach it. This shift is huge. It impacts his educational resources. His healthcare. Everything. Everything that keeps him alive is impacted by this misinformation we were given. I can’t change the new information. It is what it is. Let’s make a new list and figure out who we need to call to work through it. So, I know I need to calm down and remind myself that this is going to happen. I can’t stop it from happening so I can either stress out about it or be as prepared as I can be.

Parent respondents shared that social media connections with other PMD parents were an essential resource to parenting a child with PMD even after they felt competent in their own parenting. While she has become the resource of information for many parents in social media groups, Diana sought resources to guide her through the conservatorship process for when Clark turns 18.

We were looking at him turning 18 and in the back of my mind I knew I had to get conservatorship. I wasn’t sure how to go about it, so I contacted a parent of an older child like Clark and she helped me navigate the process. We did this all online.

**Accessing parent peers.** Online access to other parents through social media was described as a valuable resource for information and support. The parent respondents credit much of their acclimation to parenting a child with PMD to connections they made with peer parents through social media and service providers in-person. Because they often did not have in-person access to parents raising a child with PMD except through occasional disability-focused activities for individuals with disabilities, social media widened their interactions beyond geographical limitations. Lilli shared that she has “tons of followers” on social media
but struggles in finding those connections in-person. “I have friends all over the world that are like-minded just like me. They are on Instagram and Facebook. I just can’t find anyone who lives near me.” Diana shared, “When I think about my parenting before and after Facebook, I have made friends that I am now friends with in-person. I would have never had the exposure to that many special needs parents otherwise.” Parent respondents described feeling a sense of seeing themselves in the other parents they interacted with through social media. Anna shared.

It’s helpful to go on Facebook because you see other parents going through the same things you are going through. I also feel useful. To be able to give out resources and help other parents and share the things I have already figured out, that gives me a good feeling to know I have helped someone.

Parent respondents describe an emotional connection with the other parents through social media. Diana recalled, “I started parenting without Facebook and I can tell you it’s lifesaving. I wouldn’t have known that sometimes the way I felt is the way other parents feel too. They can tell you that it’s going to get better.”

While the parent respondents appreciated support and connections from a variety of sources, the most valuable information about their child’s disability and interventions such as surgeries, treatments and resources came from other parents raising a child with PMD.

My support group online is the first place I go. I promise you those moms have a lot more to offer me than any doctor or nurse. I understand that we need to ask our doctor for medical advice, but even our doctor says to ask my moms online. He knows that they have a depth of understanding that no one else has.

Without these virtual connections, the parents would be making decisions without any in-person references because of the rarity of resources pertinent to their child’s disabilities and interventions.

Parent respondents reported taking options from their physicians and vetting these options with the relevant online social media groups. Through these groups, they were able to
discuss with other parents who had made these decisions and explore possible outcomes from those that had lived the experience. Alma described the difference between the resources and support available from other parents raising children with PMD and individuals outside of that lived experience.

I would say there are people who are tangentially connected to our life. Other parents first and foremost get it. I am good friends and connected to many of his teachers, nurses and therapists, his physical and speech therapists and other people who get him and understand him as a person and just think he is a great kid. There is amazing value in that. But they don’t necessarily understand what it is like to be the mom of a critically ill child. What it is like to be responsible for this child during a stay at the hospital- to parent a child who has so many things that can go awry at any given moment. But these people are balancing in our life. They still can love and support us and there is amazing value in that too. Just in a different way.

The social connections made through social media provided a format for exchanges of ideas and resources for daily care for their children. Parent respondents were eager to share helpful items and approaches that have been effective with their child. Anna shared,

I come across some stuff that is useful or that has been helpful with the boys. I post it because I know there isn’t a lot of resources out there for parents of special needs children. I post things I know help the boys when other parents talk about the same challenges. It has been wonderful for me because I feel like I am helping other parents and I am getting help too.

The sense of parenting skill development and confidence was manifest through online connections but also provided an opportunity to be of service to other parents. Parent respondents shared satisfying feelings manifest from paying forward the help that they had received. Alma shared,

There has never been a better time to be the parent of a child with disabilities because of the access that we have to other parents. It is unprecedented. Even when Corbin was born, Facebook didn’t exist. So, to be able to parent him, especially as a single parent and to be able to forge connections like this, it is wonderful.
Connections

**Inter-relatedness of in-person interactions and virtual life.** Parent respondents described social connections as a priority in their long-term coping. Parents put effort forward towards both in-person and virtual life social connections. Parents described benefits from both in-person and virtual social interactions. However, all of the parent respondents emphasized the importance of having in-person social experiences. Maggie shared,

> While I find things like social media help, face-to-face is always better. It doesn’t always happen, but I try to at least find some way to have real face time a few times each month. I mean, there are times when things are crazy and I can’t.

These in-person interactions were described as difficult to arrange but highly valued within their lived experience.

Because these in-person interactions were difficult to arrange, virtual social connections were described as key to day-to-day functioning. These virtual connections served as bridges between in-person interactions as well as providing support with minimal personal resource investment. The virtual connections were utilized to support and arrange in-person interactions resulting in consistent interplay between the virtual and the in-person. Maggie provided an example when describing a routine appointment at a hospital two cities away from her home.

> My online friend saw that we were going to a nearby hospital for an appointment when I posted about it the day before. She messaged me that she lived near the hospital and we ended up meeting for lunch. We’ve been tight on social media and now we had this chance to meet in-person. Through social media I have ended up with real friends.

Similarly, Diana met parents online then realized they actually lived in her own town. “I met two parents from our online brain injury support group, and even though our kids are different ages and have different injuries, it turns out they live in our town so now we hang out.”

While all respondents spent time daily engaging with social media, the in-person social interactions were a significant focus of their efforts. These in-person interactions were powerful
for the parents and Maggie described them as “life sustaining.” Diana had similar feelings at her experience at the parents’ retreat she attends annually.

Once a year we go to a mom’s retreat for kids with brain injury. You follow them on social media all year and then we get together once a year. Meeting in-person is huge. I mean really huge. You know you’re not getting judged. You kind of know them already and you feel a high for a long time after that connection. Then when you follow them and their child again after, you feel even more connected.

In-person social activities include annual camp for individuals with disabilities, annual parent retreats for parents raising individuals with disabilities, social skills groups for children with disabilities and more recently, specialized pediatric daycare for children with disabilities as well as accessible, local community activities. The parents described the combination and interplay between in-person and virtual social support as key for long-term caregiving and coping.

The parents in this study utilized social media as a mode of connectivity that they easily explored without having to expend the amount of effort required for in-person interactions. The parents were able to cultivate and maintain social connections without having to physically go into the community. They are able to vet activities and relationships online prior to putting forth the significant amount of effort required to physically attend activities. Conversely, when parents made connections in-person, social media was used to maintain these connections over time and across geography. Alma highlighted, “We have met lots of other people who live in the same world we do, or should I say the same universe we do. They are scattered around in different towns.” Parents described the interplay of in-person and virtual life as key to making and maintaining social connections within the demands of the PMD parenting experience.

**Triad of social focus.** Parents identified a triad of foci in their social efforts and connections. The parents focused on their own social interactions, their child’s social
connectedness and the needs related to their child’s medical conditions and disabilities. These foci were addressed in-person and in virtual life through distinct approaches and resources.

**Parent social needs.** All of the parent respondents indicated the importance of managing their own personal interests and coping mechanisms through social connections and investments in their own interests and hobbies. Parent respondents of this study explored hobbies and activities distinct from their child and the disability. Parent respondents shared that this was a significant aspect to their ongoing social wellbeing.

In virtual-life, parents made connections to individuals through social media friendships and through Facebook group memberships. Maggie describes the role of social media connections, “Without Facebook we would be a lot more isolated. We need outlets. We need ways to connect with people. A lot of the friends I have now are because of those online connections.” Alma describes social media’s importance and availability.

We feel down on ourselves. We ask ourselves how are we going to do this? How am I going to take care of my son when I don’t feel like I can take care of me in some moments? What can we do? The online world is a very real world and a very real community of emotional support. We might be connecting through a group at three in the morning instead of in-person or on the phone but that is just because we are the only ones awake at three in the morning! I don’t know how I would parent or even who I would be or how I would cope without that kind of support. I certainly have friends in real life, but I am not going to call them at three in the morning because I can’t sleep and I feel like the worst parent in the world. Only my other hive members are going to understand where I am at that moment.

The parents very deliberately separated their social media persona and interests from their child’s social media representation and disability related posts. For example, Alma maintains a profile on Instagram dedicated to her personal running activities. She shared that she doesn’t want to bore people with “a thousand posts about running” and expressed concern that her son, Corbin’s story and messages would get lost in the feed. She worried that “people would stop paying attention to his story” amongst her running posts. While she and Corbin also run
together, those posts are shared on the Facebook profile that she uses to highlight Corbin’s life. “I use the Instagram account completely different than how I use the Facebook account.” By keeping them separate, she shared that she is able to highlight his life to a wide audience and target her running activities to her fellow runners by utilizing separate applications and profiles.

Parent respondents arranged in-person social interactions through the social media connections. While all of the parents expressed the difficulty with arranging in-person social interactions consistently, each respondent shared the importance of in-person connections for themselves. All of the parents reported that their coping strategies include social supports and connections, as well as the pursuit of personal hobbies and interests. Several respondents shared that they had social support from family and close friends. Church was an important social resource for several respondents.

The parents in this study acknowledged the ease of use of social media, its beyond immediate geographical reach, its diversity of available resources and flexibility of use as benefits, but it was also clear that social media alone did not completely satisfy their social needs. The parent respondents emphasized the importance of in-person interaction for their emotional wellbeing. The ability to connect in-person with other parents proved a powerful experience for Diana at her annual parents’ retreat. Maggie echoed this sentiment when discussing the annual camp experience for her and Brandon. “Camp is a ton of work and preparation, but we get so much out of it. We have been going for 10 years and have met and maintained so many friendships for both of us from there.” The importance of in-person social interactions was unmistakable throughout the data, but the essential role of social media to maintain and nurture those connections between in-person opportunities was evident from the respondents.
According to the parents in this study, when the initial meeting between parents raising children with disabilities took place in-person, the connection was then maintained through social media. Anna described meeting other parents raising children with disabilities at appointments or at the mall.

I will be sitting there with the boys, and someone will approach me and tell me that they have a child with disabilities or know someone close to them that does. Then they open up and start talking and telling me about the child. I will ask if they know about certain resources and before we part ways, we friend each other on Facebook.

The resulting social support and connections aide in their parenting, but the parents in this study stressed the importance of maintaining and nurturing themselves. The intensity of demands and dedication to their child’s physical and emotional existence can become all-consuming and parents of children with PMD can lose themselves in the experience. Diana emphasized the need to maintain a sense of self separate and distinct from the parenting persona.

