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Using Social Media for Parental Support in Raising a Child with a Disability:

A Critical Analysis of Facebook Postings

by

Lynn M. Fostervold Wells

A Thesis

Submitted to the Graduate Faculty of

St. Cloud State University

in Partial Fulfillment of the Requirements

for the Degree

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Chapter 1: Introduction

Overview

For most parents of a child with a disability, their child's diagnosis begins a journey into a new and unexpected world. Parents anticipate the birth of their child as a joyful time filled with hopes and dreams yet to be fulfilled. When a child has a significant medical diagnosis, such as cerebral palsy or Down syndrome, or they are demonstrating a delay in development. For example walking or talking later than same-age peers, parents are forced to change the trajectory of their hopes and dreams for their child, and shift their path to one filled with new emotions, terminology, and community professionals.

Grief, emotional distress and new demands on their time cause parents to feel extreme stress and desire for support. Eroglu, Akbaba, Adiguzel, and Peker (2014) reported that, although some mothers of children with disabilities are able to cope well, many others suffer from a higher rate of mental health risk factors such as depression, isolation and helplessness. From my experience as an Early Childhood Special Education (ECSE) evaluation coordinator, parents often reported feeling overwhelmed, confused by diagnoses, and isolated from the community, friends, and family. Parents often requested help with connections to social and mental health services and parent/child groups in the community. They often reported that new demands on their time made it difficult to participate in previously enjoyed activities. Additionally, they felt that they are not easily able to access information about their child's diagnosis from doctors and other medical professionals (Bingham, Correa, & Huber, 2012).

To support families with a child with a disability, it is important to determine what the families' needs are. The American Association on Intellectual and Developmental Disability

(AAIDD) defined the need for supports as the resulting “...mismatch between the person’s individual capacity and environmental demands” (Kyzar, Turnbull, Summers, & Gomez, 2012, p. 31).

Several studies have looked into how parents utilize what are considered formal supports, or supports that come from professionals such as medical providers, school districts, and county and other government sources (Bruce, Lilja, & Sundin, 2014; Carpenter & Towers, 2008; Fordham, Gibson, & Bowes, 2011; Whiting, 2014). Others have researched the benefit of informal supports, such as friends, family, religious groups, and online support groups (Aho, Paavilainen, & Kaunonen 2012; Barr, & McLeod, 2010; Coulson & Greenwood, 2011; Linblad, Holritz-Rasmussen, & Sandman, 2007). Various research studies have also addressed how parents benefit from a combined structure of formal and informal supports (Canary, 2008, Douma, Dekker, & Koot, 2006; Tetreault et al., 2014).

To provide a solid framework for defining identified parental supports, Kyzar et al. (2012) divided formal and informal supports into groupings of how families of a child with a disability can best be supported. They described four elements of support: 1) emotional support, that which refers to support of parents’ feelings and emotional well-being, 2) physical support, which refers to assistance for parents with meeting physical or life skills for their child with a disability, 3) material/instrumental support, which refers to support with meeting financial needs, and 4) daily responsibilities and informational support, which refers to providing support through access to information and learning resources.

In addition to the more traditional sources of informal and formal parental supports, parents may often access the Internet as a first step in reaching out beyond their immediate

family situation. Blackburn and Read (2005) reported that the Internet is used by parents of a child with a disability for everything from searching medical website terms and definitions to reaching out for community and social service resources for financial and respite care support. Even so, their 2005 study showed that parents' primary use of the Internet was simply for emailing and other types of correspondence.

Aho et al. (2012) studied mothers' use of an Internet discussion group as a means of support. They demonstrated the Internet to be an effective means of support for exchanging emotional, cognitive, and community support. Yet, the downside was the lack of non-verbal communication as a message was not always conveyed as intended.

More recently, parents of children with disabilities are now using the Internet as a means of gaining access to a new network of communication. The social media site, Facebook, has become a standard way to communicate with the outside world using words, pictures and videos that often receive instantaneous feedback. McAndrew and Jeong (2012) reported that, "As of 2011, Facebook had 800 million active users, more than 50% of whom logged onto the site on any given day. Nevertheless, there is a gap in the research regarding parents of a child with a disability and their use of Facebook.

Importance of the Study

The rapidly changing field of technology is more and more available to families. Parents can access information at the touch of a button on their phones almost anytime and anywhere. Although socioeconomic factors can impact access to the Internet for some families (Skinner & Schaffer, 2006), it has been my experience in the field as an ECSE evaluation coordinator, families typically have access to a phone with Internet service, even if service is occasionally

interrupted. I have found that parents that are accessing early intervention for their child with a disability are often on social media sites such as Facebook. I have witnessed parents scrolling through Facebook during their child's evaluation or observation, both at the school and their home. Facebook use has become so common that a few parents have asked if they could "friend" me on Facebook for ease of contact, not aware of the conflict of interest or breach of privacy this would present.

Accessing social media sites is beneficial in that they have instant access to friends and family who often respond within minutes. This virtual contact with friends and family can reduce some of the isolation that rural or homebound families face because of geographic location or daily family responsibilities. Some of these parents have reported to me that they feel like they are connected to the outside world, even if they are often at home.

Statement of the Problem

To break down the isolating experience of raising children with disabilities, parents have reported that they are depending on this rapidly growing form of communication. Yet, there are limited scholarly studies to date that have described this type of support for this population. In order for educators to better assist parents in connecting through social media, we need evidenced-based information as to what works and what does not work. To date, my literature search for my Thesis has yielded no research studies focused on the use of Facebook by parents of a child with a disability. One way to determine how parents use social media would be to examine their own words as posted on social networks to family and friends, where they are likely to feel free to express themselves honestly.

Purpose and Research Question

The purpose of my study was to explore social media postings by parents of a child with a disability to determine how they are supported by this emerging method of technological communication. The research question for my study is: How do social media postings support parents in raising their child with a disability?

Conceptual Framework–Ecological Model of Human Development

The Ecological Model of Human Development is a theory that helps us to understand the interconnectedness of family and the larger society, and the resulting socialization of a child. Bronfenbrenner (1986) described a child's development as the intertwining interaction between "systems" or "layers" of their environment. The system closest to the child is the "microsystem," including those people that have face-to-face and bi-directional interactions with the child. This means that the child is influenced by and also influences the other party. This includes their parents, extended family teacher and childcare provider, for example (Paquette & Ryan, 2001).

The second layer, or system, affecting a child is their "mesosystem." This is when two or more of their microsystems are interacting. A child's environment is directly affected by the interdependent interactions between a child's teacher and their parents, for example (Paquette & Ryan, 2001).

The Ecological Systems Theory serves as a basis for understanding how Facebook connects parents to the community at large, beyond their microsystem to the mesosystem, by the interactive structure of the tool. Parents are influencing and being influenced by society through

their intertwining interaction of words, pictures and connections to new people and places (Figure 1).

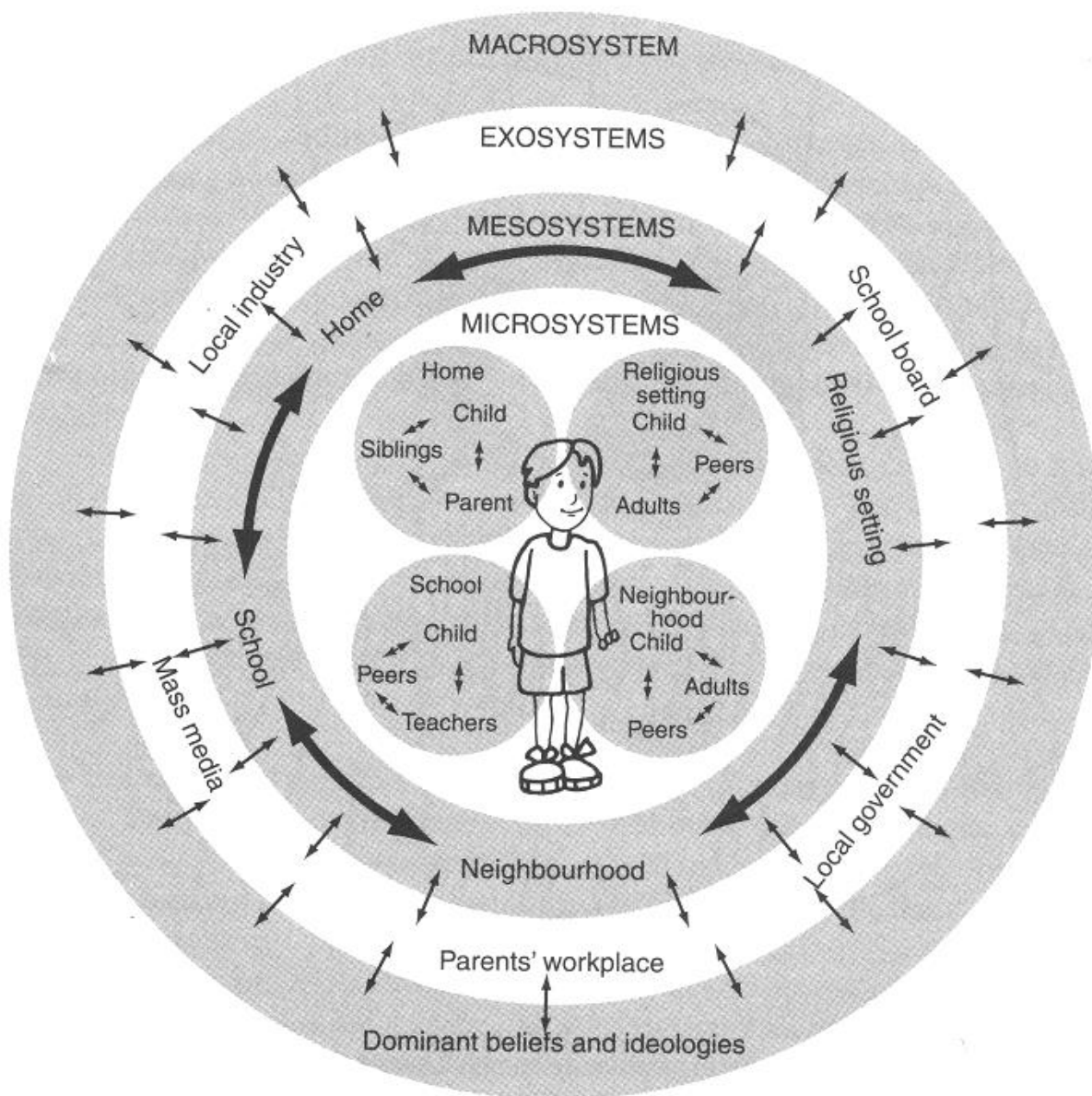


Figure 1. Bronfenbrenner's Ecological System's Theory (Penn, 2005)

Conclusion

Chapter 1 contains information on the types of formal and informal parental supports, emotional, physical, material/instrumental, and informational (Kyzar et al., 2012). It also discussed how previous research has shown how parents of a child with a disability have used the Internet to gain support. The Internet has been a way for parents to connect to society at large, their mesosystem, through this virtual world. Considering the impact the Internet has on connecting families to the greater community, it is then logical to study how parents' use of social media sites such as Facebook supports them. The purpose of this study was to determine how parents of a child with a disability find support in their Facebook posts.

In the next chapter, I review the literature pertaining to support for parents with a child with a disability and their coping strategies. I also discuss the literature regarding their use of the Internet in general, as well as for a means of support for raising their child with a disability.

Chapter 2: Literature Review

Overview

Support, both formal and informal, for families who are raising a child with disabilities is very important to parents' overall well-being. The challenges that arise in caring for a child with a disability are far reaching—from impacting parents' relationships or finances to their mental health. Chapter 2 reviews research studies to demonstrate that parents of children with disabilities have several means of coping and seeking support. Support through the use of the Internet is not a new phenomenon; for instance, parents with Internet access and the necessary technology skills can access medical information websites or online support groups. A more recent means of support has emerged online through the use of posting on social media sites such as Facebook.

Coping with Stress

Demands on time, finances, and emotions often result in stress for families raising a child with a disability. Developing coping skills and strategies to manage this stress is an important part of maintaining the strong emotional stability needed to maneuver the twists and turns of raising a child with a disability.