You have to be a parent of a special needs child. It’s not your disability. It’s the child’s disability. Too many parents make it theirs. It’s not. You can’t let it take over everything. You still have to be you.

Maintaining a sense of self, exploring personal interests and maintaining social connections outside of parenting and disability was consistently described as an essential component to coping and long-term caregiving for the parent respondents.

*Child’s social needs.* The desire for social connections in-person also transferred to efforts on behalf of their child with PMD. Every parent respondent emphasized their desire for their child to have meaningful social connections. Lili shared her hopes for Lila’s social connections. “The hardest thing is finding friends for her…to have some sort of semblance of a normal life.” Parents sought and explored social media connections for their child with PMD. All of the parent respondents shared that their child’s social life and social connections were a significant priority in their lives in addition to their own social connections. For Brandon,
Maggie described her efforts as “constant” in providing social opportunities for him. “It’s a challenge to get him socially involved. We have lots of online friends but making social things happen in-person, it’s a whole different world.” Parent respondents described creating and maintaining online posts and accounts for their child. Diana described “marketing” her son Clark’s online persona. When these online personas for their child resulted in-person social interactions, parent respondents continued to maintain these social connections via social media. The in-person interactions tended to be few in number and spread across time because of the limiting impact of physical access and intensity of medical issues.

All parent respondents actively sought social connections for their child through social media use and profiles designed specifically for their child. Lilli utilized applications for meeting other individuals with limited success. Diana shared that people recognize her son Clark through his social media persona. “People recognize him around town from his Instagram account. He was even invited to Comic Con because of his Instagram account.” Maggie aides Brandon in posting on his own Facebook profile, sending texts and emails. “I hesitated giving Brandon his own Facebook for a long time. It has been really helpful. He has a private group that I can really monitor but he does his own posts with my help.”

Seeking social experiences for their child with PMD that reflect what the respondents described as “normal life” were highly sought after. Alma pushes Corbin in his racing wheelchair on his high school’s cross-country team.

The last two years he has run with his high school cross country team. While it is demoralizing for me at 50 years old to run with a bunch of 17-year old boys- I mean, my ego really takes a beating- but his coach was really supportive and he gets to hang out with his typical peers and be a part of a team just like any high schooler.

Through social media, parent respondents are able to share opportunities and experiences in accessing the community- both successful and problematic. Maggie shared that prior to going
someplace new, she will often solicit information through a Facebook post. This allows her to maximize Brandon’s experiences in the community by being prepared for access barriers and identifying available resources in advance. Diana will similarly post activities that she and Clark attend knowing that local parents trust in her experience. Other parents know that if she and Clark are going to an activity, it is likely to be accessible and friendly to individuals with disabilities. “It is an able-bodied world,” Alma shared. “Something as simple as steps or blocked off parking access can make places and experiences inaccessible to Corbin and it breaks my heart to see him disappointed by these stupid things.” Parents plan and execute outings carefully for their children to provide opportunities to explore their interests. Brandon enjoys shopping and he and Maggie will walk to stores in their neighborhood so he can make purchases. Corbin and Alma attend running events with his racing wheelchair. “We have made friends in different towns and at different races through our online connections with inclusive racing. That’s really great for both of us…It is really nice for him to have that sort of community.”

Opportunities for in-person interactions for the children with PMD are highly valued by the parent respondents. “Every party invitation is a huge deal for us. To go to someone’s birthday party is a wonderful treat for Clark. We never say no.” shared Diana. Brandon has a friend who also has PMD that comes over for slumber parties. Maggie shared that all of the work in providing for both boys’ caretaking and medical needs is worth the fun that they have together. Lilli shared her desire for the same experience for Lila to have a childhood friend and experience a sleepover. Corbin attends a special needs daycare giving him access to other peers with PMD and this gives Alma regular access to seeing other parents raising a child with PMD in-person, if only in passing, at the daycare for drop offs and pickups. She shared,
Because I have been a part of the special needs community for 16 years, we now know a lot of kids with profound disabilities. I know a lot of parents of these kids- both in-person and through social media.

Accessing the community was often described as a double-edged sword. While being in the community was a goal, the actual experiences could serve as deterrents. Parent respondents shared the challenges of public interactions. Diana shared that these experiences can build to a breaking point.

When one more person is just staring at your kid out in the community, it pushes you over the edge. You go online to vent and say that there is no way you are going out anymore. We are just going to stay home. And the other parents on Facebook tell you that you have to go out and they help you come up with ways to handle it in the future.

Parents described taking deliberate steps to increase the quality of their child’s interactions within the community. Maggie shared that this was one of the motivations for obtaining a service dog for Brandon. “Brandon had come to hate going into public. Getting Rex [the service dog] changed everything.”

**Disability related needs.** Separate from the child’s social needs, the parents described the needs of the disability as a focus of their efforts in-person and through virtual means. While the disability is intertwined with the child and impacts social opportunities, the parent respondents addressed disability related needs as separate and distinct from their child’s social needs. While parents were unable to find other children with their child’s diagnosis in-person, they readily found children with similar diagnoses online.

We have never met anyone in-person but there is a Facebook group for Corbin’s diagnosis and that is really significant. His condition is incredibly rare. At daycare, we are surrounded by parents of kiddos who all have different rare disorders.

The disability related needs on social media were addressed mainly through membership in closed or private Facebook groups. Diana described some of the groups available to her through Facebook for just one of Clark’s diagnoses.
Like on the HIE group, there are thousands and thousands of groups internationally. Then the groups are broken down by where you live. Then there are subset groups that are just for feeding, seizures, equipment. There are groups for ages.

These closed groups limit accessibility to posted messages to approved members only. Parent respondents felt that it was important to maintain the medical and disability information separate and non-public from their child’s online persona. Anna shared:

That’s why I don’t post a lot on my Facebook page. I do post in the disability page because it is a private group and you have to be a doctor or a parent or a therapist or a family member to access the posts on the page.

Parents actively maintained separation of medical and disability information from their child’s social media presence. “My son is more than his disability. I don’t want people to focus on just his disability. He is so much more than that but that is what most people see,” shared Diana. Both Diana and Maggie felt that if people knew the medical complexity of their sons’ disabilities, people would be scared and potentially avoid interacting with him in-person. Maggie describes her approach to posting medical information on general Facebook pages.

Medically I stay pretty vague on my Facebook page. I am sure that if people knew everything, they would just go nuts. For us it is normal. It is absolutely normal life that would send most people over the edge. You learn where the line is that you can handle, and you also learn that sometimes when things look really bad, they are not that bad because we see it every day. We just follow our procedures and deal with it, and it works out.

As a result, the parent respondents post disability related questions on the private group boards or in private messages to specific parents that they trust. The parent respondents shared that this occurs at all hours of the night and day. Alma recounted her experiences of receiving texts and messages in the middle of the night.

We are all connected online. I can’t tell you the number of times I have gotten a text a 3 o’clock in the morning with pictures asking me if I think something is serious and if it warrants a trip to the ER in the middle of the night. This ability to connect beyond time and location means that we aren’t alone. We can ask for help and advice even when we are the only adult in the house.
In-person, the disability needs are met through accessing networks of services including education, medical, service resources and programs. Parents often discover available resources through online interactions with other parents in disability specific groups. Parents described a significant interplay between in-person disability related resources and the vetting of these resources through social media. Diana shared that her physician suggests she access information from her online parent group when looking at new medications and their possible side effects for Clark. Parents look to other parents living the same parenting experience for information about therapies, opportunities and resources. Referencing her online parent connections, Diana shared, “They teach me things because things have changed since Clark was little. We pass equipment and stuff, but we didn’t know each other before we met online.” Lilli has made connections as far away as England in sharing resources and ideas for Lila.

I look through the pictures on Instagram or Facebook and I see something cool in a picture for Lila. I will message the poster and see where they got it. I will post cool things I have for Lila and have had people message me about them too.

Anna shared that when her son went in for major surgery, it was her online resource of other parents that helped her through the medical intervention for her son.

When he went in for the surgery, it was the other parents on my Facebook group that helped me understand what the surgery was going to actually be like. They told me that he would be all swollen after surgery. The nurses and doctors hadn’t mentioned anything like that. I would have freaked out if no one told me to expect it. No one else could help me figure out how to do his aftercare too. No one else does what we do, and I don’t know if I could have figured it all out as well without the other parents helping me.

Locally, parents share the names of respected physicians and therapists. Parents with an understanding of accessing supports and navigating systems provide guidance to other parents who are navigating the same systems. Alma shared that when she goes online and posts a question, either someone will have the answer, or they will know someone who does. Parents
also share educational resources. Maggie and Brandon maintain a blog for adapting educational activities for physical access based upon his home instruction activities. Alma described the online community as a “hive” that is there to support each parent in their journey. She reported that this support crossed over into in-person interactions when geographically possible.

That network and having ready access to that hive mind through social media, often Facebook, is really, really important. It’s not just for advice or emotional support. Like when you end up with your kid in the hospital, having that emotional connection to moms who know what you are experiencing. They get it. They drop off food at the hospital or bring you diapers or supplies you need that the hospital doesn’t have…Your hive is here. We will help you in any way we can.

**Social media bricolage.** Parents utilized what I am describing as “Social Media Bricolage” to address their child’s complex diagnosis and medical conditions. Children with PMD often have rare diagnoses and multiple medical conditions. As such, it is problematic to find another child with that same collection of diagnoses. Additionally, children with PMD experience a range of interventions. While parents were able to find other children online with the same rare diagnosis, those children had different combinations of conditions than their child. The parents in this study described building online disability resources in a bricolage manner to reflect the specific collection of diagnoses, treatments and disability related needs of their child. Maggie built online Facebook group memberships reflective of Brandon’s complicated disabilities and disability-related interventions. She was a member of a brain injury group, an alternative communication group, a seizure group, a gastronomy feeding group, a blended diet gastronomy feeding group, and a trachea and ventilator group specific for children. These disability specific groups were private groups that required approval for memberships. Posts were unable to be shared through Facebook to non-members. Maggie and Brandon are also a member of the more public Canine Companions for Independence and Eagle Eyes communication system Facebook groups.
These virtual connections created a matching pool of resources representative of their child’s disability related needs. Diana described her reasoning for the bricolage membership in Facebook groups.

Clark doesn’t fit in anywhere. So, I have different groups online. In the total parenteral nutrition group, their kids don’t have cerebral palsy. On the cerebral palsy page, they aren’t on the total parenteral nutrition. There is one kid on the hypoxic ischemic encephalopathy group who is on the total parenteral nutrition, but he is really young, and Clark is a lot older. Then in our autism group, no one else is on the total parenteral nutrition or has cerebral palsy or hypoxic ischemic encephalopathy.

Utilizing this social media bricolage approach, parent respondents joined multiple social media groups that created a composite of their child’s conditions, treatments and needs. Alma describes her online experience.

There are online groups for all of these rare diseases that no one has ever heard of and you would never encounter anyone in your town with it. But you can find them on Facebook now. Big groups- hundreds of people raising kids all over the world even though there is not one person within 500 miles of you.

While parents were not able to find a child with the exact combination of needs reflective of their child with PMD in-person or online, they were able to build an accurate compilation virtually through membership in multiple Facebook groups, essentially creating the matching web of resources that most accurately addressed their child’s collection of complex needs.

Social Media Use

Benefits of social media. All parent respondents described using social media multiple times throughout the day. Alma described her social media use as “spending more time on it than she should.” Anna described being on it “all day every day.” The virtual life connectedness of social media played a significant role in their daily social functioning. Alma described social media as “a really important link in our lives because we are not out and about as much as typical kids would be. You know, social media is very often our link to the outside world.”
Parents described a connection with other parents raising children with PMD that includes an understanding of social media posts not readily apparent to non-PMD parents. Parents described being able to communicate differently with parents raising children with PMD and other social media participants within the same post. Maggie shared an example of this unspoken understanding of messages conveyed on social media.

I can post something, and I can do it in a way that people understand what they need to understand. I can post that we are at the ER and people will send Brandon messages of support. But those that really know us know that we don’t do ER’s. They understand the gravity of that post. I have learned that those that live this life can read between the lines. So, I have learned how to post so that some people don’t realize what is happening, but my special needs parents get it. I don’t have to message everyone separately. I don’t have time for that in that moment. I have learned how to post so that half of the people don’t realize what is happening but those that I want to know will understand.

Parents described social media as a valuable resource for sharing information, interventions, distracting themselves and receiving and providing social support. Alma shared,

There are things that I would have never known about for myself, for my child and for his disability without social media. I probably wouldn’t be running. Certainly, Corbin wouldn’t be running without social media. That aspect of his life and our lives together is huge and has opened our world up so much. I can’t imagine what our lives would be without it and it all came to us through social media. It’s a vital tool to every single parent that I know that is parenting a kid with special needs.

Alma also shared that for the parents she interacts with on social media, the online experience is emotionally real. Alma described it as a sense of connection.

People talk about social media being this fake world and, at least in our case, it’s not. It is very real, and we put all of the ugly out there. We put what we are struggling with to the other parents who understand.

**Online privacy.** Parents acknowledged that utilizing online resources to foster these social experiences includes some risks associated with social media and privacy. All parent respondents identified benefits to social media including showing pride in their child’s accomplishments, creating and accessing a base of support, disseminating information to a broad
population with little effort, informing family and friends during times of crisis with minimal use of social capital, improving disability awareness related to their child’s diagnosis, and sharing resources and cultivating and maintaining in-person social connections. They consistently shared that these benefits outweighed the perceived risks for them. Alma says that she only shares what she wants to share. “Is someone going to steal our story? I don’t know why they would want it. I guess I don’t worry about it too much.” Anna says the she “is very strategic in what I put on Facebook and what I don’t, and who can see it and who can’t.” Diana purposefully doesn’t publicly share all of Clark’s medical challenges.

People don’t need to know how serious his medical problems are. They just think he is this great kid in a wheelchair and that is OK with us. It would change how they treat him. People would be afraid. They don’t need to see what is under there. They would be scared, and I don’t want that for him.

Diana shared that she knew many parents that had become targets of derogatory online interactions, but she had not had it happen to her. “People can be cruel. They say that your kid shouldn’t be alive. They say that we are a drain on society. You just have to ignore them.”

Parents described being aware of privacy settings and utilizing them to limit and target specific virtual audiences. The disability related groups tended to be private groups with restricted membership creating a more private online setting. This privacy setting allows only approved members to view and respond to posts. Parent respondents stated that this privacy setting provided a comfort level that allowed them to more openly share private medical information about their child’s needs. Maggie shared:

Sometimes there is something going on and I will check with the doctor. We know it isn’t something we need to go in for, but I still need to figure it out. I will jump on Facebook on my special needs groups where I feel safe to post medical questions. I don’t ask these questions on my own Facebook page because I have people who I don’t want to know these details about Brandon’s life.
Parent respondents shared that the relevant information they were seeking was only available from other parents living a similar parenting experience. This provides a high motivation for participation in social media in spite of privacy concerns. Lilli shared that she understood the privacy issues associated with social media use. She felt that given the digital age we live in, this was not an issue limited to social media. “Anyone can get your information online. There are things you can do to make it harder for them but once you are online, you are out there.”

**Pitfalls of social media.** Social media as a resource of information was also described as having its drawbacks. Parents shared challenges in dealing with misinformation that can be quickly disseminated and accepted as accurate by the social media audience—especially parents seeking “cures” and “fixes” for their children. Diana described the plethora of questionable interventions she was aware of through social media.

I am glad I don’t have to experience that—what they have to deal with now. When he was little, there was no stem cell transplant. There was no going to the Philippines for treatment. There was no special program in Budapest. All of these therapies that I quite honestly haven’t seen help anyone, are out there. I don’t know how the parents of young kids handle it all now.

There were also instances of concern regarding the use of online advice in place of individualized, professional medical advice. Respondents observed online instances where parents struggled in balancing seeking help online and accessing medical assistance when appropriate. Maggie voiced her concerns about this.

You know the downside of social media is you have people asking medical questions from other Facebook users and they take the advice like it is being given by a doctor. I find myself always reminding people that this is just my experience and may not be right for your child. I worry when I see people on Facebook asking questions when it seems like they should be at the doctors.
In addition to the potential for medical information concerns, parents found the online environment could become a negative experience. Parents described social media as having the potential to become a space that promotes depressive interactions because it can serve as a place for people to primarily vent frustrations. Parent respondents described having to join several different Facebook groups before finding a good fit for their needs, personality and current situation. Online disability-related group memberships changed over time as their child’s needs changed, but the flexibility of social media group membership provides a fluid resource. Parents were able to leave and join groups as appropriate for their changing situation. Diana described group membership:

You join groups based upon what you have going on at that moment. You may be in a group for a little while because of what they [your child with PMD] have right now. Then you might move onto a different group. Then there might be 19 groups for one diagnosis and you just have to figure out which one has people you like.

Parents also described the potential unrealistic presentation of life experiences on social media. The creation of unrealistic expectations can prove detrimental to other parents. Diana shared that early in social media use she struggled with the pressure from unrealistic online profiles.

It can make you feel bad when people put up unrealistic messages. It is like keeping up with the disabled Jones’. I used to look at people’s profiles and think I was a bad parent because I couldn’t pull off half the stuff they were doing and I was working my butt off. I realized that most of those people weren’t posting their real lives. I let go of that pressure and we do our own thing.

Maggie shared having followed a family online for some time and then she and Brandon went out into the community with them in-person.

They took a couple of pictures and then wanted to leave. We weren’t there more than a few minutes. Brandon was mad because he actually wanted to spend time where we were going. I quickly realized that the outing was a photo op for the other family. They were going to the places and taking pictures and posting about what a wonderful time they had but they weren’t actually doing any of it. After that, I learned to really pay attention to
people’s posts. Now I can usually pick out who is really doing things and who is just posting pictures.

**Collective power of social media.** When asked if they utilized social media to pursue disability related activism, the parents were not able to self-identify any activism in their online activities. However, during the interviews, they shared efforts and activities related to disability awareness, community accessibility and disability related causes.

Parent respondents reported engaging in disability awareness online through posting on disability focused pages and using disability specific hashtags for pictures and posts. These hashtags associate the pictures with broader audiences and disability specific pages, increasing the audience beyond established online friends. Lilli utilizes diagnosis related hashtags when posting Lila’s pictures to share positive images of Lila smiling and laughing and being happy. Parents also share pictures of particular challenges including lack of accessible public toilets, accessibility issues in the community including lack of wheelchair access and handicapped parking infringements. They describe social media as a place to vent but also a mode to increase awareness.

Parents use online posts on social media to share resources and programs. They advocate for causes. Maggie and Brandon post about their Canine Companion for Independence, Rex, and readily share information about the canines companion program online and in-person. Alma shares inclusive racing resources and actively recruits parents into these activities. Parents share accessible activities such as camps and daycares. They connect other parents online to each other and to resources. Diana supports parents during the early time of adaptation by providing resources and connections with peer parents raising children with PMD. “We have a packet that they hand out in the NICU. Doctors have the packet too. The sooner parents get hooked up with resources and connections, the better for them.” Not all activism is of a smaller scale.
Describing a disability-focused waiver that was passed through her state’s legislation, Diana shared,

We have been trying to get this waiver passed through state legislation for 11 years. It went through because of social media. We couldn’t reach enough people otherwise. Everyone couldn’t load up their kid and stand on the steps of the governor’s mansion, but everyone can sign an online petition. It won’t help my kid because he is too old now, but it is life changing for the young children with disabilities. It will save lives.

Even though the parents did not necessarily perceive their actions as activism, they described acts of activism on individual, group and larger political levels. The strength in their collective action as evidenced through social media connections, provides a collective power in numbers potentially sufficient to affect societal change. This would have been impossible without social media connecting them and enabling online participation.

**Chapter Summary**

Chapter 4 introduces the respondents of this study. This chapter highlights the lived experiences of the study respondents based upon the transcribed interviews conducted in this qualitative phenomenological study. Within the one-hour interview, each of the five respondents described their experience parenting a child with PMD and their use of social media. Parent respondents described their social experiences in-person and on social media. All respondents reported using social media daily. Parent respondents also described the joys and challenges of raising their child with PMD.

Themes present in the data include adaptation, acclimation, social connections and social media use. Parents raising children with PMD describe experiencing an initial period of adaptation to their child’s diagnosis. This initial adaptation was characterized by a focus upon the moment, understanding system resources and not having access to in-person parent role
models. Adaptation was described by parent respondents as a stressful and socially isolated time.

Parents then describe an ongoing period of acclimation in which they become empowered in their ability to meet the needs of themselves, their child with PMD and the disability. Much of this skill development is attributed to the third theme, social connections. Parents in this study describe meaningful social connections as fundamental to their acclimation and ongoing coping with long-term caregiving demands. Parents focused their energy on three primary social areas: their own social needs, their child’s social needs and the needs related to the disability. Each focus was addressed using different online approaches with an awareness of social media audience and privacy. These connections were made in-person and in virtual life with crossover between face-to-face and virtual interactions. Parents utilized a social media bricolage approach that was reflective of the needs related to the disability. Parents described social media use as having clear benefits for parents raising a child with PMD but also has privacy concerns and potential pitfalls. Parents describe advocacy activities on behalf of disability awareness causes but did not self-identify as activists.