Several researchers have studied coping strategies of parents of a child with a disability. Focusing primarily on how the identified families handle stress, Eroglu et al. (2014) used a correlation design to determine the relationship between learned resourcefulness and stress related coping strategies in 222 mothers of children with disabilities that were attending a special education school in Turkey. They utilized The Self-Control Schedule and Ways of Coping Inventory to study this relationship. They determined that those mothers with strong learned

resourcefulness, or the ability to effectively manage their stress through positive thinking and self-control strategies, had higher levels of optimism, self-confidence, and support seeking skills and lower helplessness and submissiveness.

Another study looked at mothers' coping skills with the initial diagnosis of a child's disability diagnosis. Bingham et al. (2012) studied six mothers' memories of their experiences when they first had concerns about their child's development, when they reached out for help with those concerns, and their child's initial diagnosis of a developmental delay. Each of the six mothers were interviewed multiple times by researchers and were identified and selected from a group of parents whose child was receiving early intervention home based services and who expressed interest in the project. The researchers indicated that they were focusing on the mother's reflection of their experience some time after they experienced it, rather than an in-the-moment reaction. They determined that coping strategies were different for each of the six mothers in the study, but that they each used at least one of two different types of coping strategies: palliative and problem-solving. Palliative strategies used by the mothers included: 1) denying, or pretending that nothing was wrong or that it would resolve itself if nothing was done, 2) questioning why, or asking God or others why this was happening to their child, and 3) wishful thinking, or hoping that medical reports or evaluations were wrong, or less concerning than they appeared. Their identified problem-solving strategies included: 1) searching for information or researching and looking for answers about their concerns for their child, 2) seeking social support; for example, from church or parent groups, 3) reframing or finding the positives in what could be perceived as a negative situation, and 4) seeking spiritual support,

relying on spiritual beliefs or a higher power, and finally, 5) seeking professional support, or contacting medical professionals or the early intervention program in their area.

Ekas, Lickenbrock, and Whitman (2010) conducted a third study that demonstrated a strong link between partner and friend support to optimism, which in turn created positive outcomes for mothers of children diagnosed with Autism Spectrum Disorder. To arrive at these conclusions, the authors analyzed 119 questionnaires returned to them from families with a child under 18 with a diagnosis of Autism Spectrum Disorder. A local autism support group identified the families. The researchers analyzed the participants' responses to existing protocols and researcher-developed questionnaires in the areas of optimism, informal social support, parenting stress, positive and negative affect, depression, life satisfaction, and psychological well-being. Results demonstrated a positive correlation between partner and friend support and mothers' optimism and resulting positive outcomes.

General Support for Families

Various research studies have also addressed how parents benefit from a combined structure of formal and informal supports. Formal supports were often described as provided by a professional and informal support as provided by friends or family members (Bruce et al., 2014; Fordham et al., 2011; Whiting, 2014).

In a literature review, Canary (2008) looked at 10 years of research on familial supports. She reviewed 103 peer reviewed articles on supports for families of a child with disabilities and found nine focus areas or themes among the articles: Well-Being, Informal Support, Formal Support, Combined Support, Resources and Socioeconomic Factors, Culture and Minorities, Intervention Programs, Extended Families, and Siblings. A significant finding of this study of a

decade of research indicated that support for families of child with a disability impacted "...well-being for family members, family functioning, and the utilization of social resources" (p. 413).

Douma et al. (2006) studied what families with a child with a disability needed in terms of support, and what supports, if any, were not being met. Their study was part of a larger longitudinal study in Holland. The authors began with parents of 745 students identified from Dutch schools specifically for children with disabilities. Of these 745 students, parents of 289 children felt their child also had emotional or behavioral concerns. The researchers utilized a questionnaire to determine parents' desired supports as well as their unmet needs. Results of the study indicated that 88.2% of parents "needed some supports, especially a friendly ear, respite care, child mental health care and information" (Douma et al., 2006, p. 570). Their greatest unmet needs ranged from information gathering and available activities for their child to mental health services or referrals for both parent and child.

A final study investigated the combined formal and informal support. Tetreault et al. (2014) conducted a literature review to establish a typology of support services needed by families of a child with a disability. This typology was then cross referenced with available services in seven countries, as part of a larger study, in order to create a data base of available services for professionals to access to meet these needs for families. This research identified four major typologies of needs; support, respite, child minding, and emergency support. These categories were then defined further and fell into the formal and informal supports discussed in this chapter. The researchers emphasized the importance of utilizing the four typologies in communication with parents to connect them with appropriate support services.

As mentioned in Chapter 1, Kyzar et al. (2012) conducted an extensive literature review of articles published between 1990 and 2010 that addressed the “relationship between family support and family outcomes...for families of children with moderate to severe disabilities” (p. 31). The authors determined that four areas of support are appropriate as major themes of future research. Emotional, physical, instrumental/material, and informational themes were consistently present in their review of the literature. It was also determined that there was a strong correlation between familial support and family outcomes such as “...family functioning, family satisfaction, family quality of life and family stress” (p. 31). Their study of 20 years of research in the field indicates that family service providers can best help the child by providing supports to the family.

Several studies focused on the emotional support for mothers, fathers, and siblings. Carpenter and Towers (2008) focused on the needs of fathers of a child with a disability by conducting semi-structured interviews with 21 fathers as a part of a larger study, which was researching the issues that fathers of a child with a disability faced. Overall, fathers indicated that they want to be more involved in their children’s lives, from school meetings and father specific activities to flexible work schedules and enhanced opportunities to be involved in decisions about their child. This study demonstrated that fathers want to be more involved and want to be as supported as they perceive mothers to be.

In a study focusing on mothers of children with congenital heart defects, Bruce et al. (2014) looked at the mothers’ perceived lived experiences of support; good, bad, or nonexistent. Ten mothers selected from a pool of patients at a clinic in Sweden treating children with congenital heart defects were interviewed about what support means to them. They were asked

questions about support that they experienced, whether it was the desired support they were looking for and what support meant to them. For the participants, receiving support meant "... to receive assistance to get their needs and desires satisfied" (p. 64). Perceived poor or nonexistent support included not getting support in the way it was desired or not receiving support when it was expected.

Lindblad et al. (2007) focused their study on the benefit of informal support for parents of a child with a disability. Their research involved interviews of 13 parents from eight families receiving a government allowance for caring for their child with a disability. This stipend is awarded to families that have a child with a disability requiring a high amount of cost or major care needs. The researchers were interested in exploring the parents' perceived lived experiences of raising a child with a disability with a focus on their informal supports, rather than professional supports. Specifically, three themes emerged from their study. Parents interviewed identified "... 'being gratified by experiences of the child as having a natural place in relations with others', 'being provided a room for sorrow and joy' and 'being enabled to live an eased and spontaneous daily life'" as the resulting meaning of informal support (p. 238).

Barr and McLeod (2010) investigated the experiences of siblings of children with disabilities. Information was gathered from public postings from an Australian sibling support website operated by a disability organization. The authors focused on postings related to three themes: Experiences with strangers, experiences with peers and experiences with family. Within their analysis of 676 posts that met their key themes, they discovered emerging subthemes. In their category of experiences with strangers they found that siblings felt that "strangers stare and I feel embarrassed" and that strangers "have a negative attitude towards

people with disabilities” (p. 165). Regarding their key theme of experiences with peers, siblings reported that their peers use derogatory terms, tease, say mean things about their sibling and “...don’t understand what it’s like to be me” (p. 165). Finally, siblings reported that their experiences with their family are challenging as well. The emerging subthemes in this area resulted in the feeling that there is not enough time for them, they have to stay flexible to change in plans, and they take on a lot of responsibility, often feeling like they are not providing enough help.

In addition to Douma et al. (2006) that identified the greatest unmet needs of their participants as information gathering and referrals for mental health care for parents and children, two other studies also identified unmet support needs of parents of a child with a disability. In Whiting’s (2014) study of families’ perception of professionals’ support, he utilized semi-structured interviews with 33 families of a child with a disability. The results of this study indicated that parents struggle to find help from professionals after business hours or overnight and that their greatest unmet need was for respite care, thus family caregivers did not feel that they were able to get a break or to socialize.

Finally, Fordham et al. (2011) conducted a survey of 130 families receiving Early Intervention services in New South Wales, Australia. They utilized portions of four existing scales, The Parenting Daily Hassles Scale, the Measure of Processes of Care-56, the Family Empowerment Scale and the Family Support Scale to flesh out the survey. The authors were interested in two aspects of Early Intervention; families’ experiences with family centered services and other factors that might impact this experience. Their results indicated that “...’respectful and supportive care’...” was the family support need most likely to be met and

“...’provision of general information’...” was the need least likely to be met (p. 647). Of significance then, was their finding that there was a strong correlation between the provision of general information to families and their feelings of empowerment.

Internet Support

Studies on Internet support for parents of a child with a disability focused primarily on online support groups (Aho et al., 2012; Coulson & Greenwood, 2011; Kirby, Edwards, & Hughes, 2008). In general, the studies showed that parents found online support groups to provide a “...strong sense of community...” (Aho et al., 2012, p. 417) and that they “...may provide a venue through which individuals with similar backgrounds and experiences can both seek and provide support, particularly informational and emotional support” (Coulson & Greenwood, 2011, p. 876).

In one study of Internet support, Aho et al. (2012) used a content analysis design to describe the peer support experiences of mothers who have had a child die. This study analyzed entries in a Finnish online peer support group that utilized a discussion format. The authors organized each participants’ comments into themes and then into subcategories. From there the subcategories were reorganized into major categories. Three main categories emerged from the data analysis of this online support group; emotional support, informational support and support through communality. The research resulted in understanding that the Internet support group was a good format for people to share their feelings about similar life experiences.

In another example, Kirby et al. (2008) used a retrospective qualitative and quantitative analysis of posts on an online message board. Parents who suspected that their child may have a delay in development or health or mental health concerns were able to post about their concern

on the message center. If message posters provided an email address, professionals from The Dyscovery Centre (a University of Wales run center for assessment in the area of childhood developmental disorders who monitored the site) could reply. Or, others who used the site could respond as well. If they wished to remain anonymous, their message could be responded to publicly on the site. The researchers analyzed the messages posted for themes and frequency of responses to each theme. They determined that 10 themes emerged from the research. Motor, service provision and education were the top three areas of concern and also resulted in the highest percentage of responses to a theme. The authors concluded that parents of a child with a disability often feel isolated, and online message boards, such as the message centre, provided a community with which to share experiences that reduced their isolation.

Coulson and Greenwood (2011) utilized theory driven qualitative analysis of 487 messages randomly selected from three online discussion groups for childhood cancer to identify common themes. The authors identified five common themes; emotional support, informational support, esteem support, network support, and tangible assistance. Of the five themes, the researchers determined that emotional support and informational support were the most common among all three message boards, and tangible assistance, such as financial support, was the least common among all three boards. Two identified negatives of the message boards were first, no response to a request for advice and second, the inability to exchange contact information with other message board users.

Internet Uses by Parents with a Child with a Disability

Research is limited in the area of how parents of a child with a disability utilize the Internet. One study looked at how information concerning a child's genetic disorder was

gathered, interpreted and utilized by families of different cultural and ethnic backgrounds (Skinner & Schaffer, 2006). One hundred families were recruited from a genetics clinic in a culturally diverse area of southeastern United States to participate in the study of Internet use. The researchers discovered that most of the European- American families utilized the Internet and that Latino families were the least likely to use the Internet. They determined that, although there were some differences in Internet use between ethnic groups, this was largely due to level of education and socio-economic status rather than culture. Furthermore, it was discovered that Internet research regarding the specific genetic condition was primarily to get a second opinion or to supplement their medical provider's information.

Zaidman-Zait and Jamieson (2007) discussed the advantages and disadvantages of parents' Internet use and the implications for professionals in meeting those parental needs. The authors conducted a literature review of articles on parents of children with disabilities, their use of the Internet for support and how professionals can use the Web as a support for families as a basis for their article discussion. The researchers determined that parents utilized the Internet for seeking information after their child's diagnosis, obtaining resources from medical or educational professionals and obtaining interpersonal support. Information overload and quality and reliability of information were listed as disadvantages. It was also suggested that professionals utilize the Internet to supplement the parents' own research with recommended online sites and sources as a means of additional support.

A 2005 study looked at parents with a child with a disability Internet use and established that they used it primarily for information gathering about caring for their child, emailing and shopping for equipment (Blackburn & Read, 2005). To arrive at these conclusions, the authors

analyzed 788 qualifying surveys out of a pool of potential participants from a larger study of adult caregivers of children with disabilities in the United Kingdom. It is important to note that this study was prior to generalized use of social media. Facebook specifically did not appear until 2004 (McAndrew & Jeong, 2012).

One last study looked at parents of a child with a disability use of technology. Parette, Meadan, Doubet, and Hess (2010) utilized an online survey within the Family Center on Technology and Disability Website out of Illinois State University. One hundred and forty-four parents of a child with a disability had qualifying surveys that were analyzed to determine parents' experiences with using technology-based supports, which ones they use and what their preferences are for technology. It was determined that parent of a child with a disability used the Internet primarily to gather information, communicate with other parents, and to communicate with professionals that could help them including parent rights advocates and teachers. They determined that 43% of their participants used social networking sites such as Facebook (Parette et al., 2010).

Conclusion

In this chapter, I reviewed the existing literature that examined how parents of a child with a disability benefited from support, both informal and formal, their use of the Internet in general and for particular supports, and their coping skills. Coping skills and learned resourcefulness in parents with a child with a disability was determined to be an indicator of parent's optimism, self-confidence, and ability to seek resources (Eroglu et al., 2014). Studies indicated that parents of a child with a disability benefited from interpersonal as well as professional support and that it influences overall well-being (Bruce et al., 2014; Canary, 2008,

Fordham et al., 2011; Whiting, 2014). Additional research showed that parents use the Internet primarily for information gathering, communicating with other parents and professionals and shopping for supplies (Blackburn & Read, 2005; Parette et al., 2010; Skinner & Schaffer, 2006). It was also discovered that those parents who use the Internet for support primarily seek out online support groups (Aho et al., 2012). One study mentioned the use of social media, including Facebook but did not link it to parental emotional support, but rather to what a parent with a child with a disability accesses on the Internet for general purposes (Parette et al., 2010).

In my next chapter, I review the purpose of my study to determine how social media postings, particularly Facebook, support a parent of a child with a disability. I discuss my research design, participant, data collection, and data analysis.

Chapter 3: Method

Opening

There have been numerous research studies demonstrating the need for supports for parents of children with disabilities. For example, Canary (2008) demonstrated that support for a family with a child with a disability directly impacted families' well-being and ability to access community resources. This study was further supported by Kyzar et al. (2012) who found a correlation between familial support and positive family outcomes. More recently, the Internet offers a new option to meet families' needs for support. The accelerated use of social networks such as Facebook leaves us with the question of how families with a child with a disability might utilize these social networks. Thus, the purpose of my research study was to determine the role that Facebook postings play in supporting families with a child with a disability.

Research Question

To meet the purpose of my research study, my research question is: How do social media postings support parents in raising their child with a disability?

Research Design

In order to answer this research question, I developed a case study employing qualitative data collection and data analysis methods. More specifically, this case study described a family with children with disabilities with specific emphasis on how this mother seeks and receives support in raising her children. My primary source of data was this mother's postings on Facebook from April, 2011, to December, 2015, yielding a retrospective examination of a parent's experiences and responses to those experiences in raising children with disabilities.

Participant

The case study participant in this research project is Jenny, a 34-year-old married mother of two boys. For privacy reasons, the names of the individuals in this family have been changed. Jenny and her husband's sons, Jay, age 5, and Thomas, age 3, were both evaluated and determined eligible to receive Early Childhood Special Education services under Part C (children ages birth to 2 years 11 months) of the Individuals with Disabilities Education Act (IDEA) before their third birthdays (IDEA Part C, 2004). In the state of Minnesota, children who are evaluated for Part C services must be determined to be demonstrating a developmental delay of -1.5 standard deviations from the mean or greater in one of five developmental areas (Minnesota Department of Education, 2015). These developmental areas include cognition, communication, fine and gross motor, social emotional, and adaptive. A child can also be determined to be automatically eligible if they have a verified medical diagnosis that is known to put a child at risk for a developmental delay (Minnesota Department of Education, 2015).

If a child is determined eligible, early intervention services are provided by an Early Childhood Special Education teacher in the child's home or childcare setting. This is considered their naturalistic environment, and services are considered family guided routines-based intervention. Services are focused on helping the family to help their child develop in areas of delay through the family's already existing routines. Services also include service coordination, or connecting the family with resources, such as county services, support groups, or mental health services.

Thomas, Jenny and her husband, Sam's youngest son, was determined eligible to receive special education services at age 1 year 5 months in the developmental areas of communication

and social emotional skills, in August, 2014. Jenny reports that Thomas was born 5 weeks prematurely, and that the doctors inspected her placenta post-delivery and determined he had stopped growing at about 33 weeks gestation. He spent 2 weeks in the Neonatal Intensive Care Unit (NICU) and was discharged to spend a few days at home. Thomas then was readmitted to the NICU for 4 days after several tests results returned resulting in a diagnosis of Ureteropelvic Junction (UPJ) Obstruction (Mayo Clinic, n.d.a). It was referred to as a dilated kidney in utero. Thomas had surgery to correct this condition at 4 weeks of age. Later, at age 3, he was cleared of any further complications of the condition. Thomas was also diagnosed with hypothyroidism as a newborn, and has been taking ever increasing amounts of thyroid medication to help him maintain appropriate thyroid levels. Through all of this, Thomas has struggled to grow. At his 3-year wellness check, doctors referred him to a feeding clinic for increasing his repertoire and quantity of foods. At the time of this writing, these appointments at the feeding clinic had not begun.

Thomas received home-based early intervention services for 16 months and at 2 years, 9 months, Thomas participated in an evaluation to determine his eligibility for special education services under Part B (for children 3-6 years, 11 months of age) of the Individuals with Disabilities Act (IDEA Part B, 2004). Eligibility for Part B special education services is determined through evaluation of areas of educational need. A child is determined eligible if they demonstrate a delay of -1.5 standard deviations in two or more areas of development (communication, cognition, motor, social emotional, and adaptive), and also demonstrate an educational need as supported by a naturalistic observation (MDE). At his Part B evaluation, Thomas only demonstrated a delay of -1.5 standard deviations or more in the area of adaptive

skills, therefore determining that he was not eligible to continue to receive services and early intervention services were discontinued at age 3, in March, 2016.

Thomas' older brother, Jay, has had a somewhat different journey. When Thomas was just 4 months old in July, 2013, Jay was determined eligible to receive special education services. He was 2 years, 4 months of age and was demonstrating delays in the areas of social emotional, adaptive, and communication development. Had Jay been referred for evaluation by his pediatrician, he would have also been found to be automatically eligible for special education services shortly after his birth due to a diagnosis of failure to thrive; a medical diagnosis known to put a child at risk for a developmental delay (IDEA Part C, 2004).

When his eligibility for special education services was determined for Part C services, the school district conducted a concurrent evaluation for Part B services as well. Since he was over 2 years of age, the district was able to determine eligibility for Part C and Part B services at the same time; therefore, eliminating the need to put the child through a second evaluation a few months after his first evaluation. Jay was determined to be eligible for Part B services at this time as well. Jay received home-based services until he was 2 years, 10 months old, and then began a center-based program at his local early childhood center for 3-year-old children on Individualized Education Programs (IEPs) (IDEA Part B, 2004). He continued into a program for 4-year-olds, and then after his 4-year well child check, his pediatrician referred the family to a behavioral health clinic for a neuropsychological exam to determine a diagnosis of Autism Spectrum Disorder (ASD). The family received this diagnosis for Jay just before he started his school year in a classroom for 4- and 5-year-olds. His IEP team met, amended his IEP to reflect

this new diagnosis, and he now receives services under the educational category of Autism Spectrum Disorder.

Throughout this time of educational testing and school-based services, Jay was suffering from numerous bilateral ear infections and had several surgeries. He had eight double ear infections by 10 months old and received his first set of tubes after the eighth infection. “An ear tube is used most often to provide long-term drainage and ventilation to middle ears that have had persistent fluid buildup, chronic middle ear infections or frequent infections” (Mayo Clinic, n.d.b). At 22 months, Jay had surgery for a re-circumcision. Shortly after his younger brother was born, he had a second set of ear tubes placed, at 2 years of age. At the age of 3, 8 months after Thomas’ kidney surgery, he had his adenoids removed and a third set of tubes placed. When Jay was 4 years old, he received a fourth set of tubes when he had his tonsils removed. With his fifth set of tubes at age 5, physicians finally placed titanium tubes in his ears. Additionally, he had two surgeries on a broken elbow during the summer of his fourth year.

During this time, Jay was also receiving outside, medically-based occupational and speech therapy. Jenny and Sam felt overwhelmed, and discontinued outside speech therapy after only a few visits, reporting that they felt it overlapped services that were being provided through the school district in early intervention. The family also started social skills groups and behavioral therapy at an Autism Clinic for Jay in August of 2015. At one point, the family was juggling three outside therapy appointments, an Early Childhood Family Education (ECFE) mommy and me class for Thomas and preschool for Jay—all in an 8-hour day. Jenny works a 40 hour work week over 4 days each week. She rises at 4:30 each day to work 10 hour days that allows her one day a week for her sons’ appointments. Sam has a very demanding job, often

taking him away from the family for weekends and overnights. He also takes one day off during the week to spend with the boys.

Both Sam and Jenny have completed their Master's Degrees in their respective fields. They have a very close relationship with both sets of grandparents and other extended family members. In addition, they have a good supportive system with several close friends. They live in a metro area with high-quality school districts and medical resources, including a nationally respected children's clinic and hospital where their boys have received all primary and specialized pediatric care.

Data Collection Procedures

I used one form of data collection to complete my case study. In examining extant data from the mother's postings on Facebook, data were collected from the date of April, 2011, through December, 2015.

Data Analysis

Data were analyzed according to pre-determined specific steps to code the extant data. Coding categories was focused on parent supports. Using posts from March 2, 2011 (Jay's birth), to May 6, 2016, I will cut and paste all of the mother's Facebook posts into pre-determined categories in separate Word documents. When new categories of data analysis emerged that that did not fit into the pre-determined categories, I added these new categories to the coding process. After every post was categorized, I determine which categories emerged as dominant themes of findings that explained social media support for a parent with children with disabilities.

To provide a solid framework for defining identified parental supports, Kyzar et al. (2012) divided formal and informal supports into groupings of how families of a child with a disability can best be supported. They described four elements of support: emotional support, parental feelings and emotional well-being supports, physical supports for parents in meeting physical or life skills for their child with a disability, material/instrumental support for meeting financial needs and daily responsibilities, and informational support through accessing information and learning resources. These four categories will be utilized as original coding categories for the participants' Facebook posts, thus grounding my data analysis process in the literature base that supports my case study research project. Following this first step in the data analysis process, I focused on the resulting emotional support category and continued with a constant-comparative qualitative data analysis process that yielded themes of findings within emotional support postings (Glaser, 1965). I used descriptive statistics to describe the frequencies of postings per category across the data set to further explain how Facebook postings can serve as a source of support in parenting children with disabilities.

Chapter 4: Results

In order to address my research question fully, I have developed a Case Study of one family with two young children with disabilities. Since my research question focused on how Facebook postings can provide support for a parent of young children with disabilities, the family contextual information helps to specify the need for support. I chose to provide this family context in the form of a yearly timeline that highlights the young children's major life events. Figure 2 displays this chronology of this family's experiences.



Figure 2. Timeline of Family Events by Year in Chronological Order

Thematic Findings

The results of my constant comparative approach to qualitative analysis of my participant's Facebook postings yielded six Super Themes that are listed below in Table 1.