**Remainder of the Study**

Chapter 5 will explore the implications of the findings of this study within the context of the current body of research. The themes present in the data will be analyzed in relation to current research. Research questions will be answered. Recommendations for practice, policy and future research will be made.
CHAPTER 5: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

Introduction

Study Overview

This qualitative phenomenological study sought to explore the lived experience of parents raising a child with profound multiple disabilities (PMD) in a digital age that includes social media. Five parent respondents raising children with PMD were solicited from a Facebook post on the researcher’s Facebook timeline. Each parent participated in a one-hour interview that was recorded and transcribed by the researcher. Data was coded and the findings were presented in Chapter 4.

This chapter presents the analysis of the findings presented in Chapter 4. The identified themes of the study are explored in relation to the existing body of research. The themes include adaptation to a changed parenting expectation; acclimation to PMD parenting; social connections and social media use. Study limitations are identified. Research questions are addressed. This chapter then presents implications for practice, policy and future research.

Problem Statement

The problem this study addresses is that individuals with PMD and their families are often invisible within society and disconnected from social interactions and supports (Agmon et al., 2016). Their personal challenges are unfamiliar to a majority of people. Parents of children with disabilities often report their own lack of familiarity with disabilities prior to the birth or diagnosis of their own child (Broberg, 2011; Green, 2007). The factors impacting family life when a family member has PMD are outside of a typical parenting experience. Parenting a child with PMD involves combinations of medical interventions, behavioral support approaches,
physical access limitations and a multitude of daily care factors not present within typical family dynamics (Green, 2007). These care dynamics do not dissipate over time as care requirements do in a majority of parenting experiences. Rather, daily care requirements increase in intensity as the child grows, with physical access becoming increasingly limited, and formal and informal social support diminishing as the child ages (Hanson & Hanline, 1990).

The particular challenges of raising a child with PMD result in increased social and physical isolation and decreased social support (Hanson & Hanline, 1990). A community experience with others who are on a similar parenting journey has the potential to provide social connections to parents raising children with PMD; however, there is the potential that this community membership can provide more than just the social support benefits of community. Connections resulting in community memberships can impact decision making processes, ability to function within daily demands and overall perceived quality of life. Community members can be empowered to affect positive change including an increased sense of control, identification of desired course of action and development of skills needed to progress in the direction of personal goals.

**Purpose Statement**

The purpose of this study was to explore, document, and understand the role that social media plays in the lives of parents raising children with PMD.

**Research Questions**

The following questions guided this study:

- What are the roles of social media in the lives of parents raising children with PMD?
  - In what ways do parents raising children with PMD engage with social media?
  - In what ways do parents raising children with PMD experience community by engaging with social media?
• How do parents raising children with PMD describe social media’s influence on their parenting skills?

Review of Major Themes

The findings of this study include four themes: adaptation to changed parenting expectation, acclimation to PMD parenting, social connection and social media use.

**Adaptation to changed parenting expectations.** Parents in this study described adaptation as the shift of their parenting expectations from that of raising a neurotypical child to raising a child with PMD. They described this as shifting from something known to something unknown and unfamiliar. This initial period of parenting was focused upon medical stability and their child’s survival. Within this study, there were two parents who adopted their child. Both of these parents had previous experience in working with individuals with disabilities. The remaining three parents had no experience with individuals with disabilities prior to the birth or diagnosis of their child with PMD. This impacted the parents’ ability to understand systems of resources available to them and their child. During adaptation, parents shared that they had no in-person access to other parents raising a child with PMD. Rather, they eventually located PMD parent peers online through social media.

**Acclimation.** The parents described that after the initial adjustment to their child’s disability within their parenting experience, they began acclimating to parenting a child with PMD. The parents established a “new normal” that incorporated their child’s disability-related care needs. The parents developed skills and connections related to accessing systems of resources. As parents settled into their new normal and as their children experienced periods of relative medical stability, they focused additional personal resources into social connections for
themselves and their child with PMD. A significant aspect of acclimation for the parent respondents is the development of consistent access to PMD parent peers.

Social connections. The parents in this study made connections in-person and in virtual life through social media. There was significant interplay for the parents between in-person and virtual social connections. Parents made online connections and, when possible, had in-person social interactions with the individuals they had connected with through social media. When relationships began in-person, the social connections were maintained through social media. At times, individuals the parents had met online transitioned into in-person social interactions. Parents described the importance of in-person social interactions but also acknowledged that these meetings were a challenge to arrange and experience within their high demand caretaking role as a parent of a child with PMD.

Parent respondents consistently had three areas of focus for their social efforts. All of the parents described the importance of putting time and energy into maintaining their own social connections. They maintained relationships and pursued hobbies and interests separate from their child with PMD, in-person and through virtual social connections. They also concentrated efforts to create and maintain social connections in-person and through virtual modes of interaction for their child with PMD. The third area of focus was meeting the disability-related needs both in-person and through virtual resources. Each of these foci is addressed through separate and distinct means on social media. Parent social media presence is kept separate from the child’s social media presence. Parents tend to use a more relaxed privacy setting with their own posts. The child’s social media presence tended to be limited to specific online friends, reflecting increased privacy settings. Disability related social media posts tended to be limited to closed groups with highest privacy settings.
Parents utilized a social media bricolage approach to create collections of social media resources that reflected their child’s often rare and complicated disability related needs. Social media bricolage allowed them to build the resources specific to their children’s disabilities that often represented rare collections of diagnoses and interventions. Social media bricolage also provided the flexibility to adapt as treatments, diagnosis and interests changed.

**Social media use.** Respondents identified benefits to social media access as parents raising a child with PMD. They described the importance of forming online connections with other parents living a similar parenting experience. The ability to vet information with other PMD parents aided the respondents in accessing and navigating resources within their parenting. While all of the parents shared that they understood that there are privacy concerns inherent in social media use, every parent felt the risks were worth the benefits they received through social media use. Each parent described steps they take to minimize privacy concerns but ultimately accept the risk associated with using social media.

Parents identified pitfalls of social media use. They described seeing ineffective interventions presented as effective treatments in online posts. They described misinformation being disseminated through social media. Particularly worrisome for respondents was the potential for online non-professional advice taking the place of individualized medical treatment provided by a professional.

While parents did not self-identify as politically active, they described many online activities that can be characterized as activism. Parents engaged in disability awareness and public education through social media. Parents informed and supported other members of the disability community. Parents also described participating in online lobbying and fundraising for disability causes.
Discussion

In this section, the themes of this study will be analyzed in relation to the current body of research.

Adaptation

Parenting a child is a complex, long-term commitment. Parenting a child with PMD adds layers of complexity to this parenting journey. Research supports that mothers of children with disabilities “adapt, adjust and develop a whole range of skills as they mediate and negotiate on behalf of their children” (Ryan & Runswick-Cole, 2008, p. 204). The experiences of the parent respondents of this study echo this finding. For the parents in this study, the initial time after their child was adopted, born or diagnosed was a time of particular challenge for them. The parents shared that the initial adaptation to parenting a child with PMD was very stressful, unfamiliar and that they felt very alone in their journey. Research shows that parents raising children with PMD experience social and physical isolation and a physical toll of caretaking upon their own health (Chambers & Chambers, 2015; Resch et al., 2010). Because of their child’s intense medical issues, they focused on the immediate survival of their child. This finding is consistent with research that shows the initial time period after birth or diagnosis has been found to be the most stressful period of parenting a child with disabilities (Green, 2007).

This study incidentally included two parents with previous experience in the field of disability services who adopted their child with PMD, and three parents who had their birth child experience PMD. The parents who had their child with PMD born into their family shared that they had minimal exposure to children with disabilities prior to the birth of their child. This is consistent with previous research findings (Broberg, 2011; Green, 2007). The differences in experience between the adoptive parents with prior exposure to disability systems and the birth
parents with no previous exposure during their early PMD parenting journey supports research findings regarding difficulties accessing resources as a parent of a child with PMD. Previous research shows difficulty accessing resources is an ongoing challenge for parents raising children with disabilities (Blackburn & Read, 2005; Ryan & Runswick-Cole, 2008; Wodehouse & McGill, 2009). This study’s group of parents echoes this finding. The parents with prior experience had a resource bank of acquaintances to contact for guidance from the beginning of their PMD parenting journey. While this previous knowledge aided their navigation of resource systems, they shared that accessing resources continued to be a challenge, in spite of having connections prior to their child with PMD joining their family.

All of the parents in this study created support systems to help them navigate resources. These resource systems consisted of in-person and virtual connections. Described as the most effective source of information, the parents developed social media connections with other parents raising children with PMD. As Hartshorne and Schafer (2018) described, “There is no manual for how to raise a child with severe disabilities” (p. 434), but parents were able to find parent role models through connections with other PMD parents. This study’s parents found strength in the common experience that they were able to share through online connections. This is similar to studies involving Facebook groups for autism, lupus and craniofacial anomalies (Cole et al., 2017; Khouri et al., 2016; Wheeler et al., 2018).

Acclimation

The parents in this study describe acclimating to a “new normal” in their lives that incorporates the PMD parenting requirements. Medical procedures become incorporated into daily routine and the parents describe developing competency in navigating systems of resources. The increasing competency and knowledge of the world of disability and resource
acquisition for PMD parents is in accordance with previous research findings (Green, 2001; Ryan & Runswick-Cole, 2008; Smith et al., 2012).

Parent respondents shared that the early years of their child’s life were marked by the desire to gain resources in an attempt to ameliorate the impacts of the disabilities upon their child with PMD. This is similar to what Chambers and Chambers (2015) documented in their research. As this study’s parents acclimate to their PMD parenting, they described growing more relaxed and accepting of their child.

The increase in parenting and caretaking demands for PMD parents across ages is opposite to a neuro-typical parenting experience in which parenting demands decrease as the child ages (Ryan & Runswick-Cole, 2008). As the child ages and grows, these challenges continue through life transitions and during acute medical issues, while the physical toll of caretaking continues to increase for the parent-caretaker (Chambers & Chambers, 2015; Hanson & Hanline, 1990). This study’s findings support this previous research.

Research has also shown that as the child with disabilities ages, social support decreases for the caretaker (Hanson & Hanline, 1990). The respondents in this study had consistent support from family and close friends. Parent respondents also had active social media connections. While the parents echoed previous findings of decreased social support outside of their immediate circle of family and close friends, they also presented social media connections as an additional and consistent resource across their child’s life.

The growing size of the child has implications upon community access as well. Isolation of the parent-child dyad in the family home increases as going into the community becomes more challenging. This is due to the increase in size and weight of the child and their accessibility equipment such as wheelchairs in interaction with physical and attitudinal barriers
existing within society. This physical isolation can result in feelings of depression, helplessness and even manifest in physical ailments for the parent (Resch et al., 2010). The parents in this study described addressing feelings of isolation through virtual and in-person connections. The virtual connections alleviated some of the daily feelings related to isolation and served as a bridge between in-person social interaction opportunities. Social media also presented as a way to process difficulties experienced in the community with other PMD parents.