Using Glaser (1965) as the basis for my qualitative data analysis, I also determined Sub-categories of new information from the Facebook postings that are associated with each Super Theme below

Table 1. Super Themes with Sub-Categories

Embracing the Positive	It Takes a Village	Our Team Rocks	Keeping it Real	We've Got This	Live Life to The Fullest
Joys of Parenthood	Extended Family	School District	Grief/Frustration	Super Jenny	Routines
Blessed	Friends	Doctors/Medical Facilities	Scared/Worried	Self-Care	Family Adventures
Happy Kids	Spouse	Sports and Recreation	Exhausted	Relief/Hope	Mama Days
Boys Love For Others	Spiritual		Diagnoses	Advocacy	Weather/Outside Play
Laughter and Excitement	Animals		Stress	Team Randall	Holidays
			Caring for Sick/ Injured Children		
			Flying Solo		

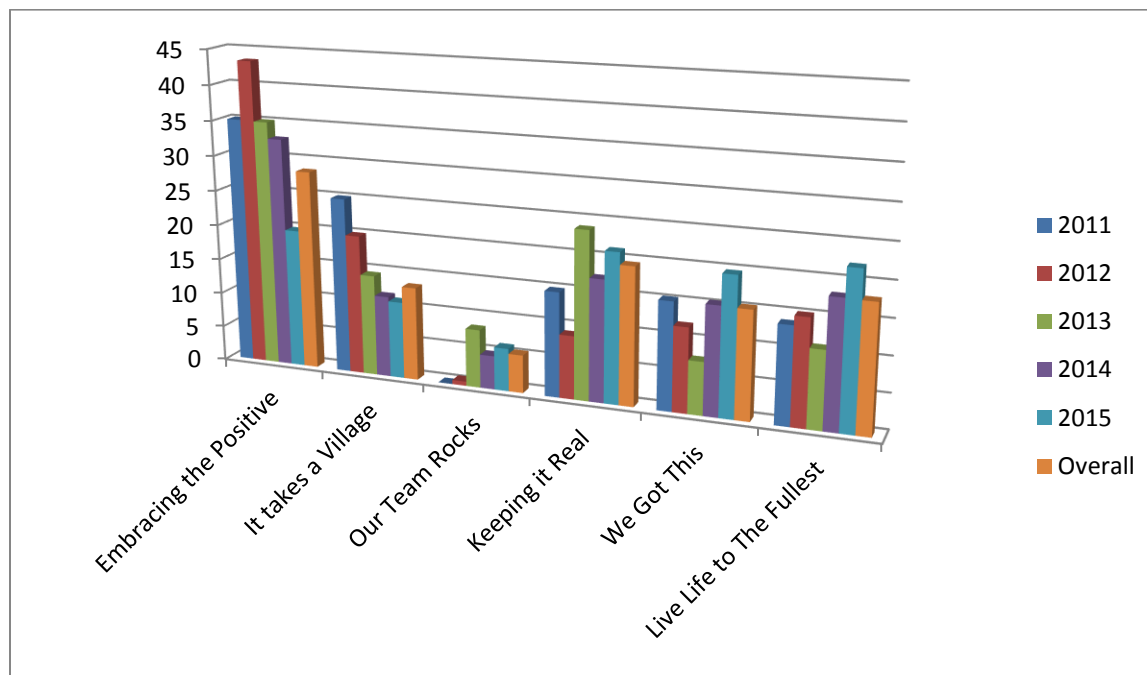


Figure 3. Percentage of Documented Super Themes per Year

Super Theme #1: Embracing the Positive

The first of six Super Themes to emerge from the research is *Embracing the Positive*, which included statements of positive emotional well-being. By positive emotional well-being, I mean feelings such as joy, gratitude, happiness, and love. These statements of positive well-being fit into five sub-categories identified that explain this Super Theme. The title for this category comes from the sentiments of a July, 2014, post:

“As I put both our boys to sleep, I can’t help but think of this journey we have been on so far. This chapter in our life has been far from easy. There are weeks it feels like we have been at the doctor more than we have been home, we have had extra appointments, labs and tests done with every type of specialist imaginable, and there are days we wish we could have just one “normal” day. But then I think, this is our normal, this is the life we know, and our boys are perfect in our eyes. It’s the way God made them, and I wouldn’t want it any other way because then we wouldn’t be blessed with Jay and Thomas. Life isn’t supposed to be easy...it’s supposed to make you happy, and my three boys bring me all the happiness in the world.”

Super Theme #1: Embracing the Positive–Subcategories

- **Joys of Parenthood** is the first sub-category that emerged from the Facebook posts addressing positive emotional well-being. More specifically, this sub-category referred to the joy that my participant felt in being a parent or pride she felt in one of her children's accomplishments. When my participant's first son independently interacted with a peer in his classroom for the first time, she was overcome with pride. Another post recounted the joy of watching one of her sons smile and discover his face in a mirror during tummy time at just 8 weeks old. A post from December, 2012, exemplified this sub-category well, "There is nothing more touching than your child taking a break from play-mode, cuddles right into you with his head on your shoulder, patting your back, and says, "oh mama"...and then rushes away back to his toys. Love this life I have." Finally, a post from shortly after her older son received a diagnosis of Autism in September, 2015, illustrated the sub-category *Joys of Parenthood*, "OMG what an epic mama-day!!!!!! The boys got fresh back-to-school haircuts, hit up the zoo and the pool, there were no tears, no fighting, plenty of laughter, and got to spend it with one of the boys' best friends Delilah! Jay ROCKED the crowds and handled himself AWESOME! I'm so proud of everything today; it makes me want to just burst with joy #mommyadventuresrock #bedtimesgoingtobeabreeze."
- **Blessed**. My participant describes herself as a spiritual and positive person, which has emerged frequently throughout the years of her Facebook postings that I analyzed. When my participant referenced counting her blessings, feeling thankful,

or wishing others a happy, blessed, or beautiful day, it was labeled as the Blessed sub-category. An example of a Blessed reference is included in her post from August, 2012, “Blessed to have a whole weekend with just my boys. We are all still in our PJ’s and plan on doing NOTHING all day! What a beautiful life we have!” Another example is referenced in her post from October, 2013, “Therapy, ECFE, and Owens OT/PT eval...so thankful for today’s medicine/services that are available that will help my boys thrive: Make it a beautiful day everyone!!!” Finally, she demonstrates this sub-category in a post from November, 2015, “GIVING is the most amazing feeling in the world! Today I went shopping and gathered all our supplies for the NIVU/Special Care Nursery care packages that Thomas and I are delivering to the Hospital NICU the week of Thanksgiving. We have enough to help 30 families!!!! So beyond blessed for everyone that has offered to help, and I love the message we are teaching our boys!”

- **Happy Children.** A third sub-category noted in this Super Theme of Embracing the Positive is Happy Children, which referred to the participant’s children’s happiness, smiles or joy. For instance, a post from June of 2015 states, “This kiddo is the bravest kid I know...he has had a surgery every year of his life, with the most impressive being two surgeries within this past week! Yet, he is still smiling! #bringonjuly #teamrandall.” My participant demonstrated elements of the sub-category Happy Children in another post from August, 2014, where she posted, “One thing I was reminded by this weekend is that family ALWAYS comes first. I ditched my 16-mile training run for extra hours of sleep and more time with my three boys.

There is nothing better than the pure joy we saw on Jay and Thomas' faces and all the love Sam and I showed them. Another amazing weekend in the books." She demonstrated this sub-category further in a post from July, 2013, "I am convinced that the only reason why Thomas wakes up in the middle of the night is to get extra mommy-time...he is nothing but smiles and joy when he sees my face: That will never get old. Happy Monday."

- **Children's Love for Others** was a sub-category discovered that reflects her children's demonstration of love to parents, siblings or others. Children's Love for Others is demonstrated in her post from November, 2014, "You are my favorite mommy and I love you as much as I love trains.' –Jay 3 ½ years. I am blown away....that's a lot of love! Much needed today." Another example of this sub-category comes from August, 2015, "Their brotherly love is growing more, and the ability to play together is amazing: They definitely have their moments, but in the end, they still show unconditional love. This picture makes my heart burst with emotion, and it even makes me all teary-eyed. #brothersforever." Other posts refer to hugs, kisses and her older son comforting her younger son when he was injured.
- **Laughter and Excitement** references their family's laughter, sarcasm, or excitement. My participant often uses laughter in her posts about events of the day. A specific example can be demonstrated by this post from July, 2015, "OMG, we just swung by Caribou for my 'pick-me-up,' the lady asked me what she could get for me, and before I could respond, Jay shouts out 'my mama needs a campfire mocha with skim because Thomas and me make her tired!' LOL do you think I have said that before

just a FEW times?!?!?” A post from the week her older son was diagnosed with Autism, she simply stated, “Sometimes you just need to laugh it off.” An example of the laughter they share is evident in this post from June, 2015, “Jay: ‘is your food spicy?’ Me: ‘yeah it’s a little spicy’ Jay: ‘is this piece of paper spicy?’ Me: “no, usually food is just spicy’ Jay: ‘is dada spicy?’ Me: ‘well...’ Jay: ‘you like spicy dada, mama?’ LOL!! This. Kid.” A specific example of how my participant uses sarcasm in stressful times is demonstrated in this post from September, 2014, “Let’s just say that both the boys are fed, bathed, and fully ready for bed...that tells you that this day needs to end and THANK GOODNESS I get another day with them tomorrow. At one point Jay may have been found on the curb with a “free” sign staked next to him. #freshstart #thomascanonlybeattackedsomanytimes #maggieneedstoppoopinginthehouse #thisismylife #stillloveyboys.”

An additional example of the elements of the sub-category Laughter and Excitement comes from November, 2014, “Dear Thomas, Your parents love you to the moon and back, and would really appreciate you sleeping through the night. It’s been 27 nights straight (but who’s counting?) and we are exhausted. Don’t make me bust out the “Go the F\$%K to Sleep” book tonight. Love, Mom and Dad.”

Super Theme #1: Embracing the Positive–Descriptive Analysis

The results of the study indicated that Super Theme #1–Embracing *the Positive* was overwhelmingly the most documented Super Theme. Over the 5 years of posts, *Embracing the Positive* components were the number one category until 2015 when two other Super Themes emerged as the top two most referenced Super Themes, *Keeping it Real and Live Life to the*

Fullest. Two sub-categories of *Embracing the Positive*, Joys of parenthood and Blessed, were referenced either the most, or second most of all references for the first 4 years, but shifted to second and tenth most referenced respectively in 2015. Joys of Parenthood was the number one documented sub-category of all, with 11% of all references over five years containing a theme of joy of being a parent or pride in a child's accomplishments. Blessed was the number two most referenced sub-category of all references documented at 8.7%. As stress-related references from the Super Theme *Keeping it Real* increased, references to feeling blessed decreased and posts about laughter increased in this Super Theme. Of 2,722 references to sub-categories recorded, components of *Embracing the Positive* were documented 778 times, placing this Super Theme at 28.4% of all references. When the posting frequencies for each Super Theme are considered, the year 2014 had the most postings for this Super Theme with 43.4% of all postings for that year.