The parents in this study served as an interpreter between their child and the world. Educators, medical professionals and the public at large often failed to recognize their child’s humanity. Parents were often accused of over-estimating their child’s abilities or cognitive understanding. This is consistent with Ryan and Runswick-Cole’s (2008) finding of the tendency to form assumptions on the part of professionals when dealing with parents of children with disabilities. Parent respondents in this study serve as their child’s main advocate across settings consistent with previous research (Ryan & Runswick-Cole, 2008; Watermeyer & McKenzie, 2014).

**Social Connections**

The parents in this study relied on connections in-person and in virtual life to address their social needs. Social interactions in-person were highly valued and preferred but difficult to arrange within their parenting demands. This is consistent with Brown (2009) who found that in-person interactions contribute to feelings of connection and a sense of truer understanding of the other person. The parents utilized an interplay between in-person connections and virtual connections. After meeting someone in-person, parents maintained a connection with that person virtually through social media interactions. Likewise, when interacting with someone initially through social media, parents of this study shared that these social connections
sometimes transferred over to in-person social interaction. Parents described virtual connections as sustaining during periods of time when in-person connections were not possible. For example, a parent followed people she met annually at a week-long camp the rest of the year on social media. The in-person interaction contributed to an increase in the feeling of connection during the year until camp occurred again. This interplay between in-person interactions and virtual interactions was not found in previous research for parents raising children with PMD.

The effort that parents put into connections were divided between three foci. They focused on meeting their own social needs. Making time to meet caregiver social needs is common among long-term caregivers (Thomson et al., 2017). The parents also prioritized the social needs of their child with PMD. Parents described establishing and maintaining social connections for their child in-person and virtually as a challenge that required a great deal of effort with mixed successes. Difficulty with making and maintaining friendships for children with disabilities is well established (Savarese, 2016). Parents actively maintained a social media presence for their child with PMD separate and distinct from their own social media presence. Virtual connections on behalf of their child were used to arrange in-person social interactions as well as maintain these connections across periods between in-person interactions for their child with PMD. In-person interactions for their child were highly valued and parents put forth significant personal effort to pursue social opportunities for their child. The use of social media in supporting social interactions for children with PMD was not evident in the current body of research.

Disability related needs were addressed separately and distinctly on social media from parent and child social needs. Disability related needs were addressed in private Facebook groups, private Facebook Messenger messages or direct text messages to trusted social media
contacts. Disability specific Facebook groups have been shown to provide health information, enable patient-to-patient interactions, allow patients to share their experiences and reduce feelings of isolation and aloneness (Rocha et al., 2018).

Utilizing a social media bricolage approach, parents built collections of Facebook group memberships that reflected the combinations of disabilities and treatments that their child experienced. While parents were unable to find other children in-person that had the rare conditions and combinations of conditions that their child had, they were able to find parents of children online in similar situations that may have one or two conditions in common with their child. Rocha et al. (2018) also found that families dealing with rare genetic conditions overcame feelings of isolation by communicating with other families via Facebook and that this trend is becoming increasingly common.

However, using a social media bricolage approach allowed parents to construct compilations of social media resources that reflected their child’s complicated conditions. Parents described their online connections as key to their parenting a child with PMD. This is consistent with research examining social media support groups for chronic illnesses such as diabetes (White et al., 2018). But given the rarity of diagnosis for children with PMD and the complex combinations of diagnosis and treatments, the use of social media bricolage through Facebook groups allowed parents to create composites of resources reflective of their child. While research shows that individual diagnosis based Facebook groups are utilized by parents raising children with disabilities (Abel et al., 2019; Cole et al., 2018; Khouri et al., 2016), the use of multiple group memberships to create a composite of resources by parents raising children with PMD was not found previously in published research.
Social Media Use

The parents in the study describe benefits to social media use. They are able to connect with other parents raising children with PMD across geography, providing peer parent interactions that they would not otherwise have access to. This finding is similar to previous research (Wheeler et al., 2018; White et al., 2018). They are able to meet their own social needs through the interplay between virtual and in-person interactions. Social media interactions are used to support in-person interactions by maintaining social connections when in-person interactions are not possible.

The parents do acknowledge that, while social media has benefits, it also presents potential risks. Parents expressed an awareness of privacy concerns. Rocha et al. (2018) found it consistent that while Facebook was the most popular resource for patients seeking information about rare genetic conditions, over half of the respondents in their study felt uncomfortable posting on public Facebook profiles. Over 80% of their study participants felt comfortable posting on the private groups, particularly if these groups focused on family members. Parents in this study were aware of privacy settings on Facebook and utilized different privacy settings for their social media presence, their child’s social media presence and disability-related posts. Parents increased privacy for their child’s posts. Disability-related posts had the highest level of privacy. Disability-related posts were made in private messages and on closed Facebook groups. The closed group privacy setting allows only approved members to view and respond to posts.

Parent respondents shared that this privacy setting provided a comfort level that allowed them to more openly share medical and disability related information about their child’s needs. This is consistent with findings regarding disability disclosure on social media (Furr et al., 2016). Tsay-Vogel et al. (2016) concluded that prolific social media users tended to have lower
perceptions of risk in social media use. They also found that a high desire for information impacts social media users’ willingness to disregard risks of social media use. The parents in this study shared that they too felt the benefits of accessing information through social media outweighed the potential risks.

Parents shared concerns about accuracy of information and interventions posted on social media. This is consistent with research findings about social media as a resource for medical information. The lack of vetting of information posted provides the opportunity for inaccurate information and illegitimate interventions to gain traction within the online disability community (Chambers & Chambers, 2015).

The use of social media as an advocacy tool of collective political action has been shown by Chalmer and Shotton (2016). While the parents in this study did not self-identify as political activists, they describe social media activities that addressed disability rights. Presence of a disability has been shown to increase political activism (Mattila & Papageorgiou, 2017). Penney (2014) found that the use of social media brought individuals who would not normally participate in political activism into participation in social media-based activism. Hemsley et al. (2017) found the use of disability associated hashtags by family members and individuals with amyotrophic lateral sclerosis to promote awareness as a form of activism. An example of successful state level legislative lobbying was shared by one parent. Respondents report engaging in social awareness of disability related causes through posts on their social media pages. While their perception of the use of hashtags, awareness and education were self-described as typical parenting activities for the parent respondents, research suggests that these behaviors have activist implications (Chalmer & Shotton, 2016; Hemsley et al., 2017).
Conclusions

This study posed four research questions regarding the use of social media in the lives of parents raising children with PMD viewed through the theoretical lenses of sense of community and empowerment theory.

**RQ1: In What Ways Do Parents Raising Children With PMD Engage With Social Media?**

Luijkx et al. (2017) found that parents raising children with severe and profound disabilities have significantly less free time throughout their day. In spite of this reality, the parent respondents of this study described using social media every day, throughout their day. Parents explored personal hobbies and activities distinct from their child and their child’s disability. Parent respondents shared that this was a significant aspect to their ongoing social wellbeing as a long-term caregiver. This is consistent with the findings of Thomson et al. (2017). Parents utilized social media to arrange in-person social interactions. These social relationships were maintained through social media between in-person interactions.

Parents utilized social media to meet the social needs of their child with PMD. Parents cultivated social media connections and maintained social media personas for their child. The parent respondents utilized social media to support in-person interactions for their children although these in-person interactions tended to be few in number.

Parents utilized social media as a resource to address disability related needs. Parents reported being unable to find other parents in-person that were raising children with the same rare conditions their child had but were able to find parent peers online through a simple search on social media.

Parents shared that they utilized these social media connections to navigate their PMD parenting experience. They shared resources with other parents, learned how to navigate
complex systems of resources and sought targeted advice about issues related to their child’s
disability. This is similar to findings for disability specific social media groups including
diabetes (White et al., 2018), lupus (Wheeler et al., 2018), craniofacial anomalies (Khouri et al.,
2016), autism (Abel et al., 2019; Cole et al., 2017), and cancer (Gentile et al., 2018).

Children with PMD have complex medical conditions. They often are diagnosed with
multiple conditions and receive a variety of interventions that are rare within general society but
more common amongst individuals with PMD. Parents utilized a social bricolage method of
Facebook group memberships to reflect their child’s combination of disabilities, interventions
and conditions. Parents assembled and built the online resources that reflect their child’s needs.
They add or leave Facebook groups as appropriate based upon the changing dynamics of their
child’s disabilities and therapies. The use of social media bricolage was not found in current
research. Current research focused on single diagnosis Facebook group participation (Abel et al.,
2019; Cole et al., 2017; White et al., 2018).

RQ2: In What Ways Do Parents Raising Children With Profound Multiple Disabilities
Experience Community by Engaging With Social Media?

Sense of community. Developed in 1976 and published in 1986, the theory of sense of
community “sought to explain the dynamics of the sense-of-community force” (McMillan &
Chavis, 1986, p. 6). Sense of community can provide support, a feeling of belonging and can act
as a hub of resources. The theory of sense of community has four main components:
membership, influence, fulfillment of needs and shared emotional connection (McMillan &
Chavez, 1986). Respondents in this study described experiencing all of the components of sense
of community in their lived experience as networked through social media.
**Membership.** The sense of community component of membership consists of apparent boundaries, emotional safety, a sense of belonging and identification, personal investment and a common symbol system (McMillan & Chavez, 1986). Respondents consistently shared a sense of membership within the community of parents raising children with disabilities. By utilizing descriptors such as “my hive” and “tribe”, respondents indicate a sense of belonging and identification within their in-person and online connections.

Parent respondents additionally were members of the Facebook or Instagram community. They became members when they downloaded the application, created a profile and established online friend connections. Further membership was established through joining topic-specific groups. Group memberships reflected the triad of foci of social media use for the parent respondents: parental social interests, child social interests and disability related topics. Some of these groups maintained a public status while other groups were more private, limited to approved members. The disability related groups were most often private groups.

Respondents indicated that they were cognizant of the privacy settings on their own social media profiles as well as on the groups they joined. All of the respondents indicated that their privacy settings provided a sense of safety and security when posting information. Community-based Facebook experiences have been shown to increase perceptions of online safety (Redmiles et al., 2019). Safe space enables community members to engage in disclosure of personal information (Rovai, 2002). McMillan (1996) emphasized that community members must feel safe to be honest, feel accepted, receive empathy and support from their community. While posting in an open environment on social media exposes a level of vulnerability (Pimenidis & Polatidis, 2019), the parent respondents all expressed that the benefits of social media use outweighed the measured risk.
These personal disclosures support member bonding (Cummings et al., 2002; McMillan, 1996). Respondents shared that they limited medical and personal posts about their child to the closed disability focused groups. Parent respondents often did not feel safe sharing this personal information on their more public profile.