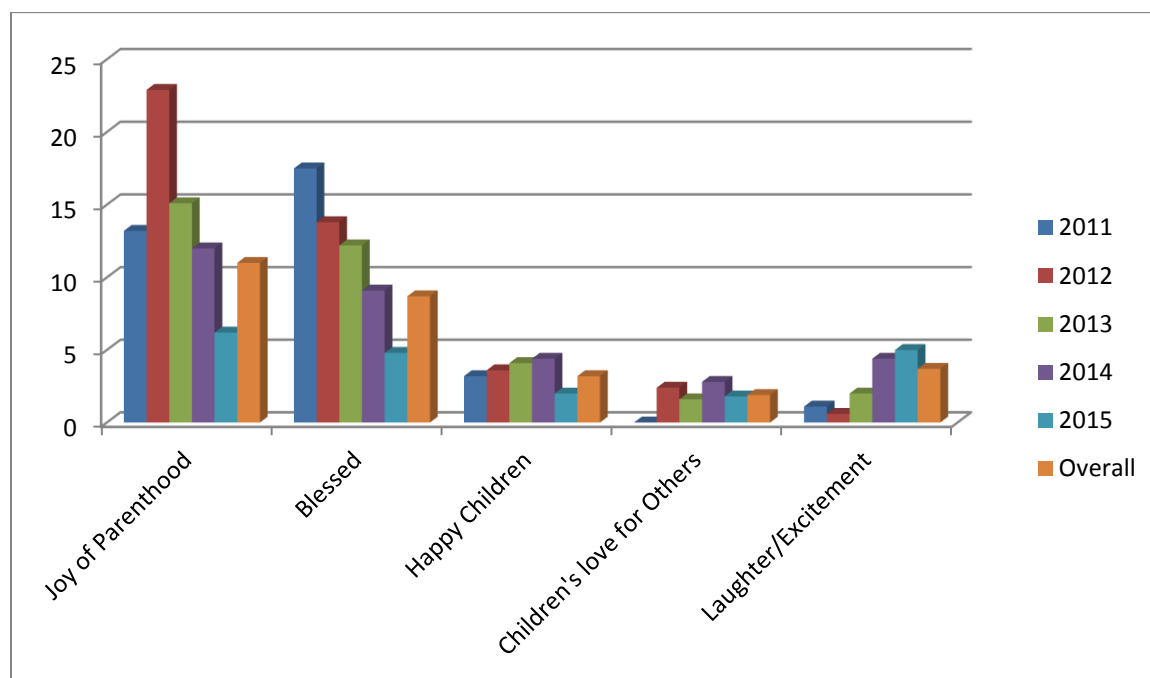


Figure 4. *Embracing the Positive* Sub-Categories Percentages by Year

Super Theme #2: It Takes a Village

It Takes a Village was the second Super Theme that emerged from the data, and included references to my participant's personal relationships with people, God and family pets. In these posts, she often made statements of appreciation or thankfulness for these relationships. These statements also reflected her reliance on these relationships and the impact they had on her family's life. A post from May, 2014, gave this Super Theme its title, "It truly does take a village...thanks to everyone who is a part of our village." These relationships fit into five sub-categories that defined this Super Theme.

Super Theme #2: It Takes a Village–Subcategories

- **Extended Family** was the first of the five sub-categories to emerge from posts that referred to her personal relationships. Facebook posts in this sub-category reflected relationships with family members outside of her spouse and children. My participant often described gatherings with parents, step-parents and siblings as a happy and joyful time. A specific example can be seen in a post from November, 2015, "My mom and I are machines! I absolutely love our tradition of Black Friday shopping! All Christmas shopping is complete, seven teacher gifts are organized, now it's time to decorate the whole house with my lil helpers! #tistheseason #themostwonderfultimeoftheyear." She often related how thankful she is for support from her extended family, both personally and with caring for her children. For example, a post from October, 2014, described how much she appreciated her mother and brother for coming to every marathon she has ever run, and how thankful she was that her sister and brother-in-law had made signs for her along the entire marathon

path. Posts in the sub-category Extended Family also included references to how she relied on them, such as one from December, 2013, which stated, “I cannot thank my mom enough for taking Jay for a few hours this morning...two challenging days back to back are starting to wear on me!” Additionally, posts such as two from the summer of 2015 demonstrated elements of this sub-category further, “Thanks Uncle Sven for pimping out Jay’s cast with a “Jay Train!” He can’t stop talking about it! #lessthan4weekstogo” and “We are so grateful for the extra time spent with my beautiful god-daughter. We love her so much, and just had to capture a few pictures this morning of the beauty in the relationship between her and our boys. Lillian, you are welcome to our house whenever you want...door is always open for you sweetie!”

- **Friends**. My participant’s Facebook postings are filled with accounts of scheduled activities with others and their family seems to have something planned to do for most days. Due to this active lifestyle, Friends is another sub-category that quickly emerged in the Super Theme, *It Takes a Village*. A Facebook post from July 2011 spoke of a lifelong friend, “Going on a walk around the lake with Abby and all our boys...bagels afterwards...let us know if you wanna join!” and another mentioned friends joining their adventures in September, 2014, “Our little apple pickers! Thank you Eleigh Parson for joining us at the apple orchard! It was so much fun!” My participant also expressed gratitude to friends for help, such as in this partial post from July, 2015, where several friends were tagged:

- “Wow and WOW! I Cannot believe all the out-pouring of love and support throughout this unexpected weekend adventure...we came home to a clean house, laundry all done, groceries bought for the week, and enough home-cooked meals to make it through the week. We cannot thank you all enough...it truly does take my breath away with everyone’s generosity and love. The words of encouragement helped me through the days. It truly does take a village...thank you for being a part of ours.”
- **Spouse.** Facebook posts that contained references to my participant’s Spouse make up the third sub-category of the *It Takes a Village* Super Theme. Many of these posts referred to celebrating Wedding Anniversaries or Father’s Day. Others indicated the depth of their love and caring for each other, such as a post from August, 2013, “A HUGE shout out to my amazing husband who is preparing to attack yet another year of athletics at State!! I know things get stressful at times, but your boys and I are your #1 fans and got your back! We love you!” Another post from May, 2012, demonstrated her appreciation, “ So I was getting ready for work today, when I stopped and listened to the conversation/interaction my husband and son were having, Sam was teaching him how to “throw/catch,” ‘be gentle with Maggie,’ ‘bounce the ball’ and reading him books. I found myself a keeper...and the love he shows with Jay just melts my heart. Great start to a short work week!” Her other references to her spouse often mentioned the little things he does that she cherishes such as bringing her coffee to work, bringing dinner home to the family so she doesn’t have to cook and running out for ice cream.

- **Spiritual/Religious**. Emerging from the data is another sub-category of the Super Theme *It Takes a Village*. Posts in this sub-category reflected my participant's requests for prayers, reliance on what she referred to as her guardian angels and her spiritual and religious beliefs. When her children had upcoming school or medical testing or procedures, my participant often asked for prayers, as demonstrated in a post from August, 2013, "Sam and I are asking for your prayers tonight as we enter into a big day tomorrow... Thomas has what we hope is his final follow up ultrasound on his kidney, and we start up our newest challenge with Jay's first day of special education services. Sam and I are fully prepared for whatever we are handed as we know we have the best support system in the world!" Another way this sub-category was identified was through posts about Christian religious gatherings such as baptisms, Easter and Christmas. An interesting discovery that emerged in the sub-category **Spiritual/Religious** was my participant's references to her deceased father watching over her family from heaven, as in a post from June, 2012, "Happy Father's Day to the best father Jay could every ask for, Sam Randall... your love toward our child is priceless... and Happy Father's day to my dad-whom I miss more than words can express... thanks papasita for looking down and keeping our family safe! I love you!"
- **Animals** is the final sub-category to be discovered in the Super Theme *It Takes a Village*. Family pets are mentioned in several posts both in frustration and as a soothing strategy for their child with autism. A humorous example included a reference to my participant's frustration with their puppy Maggie is found in a post

from September, 2014, “OMG OMG OMG. I feel like I’m in a nightmare right now!! I go to get the boys out of the bath tub and find that BOTH pooped in the tub...After I repeatedly said “oh gross” while cleaning it up, I now have Jay constantly saying that. Once I got that poop filled tub cleaned out, we go downstairs for quiet time to find that Maggie pooped all over downstairs! I am so over poop right now! On the brighter side, Papa Murphy’s has the best Gluten-free pizza AND my shows start up tonight. WOW is all I can say.” Interestingly, as my participant’s older son’s challenging behaviors increased leading up to his diagnosis of Autism; he started utilizing snuggling with Maggie as a soothing technique. A post with a picture of Jay and Maggie simply states, “Having some meltdowns this morning. Jay uses Maggie to soothe.”

Super Theme #2: It Takes a Village–Descriptive Analysis

It Takes a Village was recorded as the fifth most referred to Super Theme of the six Super Themes emerging from the data. The research indicated that sub-category items were identified in 13.3% of the 2722 documented references. Of the five sub-categories in this Super Theme, Extended Family and Spouse were the two most indicated. Extended Family was documented in 3.9% of overall references and Spouse 3.6% of overall references. The sub-category with the largest fluctuation was Spiritual, which began with 5.9% of all references in 2011 and was down to 1.1% in 2015. The sub-category Animals was the least documented of this Super Theme with only 1% of overall references. It is of interest to note that each of the sub-categories in this Super Theme, other than Animals, reached their peak documented reference in 2011. *It Takes a*

Village was the only Super Theme to have every one of its sub-categories referenced at least one time per year in each of the 5 years of postings documented.

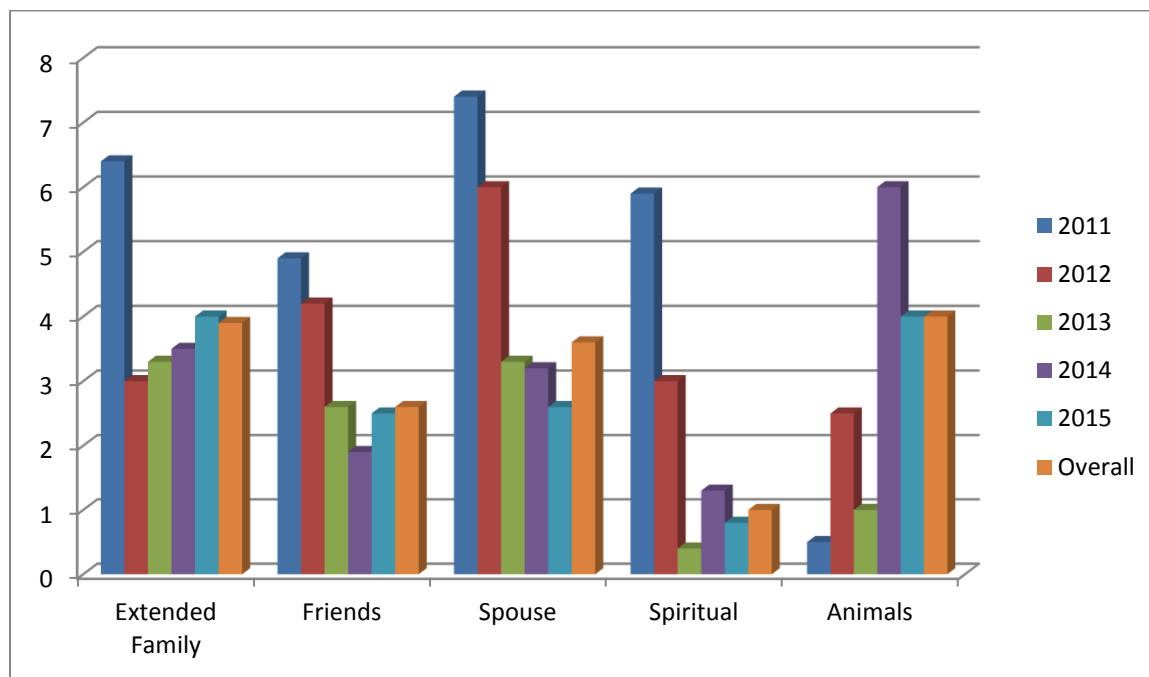


Figure 5. *It Takes a Village* Sub-Categories Percentages by Year

Super Theme #3: Our Team Rocks

A third Super Theme discovered in my research was *Our Team Rocks*. This Super Theme encompassed those components of my participant’s extended village outside of her personal relationships in the Super Theme *It Takes a Village*. Collapsed into this Super Theme were three sub-categories and it derived its title from my participant’s expressed thankfulness in a post from November, 2013, “What a day! I cannot be more thankful for the skilled teams that we have for both Jay and Thomas. Jay is thriving in the school setting and his speech is just blooming...Mr. Thomas met with his endocrinologist for the first time today and his is going to be monitored closely. I am so thankful for our Hospital and Clinics and our School District!”