The online experience of membership for parents raising a child with PMD was marked by their personal investment of time and energy into posting and responding to other parents. Even though daily life had extraordinary demands upon them physically and emotionally, every parent respondent stated that they interacted with social media everyday throughout each day.

**Influence.** Another component of sense of community is influence. Influence is the capacity to act upon and be acted upon by the community participants. Parent respondents shared that they post their own messages on social media and receive responses from others. They also respond to the posts of other parents. Parent posts could either reinforce or dissuade courses of interventions to try including items to be purchased, service options to explore or caretaking approaches. These mutual interactions appeared to be reinforcing enough to sustain ongoing participation as reported by respondents. Parent respondents indicated that social media was one of their primary and most consistent modes of accessing support, resources and advice.

**Fulfillment of needs.** McMillan and Chavez (1996) described fulfillment of needs as being a significant benefit of being a member of a community. Parent respondents described multiple aspects of needs fulfillment including information, advice, support and supplies. Parent respondents joined groups that matched their interests and needs. Parent respondents described their social media network as having the capacity and connections to meet the needs of themselves and the other group members. This targeted diversity represents an online
community replete with a variety of resources relevant to various diagnosis, ages, interests, and experiences.

As Grave (1992) shared, the community membership must be diverse enough to meet needs and similar enough to support bonding. According to McMillan and Chavez (1986), fulfillment of needs furthers personal investment in the community. Parent respondents described the feelings of usefulness and “paying it forward” by providing information and support to other parents of children with PMD. Without this positive reinforcement, participation would likely be unsustainable over time. Satisfying personal needs drives the development and sustaining of a community (West & Kahle, 1993).

Because of the difficulties with having consistent social interactions in-person with other parents raising children with PMD, interactions through social media provide consensual validation from others living a similar life. The online network contributed to in-person social interactions for the parent respondents and their children. These in-person interactions were highly valued. The interplay between virtual connections and in-person connections was ongoing and dynamic for parent, child and within disability related needs.

**Shared emotional connection.** According to McMillan and Chavez (1986), the emotional connection experienced within sense of community is based upon a shared history. The parents in this study describe a shared lived experience although they lived geographically separate lives. In spite of geographical distance, the shared experience of parenting a child with PMD proved meaningful and powerful within the lives of the parent respondents. McMillan (1996) described a community as a space where we can “see ourselves mirrored in others” (p. 315). Parent respondents described feeling a sense of seeing themselves in the other parents they interacted with through social media.
**Sense of community summary.** When asked to describe their own community membership, none of the parent respondents included social media as a community. However, each parent respondent reported the components of sense of community when describing their experience interacting with other parents raising a child with PMD through social media. All of this study’s respondents described social media as a network that provided feelings of membership, capacity to influence and be influenced, to act as a resource for fulfilling needs as well as having their needs fulfilled and a source of shared emotional connection with other parents raising a child with PMD. Lifang (2018) found that the perception of virtual community membership influences group behavior. If members experience trust and commitment to each other, they are more willing to actively participate in online groups. This study’s respondents shared feelings of trust and commitment to each other through virtual interactions. The study respondents may not perceive social media as a community, but they experience the components of sense of community through their social media network. This network facilitates community membership and social experiences beyond the virtual setting and into face-to-face interactions.

**RQ3: How Do Parents Raising Children With PMD Describe Social Media’s Influence on Their Parenting Skills?**

**Empowerment theory.** Empowerment is the result of individuals working cooperatively to arm participants with knowledge and skill to improve personal and group lives through interactions with their social and political environment (Speer et al., 2001). Barak et al. (2008) and Bayes (2015) both describe empowerment as originating from disenfranchised groups. The disenfranchised experience of individuals with disabilities and their families has been well established (Kudlick, 2003).
A criticism of empowerment theory has been a deemphasis of community and cooperation through a focus on the individual (Speer, 2000). In this study, parent respondents described experiencing the components of community and shared examples of both individual empowerment as well as group empowerment as a result of the community membership experience. Given a common life experience, parents raising children with PMD seek to develop skills and knowledge in themselves and other parents as they interact through social media. They seek to improve their own knowledge and parenting skills, aide others in the development of their knowledge and parenting skills and increase personal resources and confidence. They seek empowerment.

Empowerment theory has intrapersonal, interactional and behavioral domains (Moran et al., 2017; Speer et al., 2001).

**Intrapersonal domain.** The intrapersonal domain encompasses the internal locus of control over one’s own life. Individuals who experience intrapersonal empowerment shift their perceptions of themselves, their competency and ability to control and influence their life experience to themselves from external loci (Moran et al., 2017; Zimmerman, 2000). Parent respondents described increased intrapersonal empowerment as they interacted through social media with other parents raising children with PMD. These experiences are consistent with research in chronic disease management online support group outcomes (Huh & Ackerman, 2012). Parents described becoming confident in their ability to work through not only present challenges, but future challenges as they arose. This was due in large part to having access to parents in similar experiences providing a continuum of parenting PMD expectations across ages and diagnosis.
**Interactional domain.** The interactional domain of empowerment theory consists of how a person thinks about and relates to their environment. This includes their awareness of social and political forces that help or hinder their progress towards personal goals, as well as their understanding of resource systems and how to effectively operate within the forces that shape their experience (Speer, 2000). Parents raising children with PMD describe an increased understanding of the complex systems of services that they have to navigate on behalf of their child. They shared an understanding of the social forces impacting the perceptions of their child within society. They found like-minded individuals within the social media experience to process and manage the implications of these forces.

**Behavioral domain.** The behavioral domain of empowerment theory includes actions that address needs in a specific context (Moran et al., 2017). According to Speer (2000), this can include behaviors ranging “from individuals adjusting to adverse conditions that are not malleable to change, to working with others in a voluntary organization to alter the distribution of community resources” (p. 52). Parent respondents shared instances of both the individual response and the communal response.

Individual empowerment responses in the behavioral domain included acclimation to the impacts of the disability. Maggie described initially seeking every therapy available to “fix” Brandon. Over time, she shared that she relaxed and accepted him as he was. She adjusted to the non-malleable presence of his disability without disbanding her efforts on Brandon’s behalf. She became empowered within her parenting role and, by self-report, became a more effective and productive parent. In turn, she sought to “pay it forward” by assisting other parents in this process. The development of skills involved in advocating and negotiating for their child with
PMD and resisting the ableist social order through education and activism reflects previous research findings (Ryan & Runswick-Cole, 2008).

In addition to individual empowerment in the behavioral domain, parents in this study exhibited community-based empowerment. Parent respondents of this study engage in advocacy related to their child’s disability and their child’s interests and needs. Parent posts on social media advocated on behalf of their child but also press for disability awareness, access and disability rights. An example of state level political lobbying for disability legislature was shared within the study data. Parent respondents all described utilizing social media and in-person interactions to educate, support and empower other parents raising a child with PMD.

**Empowerment theory summary.** With some overlapping components with sense of community, empowerment theory is “comprised of a safe participatory environment, membership based upon participation, sharing of power, focus on both the individual and community, as well as a larger focus upon activism within society and a reflective evaluation of the process” (Bayes, 2015, p. 9). The parent respondents in this study indicated that they experienced all of the components of empowerment theory through interactions within or facilitated by social media.

Parent respondents described the process of their empowerment as parents raising children with PMD as being impacted by their successful skill development in meeting the diverse needs of their child with PMD. This is consistent with research on raising a child with disabilities (Smith et al., 2012). Social media served as a component of this skill development by connecting parents within a networked community.
Central RQ: What Are the Roles of Social Media in the Lives of Parents Raising Children With PMD?

For the respondents of this study, social media plays a significant role in their lives. The parents reported using social media on a daily basis, multiple times each day. While they reported difficulty with arranging in-person social interactions, they socially sustained between in-person interactions through social media connections. Social connections can aid in alleviating some of the feelings associated with physical isolation (Ambikile & Outwater, 2012). While social media has the potential to mediate feelings of social isolation through virtual connections in a way that does not require physical presence (Parks, 2010), the parents of this study shared that the in-person connections were important to them.

The parents in this study used social media to make connections for themselves, their child and for disability management needs. For their own social needs, parents supported friendships, hobbies and interests through social media similar to typical social media use as reported by Manuoğlu and Uysal (2019). The parents report utilizing social media on behalf of their child with PMD. They sought and supported social connections for their child separate from their own social media presence. They also utilized social media connections in their parenting by interacting with other parents raising children with PMD. These connections with other parents raising a child with PMD were used to seek guidance in managing their child’s disabilities and treatments as well as negotiate systems of resources and services. Similarly, social media platforms have been shown to support self-management of long-term illnesses (Angelis et al., 2018). Social media has also been shown to be a source of social support for migrant populations, cancer patients, political organizations and unions (Dekker & Engbersen, 2014; Liu & Lu, 2018; Panagiotopoulos & Barnett, 2015; Sugawara et al., 2012).
The parents in this study described experiencing the components of sense of community as described by Chavez and McMillan (1986) through their social media connections. As a result of these connections and the community support they receive through social media, they become empowered within their own parenting experience. This concept of networked community empowerment takes the previous research on networked empowerment by Ammari and Schoenebeck (2015) and applies it to the lived experience of the parents raising children with PMD in this study.

Ammari and Schoenebeck (2015) identified the concept of networked empowerment on Facebook among parents of children with special needs. Networked empowerment describes “how parents find other parents, access resources, and explore new ways for promoting health advocacy among caregivers at a local and national level” (p.2805). Research has consistently shown that online groups and Facebook interactions can provide support across geography for social media users (White et al., 2018). The online setting presents a perception of a safe environment for sharing that promotes learning and skill development (Redmiles et al., 2019). Parents turn primarily to social media sites for access to information and support regarding their child with disabilities (Abel et al., 2019).

The Ammari and Schoenebeck (2015) study utilized Zimmerman’s empowerment theory (2000). The theoretical lens of this study combines empowerment theory with sense of community theory in order to explore the role of social media in the lives of parents raising children with PMD as it relates to feelings of community, empowerment and social interaction. This study examines online social media as a virtual community in which parents raising children with PMD reported experiencing the components of sense of community and, through
this community membership, became personally empowered as parents raising a child with PMD.

However, this networking and transformation is not limited to the virtual world. The parent respondents in this study utilize the social media network to forge and sustain social connections in-person. These in-person connections are maintained through social media across distances and time as the parents raise their children with PMD, seeing them through the demands of daily care, life transitions and medical challenges. Social media serves as the network for these ongoing connections both virtually and in-person. Parents maintain and cultivate these connections within a lived experience that includes limited time and resources for social connections, specialized and demanding PMD caretaking requirements. The parents in this study include their child with PMD in the focus of the social networking beyond the needs specific to their disability. The parents in this study support their child by developing social experiences of their own within a society that previous research has shown to isolate them (Luijkx et al., 2017; Ryan & Runswick-Cole, 2008).