Super Theme #3: Our Team Rocks–Subcategories

- **School District.** The first of the three sub-categories in the Super Theme *Our School Rocks* is School District. My participant came to rely on the special education team through their local school district when her first son was determined eligible for special education services at about 2½ years old. Posts in this sub-category are comprised of references to special education teams, services or the school district. A post from December, 2013, exemplified the impact the special education teachers have had on my participant’s family, “Tears were exchanged and hugs were given. What an amazing individual Jay’s special ed teacher is who clearly made a huge impact on our toddler’s young life. She walked out the door and Jay turns to me and says ‘Mama, I miss Staci.’ Teachers in general are amazing people, hands down.” The beginning of her younger son’s special education journey is summed up in a post from August, 2014, “This afternoon we learned that our little peanut qualifies for special education services through our school district. He qualifies in both social and communication/language areas. They are minor delays and far less intense than Jay, so hopefully with a little help from Early Childhood Family Education and home visits he will be caught up in no time. We are so thankful for amazing school district. #neverdoubtamothersinstincts.”
- **Medical Personnel and Medical Facilities** were recognized as the second sub-category in the *Our Team_Rocks* Super Theme. These references emerged as my participant’s younger son’s medical concerns became apparent. These sub-categorical posts referred to my participant’s experiences with her children’s doctors,

therapists, medical facilities and medical appointments. Two posts sum up the sub-category Medical Personnel/Facilities well; the first from September, 2014, expressed her gratitude with her world renowned clinic:

“Going to the doctor with two kids is always stressful but when you go to OUR clinic, they are the most helpful! The nurse took Jay out to play while Thomas got labs, and our endocrinologists’ nurse played trains with the boys while I got to talk with Thomas’ doctor! I am beyond excited to announce that Thomas’ endocrinologist is so thrilled with his growth that we aren’t going to have to do growth hormone treatment!!! He is 20 lbs. (0-3rd percentile) and 30 inches (6th percentile!) Grow Thomas Grow!”

The second post from June, 2015, combined her appreciation of her medical team with some typical sarcasm presented in many of her posts after her older son had 2 surgeries in a week for a broken arm,

“Well Hospital, it’s been real. You have the BEST staff; doctor’s with AMAZING bedside manner, and top notch surgeons, but the Randall family needs a break from you. You will always be our ‘go to’ but our kids need to be kids for a while before any future visits. Six surgeries, five times being admitted, numerous hospital visits and close to 100 doctor appointments between the two boys...you guys are simply the best: We are home with our Jay, recovering nicely. Until we meet again, the Randall Family.”

- **Sports and Recreation.** The final of the three sub-categories in the Super Theme *Our Team Rocks* is Sports and Recreation. The posts in this sub-category referred to my participant’s child’s participation in community sports and recreation teams. This sub-category emerged late in the data collection as it was 2015 before her older son joined a community education sports and recreation team, participating in t-ball and soccer. References to this sub-category embraced the fears and joys of her child’s experiences on these teams with worries about his Autism diagnosis. A post from September, 2015, described this element of this category best,

“What a season! This kiddo makes us so proud! We started the season out with me out on the field 50% of the game with him, and ending the season with me on the sidelines cheering him on 100% of the time. As chaotic as the game of soccer is (no order), he handled himself so well! He respected his coaches, encouraged his teammates, and most importantly, had fun. He ended the season in net and had six saves!!! #proudmom #soccermom #takethatautism PS How cute is he!”

Super Theme #3: Our Team Rocks—Descriptive Analysis

The Super Theme *Our Team Rocks* was the least referenced in the 5 years of Facebook posts analyzed. This Super Theme has only three sub-categories collapsed into it, School District, Medical Personnel/Facilities, and Sports and Recreation, which provided less data collection points. Furthermore, none of these sub-categories was documented in 2011, only one in 2012 (Medical), two in 2013 (Medical and School District) and it is not until 2015 that all three sub-categories are referenced. This was due in part to the nature of the sub-categories. One could assume that the school district would not appear until pre-school age at the earliest, but with special education, services are available at birth if a child is determined eligible. In this case this happens at 2½ for their older child and 17 months for their younger child. Additionally, many sports and recreation team activities are not available for children younger than 3; therefore, this sub-category appeared on the timeline at a fairly typical age of 4 years for their older child. References to the doctor, therapists and medical facilities reached a high in 2013 with the birth of their younger son and his resulting medical difficulties as well as the addition of occupational and speech therapy services for their older son. The sub-category School District is also referenced at its highest percentage in 2013 with their first born child's eligibility for special education services determination during July of that year. The Super Theme *Our Team Rocks* made up 5% of all documented references for all six Super Themes.

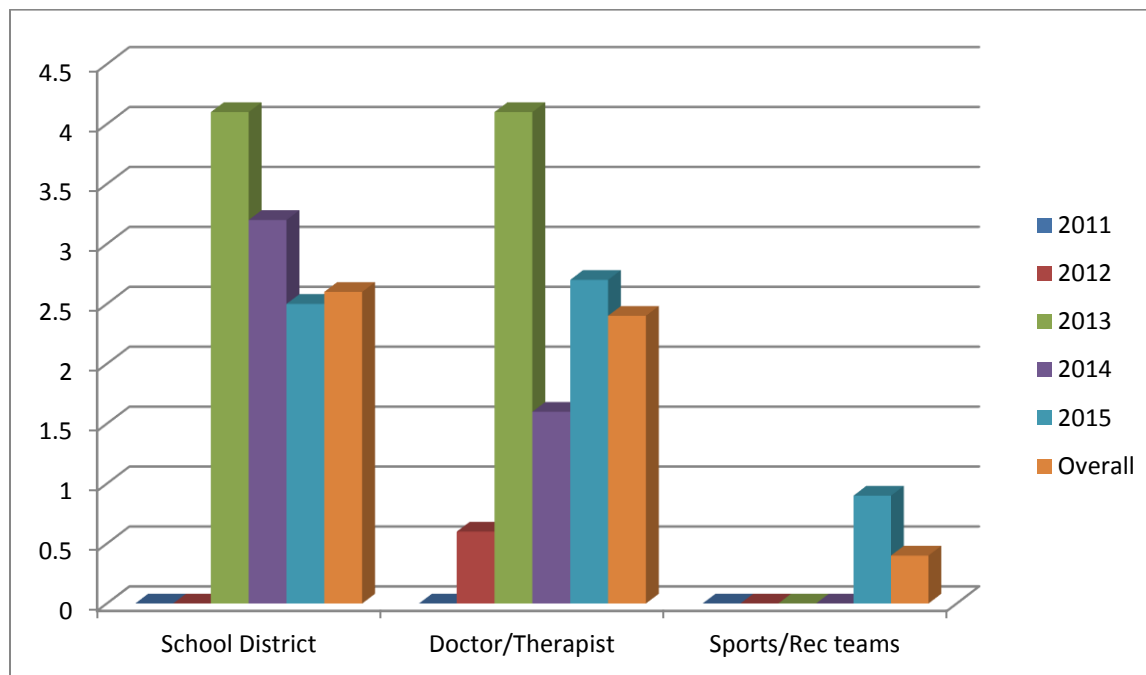


Figure 6. *Our Team Rocks* Sub-Categories Percentages by Year

Super Theme #4: Keeping it Real

A fourth Super Theme emerged from seven similar sub categories of posts that referenced negative emotions or reporting life happenings that are difficult. The Super Theme *Keeping it Real* included the largest number of sub-categories and gets its name from several of my participant's Facebook posts with the hashtag #keepingitreal, which she used with posts that described challenging days.

Super Theme #4: Keeping it Real–Subcategories

- **Grief/Frustration** was the first sub-category to emerge from the research in the Super Theme *Keeping it Real*. My participant's posts to Facebook that comprised this sub-category carried references to grief, sadness or frustration. Each year she expressed her grief regarding her father's sudden death at a young age and the miscarriage of their "angel baby" on the anniversary of those events. Often the grief

or sadness communicated loss of dreams for her children, for example in a post from July, 2013, “Today we were informed that Jay qualifies for special ed services through our school district...although this is something no parent wants to hear, we are hopeful that these services will help him ‘catch up’ and that Sam and I will learn a thing or two. God chose us to be his parents and we will give him all our support to help him thrive in life.” Another post expressing grief and sadness appeared in September, 2013, “I never realized how hard it is to watch your child struggle until today...very rough first day at ECFE, but I am very thankful for the services that we are currently receiving!” Finally, my participant’s posts displaying her frustration are demonstrated in excerpts from this post from October, 2013:

“Today has probably been one of the most challenging days of being a parent...’Jay we don’t hit Maggie. Jay we don’t eat dog food. Jay we don’t stiff-arm Thomas. Jay we don’t throw train tracks in the toilet...Jay we don’t throw daddy’s boxers in the shower while he’s showering. Jay we don’t bite mommy (yes he drew blood)...Yes I’m exhausted. Somehow, our house is still in one piece, everyone is alive and we are leaving the house for a few hours.”

- **Scared/Nervous.** Posts that communicated feelings of fear or nervousness are compiled in the sub-category Scared/Nervous in the fourth Super Theme. These sentiments differ from grief or frustration in that they referred to something my participant is anticipating and is worrying about rather than something that is happening or has already happened. For example, a post from December, 2013 stated, “Tonight our family asks for your prayers as we enter into our day tomorrow: Thomas, Sam and I have our big genetics intake at the hospital to rule out just about any possible syndrome, disease, etc. If everything comes back normal, we can finally accept that fact that Thomas is just small, and that he will catch up over time.”

- Another example of a Scared/Nervous reference in the *Keeping it Real* Super Theme came from June, 2015, “I was so nervous to sign Jay up for team sports this summer because of his anxiety and how much he was too scared to try new things...but my goodness, this was the best decision we made together! Jay is playing on a team and loving every minute he is with his teammates and told me before the game ‘it’s not about winning mama, it’s about having fun” #proud mama #yankeestball.”
- **Stress** was the third sub-category to surface from the data analysis in the Super Theme, *Keeping it Real*. As a parent of two children with disabilities, my participant often referred to feeling overwhelmed, challenged or stressed. These posts were placed in the sub-category Stress in the fourth Super Theme to be identified. A demonstration of the characteristics of this sub-category were seen in a post from September, 2013, “This waiting game is sure starting to take a toll on me...still waiting on one set of Thomas’ labs, and his genetic results...praying we get these results before Sam’s surgery next Tuesday...this mom/wife can only take so much at one time...I hope someone is ready to have a beer with me once it’s all done!” A post from May, 2015, helped define the emotions of this category, “Hot Damn. I am soooooo over this week: just took Thomas in to urgent care...UTI: check. Double Ear Infection: check. Sinus Infection: check. Three out of the four Randall’s are a hot mess (Sam has a double ear infection too!) Oh, and did I mention I’m flying solo the rest of the week? #ideserveabeer #gobigorgohome.” Although my participant typically wrote paragraphs for her posts, sometimes she expressed herself in one

simple sentence such as one from June, 2014, “I am 100% convinced my Thomas doesn’t want me to sleep ever again.”

- **Diagnoses.** Another sub-category to become apparent from the research in this Super Theme is Diagnoses. This sub-category included my participant’s references to her children’s medical diagnoses and specific medical testing, for instance, childhood illnesses such as croup and strep, occupational therapy evaluations and more significant diagnoses such as Autism Spectrum Disorder. In a post from November, 2014, my participant related a challenging experience with getting a proper diagnosis:

“ER trip round 1: ‘It’s just a virus.’ ER trip round 2: ‘strep, UTI, and dehydration, let’s get him some antibiotics and fluids and let’s get you out of here!’ A HUGE thank-you to our hospital for doing your job! Maybe the first ER doc should take some notes and get a full medical history (like that my child had kidney surgery at 4 weeks old and is more susceptible to kidney and urinary tract infections, or that my husband had strep last week!). So glad I listened to my gut. #dontmesswithanexhaustedmom #ourhospitalrocks #momsknowbest.”

Another one of her posts referred to her children’s recent multiple medical concerns:

“I am soooo not one to host a pity party for our family, but with the summer we had consisting of two elbow surgeries, a tonsil/ear tube surgery, weekly doctor appointments, and a diagnosis of Autism I’m so beyond thrilled summer is over, and I’m welcoming fall with arms wide open! Bring on pumpkin everything and beautiful crisp weather!”

Finally, in researching her son’s recent Autism Diagnosis, she shared an article on her Facebook page about children with Autism and an intense interest in trains, “Sooooo THIS explains a lot about Jay’s train obsession. I think it’s amazing.”

- **Exhaustion.** A sub-category to emerge that is familiar to most parents of very young children, but that can continue much longer for parents of a child with disabilities is Exhaustion. This sub-category of *Keeping it Real* consisted of my participant’s references to feeling exhausted or not getting enough sleep. One post from October,

2015, conveyed this message clearly, “I think it’s ok that since everyone else in my house is sound asleep by 7:30 p.m. it’s only fair that I join the party. Sometimes Autism is exhausting, for all parties involved.” Another post that referred to the exhaustion that a parent with a child with disabilities feels comes from September, 2013, “Summary of therapy: throwing of trains, train tracks and puzzle pieces... thankfully I’m an athlete and caught them all mid-air before they hit our teacher’s head or face. Positive: Jay said a sentence with six words in it, speech was impressed. As for Thomas, still no results from his lab work and genetics department will look over their tests within the next 72 hours. Early bedtime for the boys tonight, and a much needed beer for mom. I’m BEAT.” Lastly, the exhaustion most parents feel with a newborn is evident in this May, 2013, post, “Yes, I am so exhausted from my first week back at work that this morning I pushed snooze three times, put body wash in my hair after I already washed my hair, and put shaving cream in my hair instead of my hair product. I am beyond thrilled it is Friday!!!”

- **Caring for Sick Children.** The Super Theme *Keeping it Real* also includes the sub-category of Caring for Sick Children. My participant’s posts included in this sub-category contained mentions of taking care of her ill or injured children. Her Facebook post from October, 2013, demonstrated this sub-category, “Thank you for all the phone calls, texts, messages, comments for our precious Thomas. I have never seen such a sick kiddo before...cough is worse, no voice, high fever, and eating about a third of what he normally eats. I am so sad right now...I know our fighter will

rally...praying for more than 2 hours of sleep tonight.” Whereas caring for her injured child is expressed in this June, 2015, post after her older son broke his elbow:

“A conversation at Jay’s follow up:

Doctor: ‘so in the next 4 weeks, make sure he isn’t doing anything that could cause any further injury to his arm.’

Me: ‘hmmm. He is a kid. And he is 4 years old.’

Jay: ‘yeah I’m a monkey that likes to ride bike and jump off playgrounds and swing sets!’

Me: ‘hmmm...what he said.’ #goodlucktous #activetoddler #nofilter.”

- **Flying Solo**. The final of seven sub-categories in the Super Theme *Keeping it Real* was Flying Solo. This sub-category referenced when my participant posted about caring for her children alone while her husband is out of town for work, which is a regularly occurring expectation of his employment. One of my participant’s posts from August, 2015, demonstrated the elements of Flying Solo, “I finally came out of denial and physically wrote down all of Sam’s fall sports he will be working (seeing that they start this week!). And there was a reason why I waited this long...no open weekend til Christmas! Anyone wanna hang out this fall with two adorable boys and me? #singlemomtilmay.” Another example of this sub-category is noted from June, 2013, “Knowing I would be husband-less tonight, I played super-mom today...had two successful play dates, got the whole house cleaned, made an awesome homemade dinner, both boys bathed and went on an amazing run with them...all by 5 pm.”

Super Theme #4: Keeping it Real–Descriptive Analysis

The Super Theme *Keeping it Real* consisted of seven documented sub-categories.

Keeping it Real sub-categories appeared in 19.5% of the 2722 documented references, and were the second most referenced theme of all six Super Themes over the 5 years of analyzed Facebook

posts. In looking at individual years, this Super Theme reached its highest categorical placement as the second most referenced Super Theme in 2013 and 2015 with 23.8% and 21.2% of total references, respectively. Its lowest placement was in 2012 when *Keeping it Real* was the fifth most referenced Super Theme at 9% of all references. Of the seven sub-categories in this Super Theme, Grief was the most documented sub-category with 5.2% of all references. This sub-category reached a high in 2013 with 7.1% of all references and the third highest of all 30 sub-categories for that year. Stress, at 4.3% and Diagnoses, at 4.2% of all references were two other notable sub-categories. References to Stress reached 5.5% in 2013 and Diagnoses reached 5.3% in 2015 to increase their overall percentages to the second and third highest overall sub-categories in this Super Theme, even though neither was noted until 2012. The least referenced sub-category overall is also indicated in the Super Theme *Keeping it Real*. Flying Solo did not appear in the references until 2013 and was indicated in only .2% of all references in the 5 years of Facebook posts analyzed. Looking at overall sub-categories referenced, the Super Theme *Keeping it Real* had three of the top 10 referenced sub-categories, Grief, Stress and Diagnoses at fifth, sixth, and seventh most referenced sub-categories respectively in the 5 years of Facebook posts analyzed.

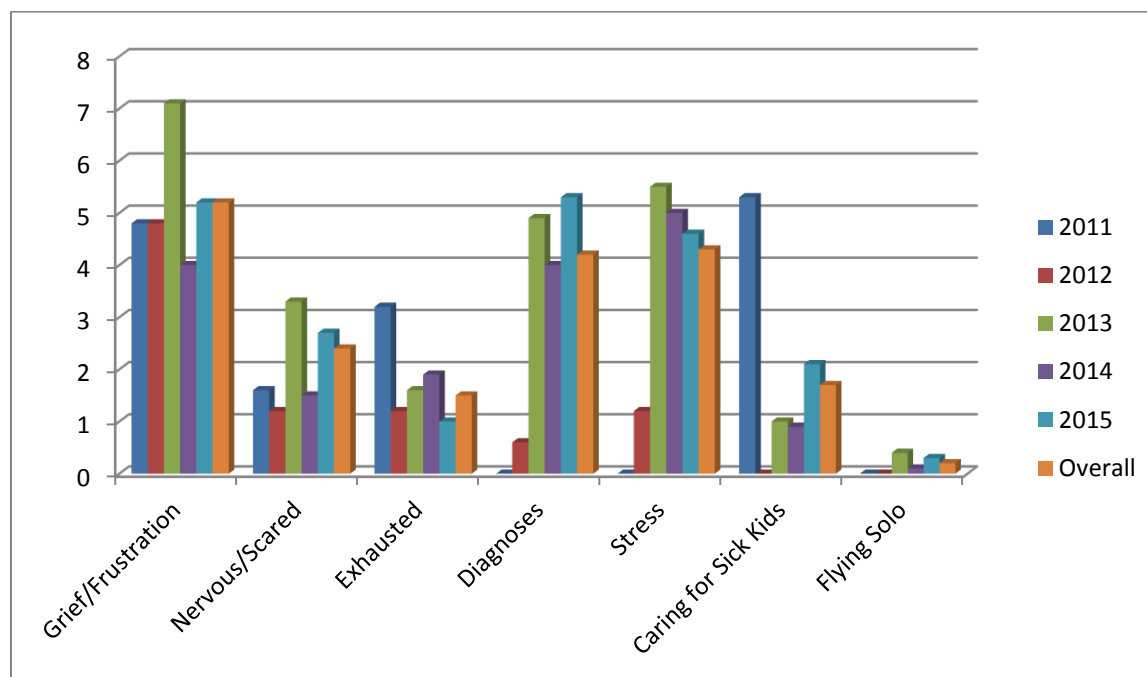


Figure 7. Keeping it Real Sub-Categories Percentages by Year

Super Theme #5: We've Got This

The fifth Super Theme that emerged from the data was one titled *We've Got This*. This Super Theme is derived of five subcategories that encompass my participant's documented attitude that nothing will stop them from being the best parents they can be for their boys, regardless of the obstacles thrown at them. The Super Theme *We've Got This* is named for elements of a post from the day my participant received the news that their older son was diagnosed with Autism, in August, 2015:

“...As Scary as this journey will be for Sam Randall and I, we have an out-pouring amount of support from both family and friends, and I know we will take this next chapter of our lives head on together. Although it's a diagnosis, this does NOT define Jay and the sweet child he is. We love him to the moon and back, and we will gladly accept our role helping him understand and make progress along the way. WE finally have an 'explanation' for some of his behavior and I cannot wait to get educated on how to better parent our amazing child. #teamrandall.”

Super Theme #5: We've Got This–Subcategories

- Super Jennifer is the first sub-category discovered in the Super Theme *We've Got This*. My participant occasionally refers to herself as Super Jennifer in Facebook posts that contain statements of self-pride or the relaying of events of the day where she feels she achieved above and beyond the typical as a mom or in regards to life in general. Some of these references are a simple statement of self-confidence such as a post from October, 2013, “There are some days I feel like a rock star super-mom, today is one of those days. Let’s just say I am dominating life...and ending my day with a beer.” Other posts relay lists of everything she was able to accomplish in a day, as in a post from April, 2012, “Totally dominated my day off; got groceries, ran 3 miles, delivered dinner to a good friend who just had a baby, mowed the lawn, weeded the gardens, raked up the dead stuff, walked 4 miles with our neighbor and our boys, made dinner, and bathed our child! I’m on a roll!! Anyone need anything?” Lastly, some of the references to Super Jennifer in my participant’s posts refer to her pride in her ability to handle the stress of having two children with disabilities, as described in this post, from November, 2015:

“Today was the most refreshing day I have experienced in a REALLY long time...don’t get me wrong, there was plenty of fighting, tantrums, and ‘mom, Maggie ran away again’ moments, but the difference was NO APPOINTMENTS!!! No reminders that our child has autism, no public outings where I’m holding my breath just to make it through; we just lived in the moment. Not only was the weather amazing, but it was a bonus mama-day! Some days you just feel like you have it all.”

- From the data, it is apparent that my participant is a very active person, with a full time job, caring for two boys with special needs and maintaining a busy family social calendar. One sub-category that emerged early in the Super Theme *We've Got This*

was that of Self-Care. This sub-category includes references to the indulgences that my participant either prioritizes into her schedule or treats herself to as a small luxury to help sustain the hectic life she leads. She often refers to trips to the coffee shop, enjoying a beer at the end of a long day, or delicious snacks or meals their family loves. These are small pleasures that she looks forward to. On a larger scale in the sub-category of Self-Care is my participant's scheduled running. As a marathon runner, she has to set aside time in her schedule to maintain her marathon training, which she mentions often in her Facebook posts. One such post is from September, 2014, "20 miles COMPLETE, 3 hours 44 minutes, and I officially feel 100% ready for the marathon in 3 weeks! I cannot thank Sam Randall and our boys enough for all the love and support through this training! Even when I'm stinky and exhausted, they still love me! BRING ON 26.2!" The importance of running is also evident when she is unable to fit it into her life, as demonstrated in this post from July, 2011, "Officially had to make the decision to NOT run the City Full Marathon in October. It was a tough decision, but a given one. My responsibility as a mother is to always put my son's needs in front of mine, and I wouldn't want it any other way. There are many marathons out there and there is only one time you can give your child the best care—that time is now." Finally, two more activities are often mentioned in my participant's Facebook posts as "me time," and are elements of the sub-category Self-Care. One is her passion for photography and her side business of family portrait photography. The other is when her friend comes over to cut and color her hair, as in this post from December, 2014, "Life doesn't get much better than when one can get

her hair done, in her sweats, at HOME, drinking a beer, and her hair stylist is picking all your gray hairs out...Catie, you are the BEST!!!”

- A third sub-category in the Super Theme *We've Got This* is Relief/Hope. My participant and her husband have endured multiple medical and special education evaluations, medical procedures and on-going concerns about growth and development for their children over the 5 years of this retrospective study. Through it all, many of her Facebook posts have reflected several accounts of relief and hope.

One lengthier post from December, 2014, encapsulates this sub-category:

“Updates on the boys: Jay had his IEP meeting yesterday, and he is making some AWESOME progress. Speech is working really hard with him, and its showing. The teachers said that he is such a goofball (hmm, I wonder where he gets that from!) and such a joy to have in the classroom. He is also started up with private OT today, and is already showing signs of growth! His large motor skills were displayed tonight when we were getting his jammies on, and he said ‘I can do it mama!’ and took his shirt and pants off—THIS IS A BREAKTHROUGH!!! His fine motor skills were shown off proudly when he showed us he can make the letter ‘t’ and wrote all the letters in his name!!! I love seeing how proud he was when he was showing us! In Thomas news, he had his follow-up with endocrine, and he is a whole whopping 21 lbs. (almost 22 months old!) and creeping closer to being ON the charts. This is the first time we haven’t had to increase his thyroid medication. AND in speech, he is now starting to run the house; by saying ‘NO’ and ‘MINE’ it’s quite cute! I love the new words! Again, this may not seem like a big deal, but they are break-through moments at our house, and these parents couldn’t be more proud #proudparents #premiepower #mustbedoingsomethingright.”