The parent respondents utilized their networked community to empower each other in-person and in their virtual life. Networked community empowerment describes this interplay between in-person interactions and virtual life found in this study. The only other examples of active focus between in-person and virtual life interplay facilitated by online connections found in research was in online dating studies (Couch & Liamputtong, 2008).

Networked community empowerment describes a disenfranchised population living a highly demanding existence with limited social capital and access. The population utilizes social media and in-person social connections as a network to meet a variety of needs in a targeted and deliberate manner. The outcome of the online interactions includes in-person social interactions
which are then maintained between in-person interactions through social media. Personal and community empowerment result from the networked experience of the community members.

**Summary of the Role of Social Media in the Lives of Parents Raising Children With PMD**

The role of social media in the lives of parents raising children with PMD has similarities with how a majority of users utilize social media. Parents join interest-related Facebook groups, post about interests and activities, form virtual friendships, interact with the posts of others and seek information about events and activities for themselves. These activities are similar to typical social media users (Manuoglu & Uysal, 2019).

In response to their lived experience as a parent raising a child with PMD, the parents also utilize social media to cultivate and maintain social connections for their child with PMD. They maintain and market their child’s online persona, facilitate online interactions and connections for their child. These virtual connections can then translate into in-person social interactions. The in-person social interactions are highly valued by the parents for themselves and their children. Parents shared that maintaining their own social connections aides with long-term caregiving and coping. Parents also share that their child’s social life and interactions are a high priority for them. As a result, they put forth a great deal of effort in-person and through virtual modes of interactions to create and cultivate their child’s social connections.

The parent respondents also utilize social media to address disability-related needs. They join specific groups to comprise resources reflective of their child’s complex combinations of diagnoses, treatments and disability related needs in a social media bricolage approach. The disability related posts tend to be segregated to private group message boards or private messages to specific trusted individuals. This is similar to online support for parents raising children with diabetes (White et al., 2018), lupus (Wheeler et al., 2018), craniofacial anomalies
(Khouri et al., 2016), autism (Abel et al., 2019; Cole et al., 2017), and cancer (Gentile et al., 2018). Current research is unclear if the parents in non-PMD support groups utilize social media bricolage in addressing their child’s needs or if this is specific to raising a child with PMD.

Parents are able to join Facebook groups utilizing this social media bricolage approach. They join multiple groups that reflect the numerous diagnoses and interventions that their child with PMD experiences. While finding another child with their child’s exact collection of diagnoses and interventions would likely be impossible, they are able to build, through multiple group memberships, an online resource that reflects the combination of their child’s disability related needs.

**Study Limitations**

This study faces several limitations related to a narrow demographic and small respondent pool size. The low incidence nature of PMD results in a limited pool of available respondents. While efforts were made to negate geographical limitations through the use of technology for long distance interviews, this study’s respondents live in three states with three respondents living in the same state which can result in unintended geographical influences. The low number of respondents impacts the overall diversity of the sample pool.

Because study participants were solicited through Facebook, the pool of respondents was by definition already active on social media. This may skew the data towards strong social media use that may not be consistent if the respondents were selected from a non-social media source.

All of the respondents in this study identified as female. Evidence suggests that single mothers are more likely to be parenting children with disabilities (Levine, 2009) and research has primarily focused upon maternal caregivers, but the potential for gender dynamics influencing
the parenting experience is a possibility (Ryan & Runswick-Cole, 2008). The current study represents a gender skewed respondent pool.

Four of the five parent respondents were raising children with PMD over the age of 10. As the dynamics of parenting a child with PMD transition over the child’s lifetime (Chambers & Chambers, 2015), the data collected is biased towards the lived experience of raising a child with PMD after a decade of parenting. The age of the children also biases the experience of the social media user as the primary social media applications mentioned by respondents in this study were just becoming established after the birth of their child with PMD. Parents who themselves grew up with social media and whose children’s birth or diagnosis occurred after the establishment of social media may have a different experience, particularly in the early adaptation period after birth or diagnosis.

**Recommendations**

**Practice Recommendations**

Based upon the findings of this qualitative study, several recommendations can be made in regard to social media and parents raising children with PMD. This study’s respondents consistently turn to social media as a resource in their parenting and coping, consistent with previous research indicating preference for online support groups in lieu of face-to-face support groups (Abel et al., 2019). Parents found online interactions aided in resource acquisition, parental decision-making, quality of life contributions and overall coping. The use of social media bricolage aided parents in creating collections of social media resources reflective of their child’s rare and complex diagnosis and needs. Parents reported finding the components of sense of community through social media use. Social media aided in their feelings of empowerment as parents raising children with PMD.
Based upon these findings, social media represents a mode of access to resources for this often isolated and marginalized parent population. This study shows that parents raising children with PMD are utilizing social media in manners that suits their needs without the guidance or assistance of professionals. This empowered use of social media enables parents to locate and utilize what is appropriate for their individual experience.

**Connecting parents.** The parent respondents raising children with PMD in this study are active users of social media. They report strong and active communities that seek to support and empower other parents and caretakers raising children with PMD. As such, social media is a method to reach similar parents with relevant information and resources. Social media can serve as a conduit to connect parents living a similar parenting experience. All of the parent respondents in this study shared feelings of being overwhelmed, isolated and in need of support in their parenting journey. Professionals in frequent contact with parents raising a child with PMD including teachers, doctors, therapists and service coordinators benefit from an understanding that this online community exists and has the capacity to aid in coping, connecting and empowering parents. This online social media community provides a ready resource to make available to parents raising children with PMD. Connecting parents raising children with PMD to each other without requiring physical attendance at a support group or gathering can prove to be a powerful resource. As social media is not geographically limited and is flexible to use with minimal resource output, professionals can encourage parents raising children with PMD to explore social media resources and connect parents raising children with PMD beyond geographical limitations.

**Understanding risks and pitfalls.** Social media use presents potential risks and pitfalls. Online, misinformation can be easily spread and be misinterpreted as fact. Social media users
may not be aware of the risks they are taking in using social media. Privacy concerns can be mitigated by controlling settings on personal profiles. Being aware of some of the challenges and potential pitfalls of social media use may aide parents in maximizing their privacy and safety when accessing social media resources.

Professional resources can develop and incorporate social media awareness guides when interacting with parents raising children with PMD. Through these educational resources, professionals can help parents navigate in-person and virtually based resources for their family situation while minimizing online risks and avoiding potential pitfalls.

**Early outreach.** The parents in this study confirmed previous research in the earliest time of their child’s life being the most difficult for the parent (Green, 2007). The parents focused on their child’s survival and felt overwhelmed by trying to understand systems of resources. They lacked face-to-face real life role models of parents raising a child with PMD.

This reemphasizes the importance of early outreach during the initial period of adaptation for parents raising children with PMD. Early intervention practitioners should include locating PMD parent mentors in-person and through virtual means as early as possible for new parents. Providing access to resource systems is not sufficient. Parents raising a child with PMD require peers for support and guidance beyond mere knowledge of resource availability. There is knowledge and information that only another parent living the same experience has. The value of PMD parent peer connections is a strong message from this study.

**Social interactions.** The data of this study shows the importance of in-person social interactions for parents raising children with PMD. Service systems and support providers should address this need within their service practice. While many disability related activities that bring parents and their children with PMD together are offered by service systems,
providing purely social activities for parents and children with PMD is clearly an area of need for families.

A focus on social opportunities for children with PMD is also a clear need. The parents in this study put forth a great deal of effort to develop social connections in-person and through virtual modes for their children. This study allows the parents’ voices to be heard in prioritizing the social needs for children with PMD.

**Policy Recommendations**

**An online resource presence.** Because of the social media use for information and resources by parents raising children with PMD, disability resource networks have the potential to increase access to and exchange of information by exhibiting an online presence through social media. This would ease dissemination of resources directly to parents raising children with PMD through the established social media network. Such social media communication systems have proven successful for some public-school systems (Lavergne, 2017) and have the potential to increase accessibility and communication for physically isolated populations.

An online presence by resource networks may also aide in clarifying the accuracy of information related to their resource provision. As misinformation through social media can be problematic and quickly disseminates in this virtual medium, the presence of resource providers can clarify information for accuracy quickly and efficiently (Caulfield et al., 2019; Gentile et al., 2018).

**Connections early and often.** The parents in this study were either connected informally by an individual service provider or through their own outreach efforts on social media. Given the benefits that parents report from connecting with other parent peers through social media, service providers should offer opportunities for parents to connect online early in
their child’s life and often throughout service provision. A social media presence such as a Facebook group or page profile may provide multiple opportunities across time for parents to connect online. Special needs activities, daycares, service systems such as regional centers, disability associated programs can serve as conduits of social media connection through establishing and maintaining their own Facebook pages and groups.

**Future Research**

This study represents an initial exploration of the role of social media in the lives of parents raising children with PMD. This traditionally understudied population represents an uncommon parenting experience within American society.

Possible future studies for this population include a qualitative ethnographic examination of parenting a child with PMD. Data from this study suggests that the lived experience of parenting a child with PMD may reflect aspects of a lived culture. This potential culture is experienced in geographical isolation while connected by social media. This study could examine the ways that parents raising children with PMD experience similarities in their parenting lives across geographical distances.

The current study was limited by a small sample size and narrow demographic pool. A repeat of this qualitative phenomenological study with a larger sample size and diversified demographic including various races/ethnicities, socioeconomic statuses and genders can explore the findings of this study further.

A quantitative examination of social media use by a diverse pool of parent respondents would examine similarities and differences of social media use by parents raising children who are neuro-typical, children with a variety of disability types and severities including children
with PMD. This study could potentially explore correlations between social media use and self-efficacy.

A quantitative exploration of social media bricolage by parents raising children with a variety of disabilities has the potential to examine if parents raising children with various disability diagnoses and intensities utilize social media groups in this manner or if this is associated specifically with parents raising a child with PMD.

This study’s findings suggest examining the parenting experience across ages of the child with PMD may provide insight into the lived parenting experience across the child’s lifetime and refine service provision offered as the child ages. Therefore, a qualitative phenomenological study with a parent sample reflective of infancy, early childhood ages, elementary school child ages, secondary school ages and adult children with PMD would provide this cross-sectional information capable of informing policy and service provision.

The parent priority of their child with PMD’s social connections suggests that this is an area of research need. In-person, children with disabilities often experience limited social connections (Savarese, 2016). A qualitative examination of social activities, interactions and connections for children with PMD has the potential to examine the ways that children with PMD interact socially. This information has the potential to create and support an increase in social connection opportunities for children with PMD.

A qualitative examination of the components of networked community empowerment across other marginalized groups on social media may provide information on factors that support empowerment of marginalized populations. Marginalized populations have been shown to utilize social media to create support and mold that support into action (Dekker & Engbersen, 2014; Liu & Lu, 2018; Panagiotopoulos & Barnett, 2015; Sugawara et al., 2012). Understanding
the dynamics of networked community empowerment factors in this process has the potential to facilitate community empowerment and promote de-marginalization of populations within society.

This study found that parents raising children with PMD utilized social media connections to arrange in-person social interactions. A qualitative study of populations of marginalized groups to examine if the crossover between in-person and virtual-life use of social media is specific to parents with PMD or common amongst other social media group users represents a potential area of future research.

Because this study recommends the use of social media as a systemic resource, a quantitative study examining the user satisfaction of such an online resource can help identify best practices for online resource provision. De Angelis et al. (2018) conducted a systematic literature review and concluded that online interactive forums have promise for supporting management of chronic illnesses, but they also found further research in this area was also needed.

For most of the parents in this study, their child was born prior to or just as Facebook was gaining in popular use within American society. Baker et al. (2017) found that younger parents of younger children used social media for more hours. Repeating this study with a targeted demographic of parents raising children with PMD who have grown up with access to social media throughout their life could provide insight into the social media use of digital natives.

The challenges the study’s parents described regarding community access warrant further investigation. Qualitative examinations of the experiences of individuals with disabilities accessing their geographical communities may shed light on barriers to active community participation and citizenship for individuals with disabilities and their families.
This study represents an initial exploration of social media in the lives of parents raising children with PMD. Social media presents other research possibilities for parents raising children with PMD. A qualitative examination of public parent social media profiles including posts and comments has the potential to add to the depth of understanding of the role of social media in the lives of parents raising children with PMD.

This study included two parents who adopted their child with PMD within the respondent sample. A qualitative study exploring the parenting experience of adoptive parents raising children with disabilities has the opportunity to explore the parenting experience of this group of parents.

**Concluding Remarks**

This study sought to document the lived experience of an understudied and marginalized group of parents—those raising children with PMD. The study design focused on the role of social media in the lives of these parents due to their social and physical isolation. Social media connections were explored, and it was found that parents raising children with PMD rely on social media for social support, resources and information. Parents exhibited three foci of social media use: their personal social needs, their child’s social needs and disability related needs. The parent respondents utilized a social media bricolage approach to address their child’s complex disability-related needs.

Parents supported their own interests, coping and social relationships through virtual connections in groups and with social media friendships. These virtual connections often translated into in-person social interactions. Conversely, in-person interactions were supported across time through virtual social media interactions. This allowed parents to maintain social
connections in a flexible manner allowing them to attend to their child’s often intense care and medical needs while maintaining social connectedness even when unable to connect in-person.

All parent respondents of this study prioritized their child’s social needs and took active steps to ensure their child with PMD had in-person and virtual social connections. They posted their child’s accomplishments, activities and interests. Parents built online networks of support for their children. These online connections also translated into face-to-face social connections. Just as the parents utilized social media to maintain in-person connections across time through social media for themselves, they utilized social media to maintain their child’s social connections across time. However, they did so by maintaining separate and distinct online profiles for their child from their own personal online persona and accounts.

Disability related needs were also addressed through social media. Parents utilized social media bricolage to create a collection of resources that represented the complex collection of their child’s disability needs. Multiple diagnoses, treatments, and resource needs were represented by separate membership in private Facebook groups that were compiled, group by group to represent their child’s often rare conditions, treatments and diagnosis. These compiled groups of resources were flexible and dynamic. Parents found new groups as new needs arose and exited groups that were no longer relevant.

Parents raising children with PMD consistently sought advice through social media from other parents raising children with PMD living a similar experience. Parent respondents described their online “hive” as the only place where the requirements of parenting a child with PMD was truly understood and where advice and resources were targeted and applicable in their parenting. Parents raising children with PMD did not rely solely upon social media for resources. They described medical, educational, service providers as resources they used
consistently. They also vetted information obtained through in-person interactions within their online communities in decision-making processes.

Parents raising children with PMD reported each aspect of sense of community when describing their social media experience. However, when asked if they were members of any particular community, none mentioned social media specifically. All of the parent respondents described becoming empowered as parents of children with PMD across their parenting experience with the support of other parents raising children with PMD as accessed primarily through social media. They developed resources, skills and confidence in their parenting journeys. They aided other parents in developing their skills. They participated in collective actions focused on disability-related causes. Parent respondents described social media as access to a population with a lived experience similar to their own that they would otherwise be unable to interact with.

The online community experience facilitated their empowerment as parents raising children with PMD. This networked community empowerment provided interactions between in-person and virtual community connections for geographically isolated parents dealing with a highly specialized parenting experience. Through online social media access, parents were able to experience the components of community. Through the experience of membership, influence, fulfillment of needs and shared emotional connection, these parents raising children with PMD became empowered in intrapersonal, interactional and behavioral domains. Linked by the rareness of their parenting experience related to the intensity and complexity of their child’s disabilities, and their resulting membership in a marginalized community of parents raising a child with PMD, the online community provided the supports and resources for empowerment. Parents described moving from feeling helpless to experiencing a shift from external loci of
power to internal control. They developed competency and supportive social connections and interactions which they use to collaborate with other parents living a similar parenting experience in an ongoing in-person and virtual network of social support.
REFERENCES


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APPENDIX A: DEMOGRAPHIC SURVEY

Demographic Questions:

Age: What is your age?
  o 20-24 years old
  o 25-34 years old
  o 35-44 years old
  o 45-54 years old
  o 55-60 years old

Ethnic origin: Please specify your ethnicity.
  o White
  o Hispanic or Latino
  o Black or African American
  o Native American or American Indian
  o Asian / Pacific Islander
  o Other

Education: What is the highest degree or level of school you have completed? *If currently enrolled, highest degree received.*
  o No schooling completed
  o Nursery school to 8th grade
  o Some high school, no diploma
  o High school graduate, diploma or the equivalent (for example: GED)
  o Some college credit, no degree
  o Trade/technical/vocational training
  o Associate degree
  o Bachelor’s degree
  o Master’s degree
  o Professional degree
  o Doctorate degree

Marital Status: What is your marital status?
  o Single, never married
  o Married or domestic partnership
  o Widowed
  o Divorced
  o Separated

Employment Status: Are you currently…?
  o Employed for wages
  o Self-employed
  o Out of work and looking for work
o Out of work but not currently looking for work
o Work at home, not for outside agency
o A student
o Military
o Retired
o Unable to work

Is your household income...?:
  o Less than $20,000
  o $20,000 to $34,999
  o $35,000 to $49,999
  o $50,000 to $74,999
  o $75,000 to $99,999
  o Over $100,000

Gender:
  o Male
  o Female
APPENDIX B: INFORMED CONSENT

Department of Education, University of the Pacific

CONNECTIONS: SOCIAL MEDIA AND PARENTS RAISING CHILDREN WITH PROFOUND MULTIPLE DISABILITIES

Amy Terra, M.Ed.

Your consent is being sought to participate in a research study, and your participation is entirely voluntary.

My name is Amy Terra, and I am a graduate student at the University of the Pacific, School of Education. You were selected as a possible participant in this study because you are the parent of a schoolage child identified as having profound multiple disabilities and you are active on social media.

A. Description of Research.

You are invited to participate in a research study which will involve a one-hour long one-on-one interview designed to explore the role of social media in the lives of parents raising a child with profound multiple disabilities. The purpose of this research is to explore the role of social media in the lives of parents raising a child with profound multiple disabilities.

B. Description of Identifiable Information.

If you decide to participate, you will be asked to complete a recorded interview at the time and location of your choosing. The interview may also be completed by FaceTime or Skype upon your request. Your participation in this study will last approximately one hour for the interview.
Follow up questions for clarification may be needed. You will be asked to verify your input by reviewing the transcript of your interview. Interviews will be recorded with your permission.

C. **Foreseeable Risks.** There are some possible risks involved for participants. This includes the potential for emotional distress. Some participants may feel uncomfortable discussing or writing about their personal health, family dynamics or parenting challenges.

D. **Benefits.** There are some benefits to this research, particularly that the study findings may benefit other parents raising children with profound multiple disabilities.

E. **University Contact Information**

If you have any questions about the research at any time, please call me at (209) 329-4801, or Thomas Nelson at (209) 946-3253. If you have any questions about your rights as a participant in a research project or wish to speak with an independent contact, please contact the Office of Research & Sponsored Programs, University of the Pacific at (209) 946-3903 or by email at IRB@pacific.edu

In the event of a research-related injury, please advise us, and then contact your regular medical provider and bill through your normal insurance carrier.

F. **Confidentiality**

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. Measures to ensure your confidentiality are use of a pseudonym, transcript and recordings to be maintained in a secure location.

G. **Duration of Storage, Maintenance, Use.**
Transcripts will be destroyed after the successful defense of the dissertation associated with this study or three years, whichever arrives first. All materials associated with your interview will be maintained in a locked computer device and paper copies maintained in a locked cabinet.

H. Whether Research Details to be Provided.

The results of this study will be made available to you upon completion of the study.

I. Participation

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

Your signature below indicates that you have read and understand the information provided above, that you have been afforded the opportunity to ask, and have answered, any questions that you may have, that your participation is completely voluntary, that you understand that you may withdraw your consent and discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled, that you will receive a copy of this form, and that you are not waiving any legal claims, rights or remedies.

Signed: ____________________________ Date: __________________________

Research Study Participant (Print Name): _____________________________

Researcher Who Obtained Consent (Print Name): _______________________

IRB Approval of Consent Form Date
Your proposal entitled “Connections: Social Media and Parents Raising Children with Profound Multiple Disabilities,” submitted to the University of the Pacific IRB has been approved. Your project received an Expedited review.

You are authorized to work with 10 parents of children with multiple disabilities (20-60 years of age) as human subjects, based on your approved protocol. This approval is effective through July 31, 2020.

NOTE: Enclosed is your IRB approved consent document with the official stamp of IRB approval. You are required to only use the stamped version of this consent form by duplicating and distributing to subjects. (Online consent should replicate approved consent document). Consent forms that differ from approved consent are not permitted and use of any other consent document may result in noncompliance of research.

It is your responsibility according to the U.S. Department of Health and Human Services regulations to submit an annual Active Protocol Status/Continuation Form. This form is required to request a continuation or when submitting your required closure report. Please be aware that procedural changes or amendments must be submitted to the IRB for review and approval prior to implementing changes. Changes may NOT be made without Pacific IRB approval except to eliminate apparent immediate hazards. Revisions made without prior IRB approval may result in noncompliance of research. To initiate the review process for procedural changes, complete Protocol Revision Form and submit to IRB@pacific.edu.

Best wishes for continued success in your research. Feel free to contact our office if you have any questions.