- **Advocacy**. A sub-category of the Super Theme *We've Got This* emerged mid-way through the 5 years of posts analyzed. My participant’s posts regarding Advocacy contained references to her advocating for her children as well as sharing educational information to her Facebook audience and providing help to other children with special needs and their families. Her advocacy through education began to emerge

through the research she was doing for her own children, and then sharing on Facebook, as demonstrated in a post from July, 2014:

“Today we learned info about why Thomas isn’t talking age appropriate: He was evaluated by audiology and found that he cannot hear high decibels. With this learned, they referred him to radiology where they will sedate him and hook up electrodes to his brain to monitor the sound waves and how they translate to his brainstem. It is a 4 hour test called Auditory Brainstem Response or ABR. I feel relieved that we have answers. We also had the initial eval for Help Me Grow. I feel overwhelmed. I know this is a common test but it’s still scary. WE have amazing support so regardless the outcome, it will be good. #keepingitreal #motherknowsbest #thesekidsgivemegrayhair.”

My participant posted on a number of occasions about going to the school district, doctors or therapists with questions and concerns for her kids, that were later proved to be a founded concern. Additionally, she mentioned advocating for families that have lost a child to miscarriage as well as those that have had a premature baby, having gone through these experiences herself. When my participant’s older son was diagnosed with Autism, her posts in this sub-category became more frequent. As she researched and learned, she also shared on Facebook. A post from the week of his diagnosis, in August, 2015, demonstrated this process:

“I have read the intro chapter of one of our books and this is what I have taken from it: Autism will never define our child, it’s just a piece of him. His senses are out of sync; meaning hearing loud noises and being placed into environments where there is too much chaos, Jay’s brain cannot filter all the input and he becomes overloaded. I might slap you if you ever ask me ‘does your child suffer from Autism?’ Some days the only predictable is the unpredictability. And finally, our child’s Autism does NOT mean he cannot live a full and joyous and meaningful life; you have complete control to living that type of life and I know Jay will live a ‘larger than life’ life. There. Just a glimpse into the journey ahead.”

In a post from 2 months later, my participant started to realize the power of her own advocacy, “It’s so crazy to look back at ‘see your memories’ on Facebook and see all my posts that had ‘Autism’ written all over them, but we didn’t have a clue. I feel so

much more educated and am a much stronger advocate for our son ever since we received his diagnosis. It's all about Early Intervention and I am so happy I followed my gut! #teamrandall.”

- **Team Randall**. The final sub-category that emerged in the Super Theme *We've Got This* is Team Randall. My participant started to use this to describe their family's will to pull together to face obstacles head on and adds to her posts using hashtag #teamrandall. This term emerged fully when my participant's older son is diagnosed with Autism. My participant's post from October, 2015, contained an example of the sub-category Team Randall, “It's amazing how a simple hug can make the biggest impact. Autism was kicking our butt tonight, until I asked Jay if he wanted a hug. He melted right into my arms and all in the world was right again. #teamrandall.”

Super Theme #5: *We've Got This*—Descriptive Analysis

The fourth most referenced Super Theme in my participant's 5 years of Facebook Posts was *We've Got This*. This Super Theme's sub-categories were noted in 15% of all documented references. Self-Care was the most referenced sub-category with 5.7% of overall references. Self-Care was also the fourth most referenced sub-category of the thirty sub-category identified overall. Of the 5 sub-categories in the Super Theme *We've Got this*, Advocacy did not appear until 2013, and steadily increased in appearance from .2% in 2013 to 5.2% in 2015. Team Randall was noted one time in 2014 and again in 1% of total references from 2015. The sub-category of Relief was referenced one time in 2014 and also steadily increased in references to 5.2% in 2015. Relief was identified in 3.4% of all references. Super Jenny was referenced in each of the 5 years of posts for a total of 3% of all references. As my participant's children's

diagnoses and special education services increased, so did her Advocacy references, but her Self-Care postings decreased as Grief and Diagnoses increased.

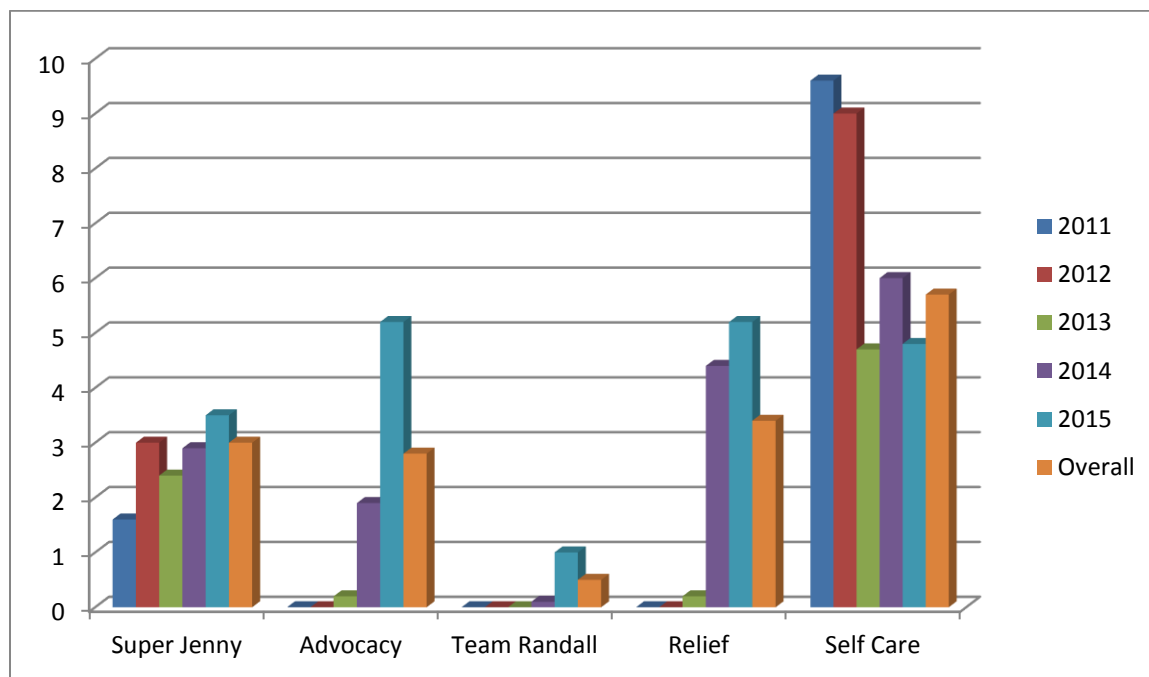


Figure 8. *We've Got This* Sub-Categories Percentages by Year

Super Theme #6: Live Life to the Fullest

The sixth and final Super Theme that emerged from my research study is *Live Life to the Fullest*. This Super Theme consisted of five sub-categories that related to posts about enjoying each day and getting the most out of it. A post that expressed the spirit of this Super Theme came from December 2014, “To this 3-year-old, this weekend wasn’t just a train ride, it was THE train ride of a life time. You could tell that he was inside the story, and taking in every moment. As difficult as most of our days are, we will forever be grateful for Jay’s smiles and the appreciation he shows. It’s the little things in life that make the biggest impact.”

Super Theme #6: Live Life to the Fullest–Subcategories

- **Routines** was the first of the five sub-categories to be revealed in the Super Theme *Living Life to the Fullest*. Throughout the 5 years of my retrospective study, my participant referred to specific daily activities that are an important part of her family's life, such as bedtime, calm down time, daycare, bath time and dinner time. These daily activities are the components of the sub-category Routines in the Super Theme *Living Life to the Fullest*. Sometimes noted in this sub-category are simple pleasures, such as a post from June, 2015, "You know its summer time when ice cream becomes part of your daily routine, and the hair turns blond.

#summerhasarrived." One post from May, 2014, references the importance of these routines to my participant:

"Today Jay decided he wasn't going to eat dinner with us. He knows it's a rule that if he isn't going to eat, he at least needs to sit while we finish. He continued to throw food all over and I was head-butted, kicked, and was slapped in the face. While all of his chaos was going on, I ignored him and praised the heck out of Thomas for eating dinner. Jay hated this, and before I knew it, he was picking up every piece of food off the floor, and ran over to me, climbed into my lap and said, 'I want to make mama happy' and gave me the biggest hug. Moments like these remind me how much parenting challenges me, and how much I love my boys for making things right without me having to ask."

She often mentioned routines as a way of describing events of the day, but has the ability to stay flexible, as in this post from November, 2013, "You know you are exhausted when both boys are bathed, and I allow movie night to start early while eating dinner and Halloween candy at the same time! LOVE my Friday nights at home in my sweats, with beer in hand." My participant also mentions Routines as a time when she reflects on and appreciates her life, as in a post from August, 2013,

"Instead of saying good night to all of Jay's things as we were rocking together, I told

- him Grandpa Carlson stories. He giggled, hugged me, and snuggled in close. I think he enjoyed story time.”
- **Weather**. A second sub-category to emerge from the data in the Super Theme, *Live Life to the Fullest* was Weather. This sub-category included posts that referenced enjoying outside activities, beautiful days and changing seasons. Several times my participant mentions sunny days, beautiful fall days, and rainy days as a wonderful time to get outside and take advantage of the day. For example, in October, 2014, she posts, “It’s the little things: 70 degree day in October, fresh air and smiles on the boy’s faces. #ilovefall #simplethingsbringthemostjoy #breakfastfordinner #ilovelife #vitaminD.” Another post from November, 2014, demonstrated how much my participant loves to be with her family outside, “The best days are those when you realize you haven’t showered and you are wearing the same clothes you woke up in, and that 6 hours were spent outside in the fresh air. Now it’s time for cuddles, popcorn, and a movie with my favorite boys.” Finally, a post from the sub-category Weather from December, 2015, that displayed my participant’s determination to enjoy all seasons with her family, “There is nothing more perfect than to come home from a crazy day, go sledding, have a snowball fight, play chase and purposely fall down in the snow, and then warm up with hot chocolate!! It’s a beautiful winter wonderland.”
 - **Family Adventures** was the third theme to be discovered in the Super Theme *Live Life to the Fullest*. My participant speaks often of all of the spontaneous and well planned adventures in which their family participates. These self-described Family

Adventures range from simple everyday happening like picnics in the backyard and trips to the local pool to road trips to Chicago and trips to see Thomas the Train.

Posts such as one from December, 2015, were common, “The Randall Family is always looking for adventures during the holiday season (usually has to do with fun train things!).” She describes their adventures with enthusiasm, as seen in December, 2014:

“The Randall Family traveled four hours to hop aboard the Polar Express and take it to the most magical place ever: The North Pole. The boys rode the train in their Christmas jammies, were served hot chocolate and a train cookie, read the book ‘Polar Express’ with the hot chocolate dancers, and went to the viewing train car to see Santa Clause and all his elves. This was by far the most amazing trip and we are so happy we got to go on this adventure together! All Aboard!”

Their Family Adventures did not always require fancy get-aways, as my participant described spending time together as the most cherished, as in this post from July 2014, “The best weekends in the world are the ones Sam Randall is unexpectedly HOME!!! Looking forward to lots of fun family time including the zoo’s pool toddler time, walk to the DQ, a trip to the train restaurant for the revealing of Thomas the Train’s friend and the ‘Jay Train,’ a birthday party, and seeing dear friends and their beautiful family.”

- **Mama Days** are a sub-category of Super Theme *Live Life to the Fullest* that included my participant’s Facebook posts describing the appointments, adventures and activities that she and her boys attended when she is off of work on Tuesdays each week, or when her husband is out of town for work. The term Mama Days is a part of their family terminology, as demonstrated in a post from May, 2015, “it melts my heart when I pick up the boys from daycare and Jay says with excitement (and the

cutest face), ‘we get two mama-days now, right mama? And that means WE GET TO GO ON ADVENTURES!!!!’ I love that he sees life as one big adventure!

#itstheweekend #mommyadventuresrock #80sinourweekendforecast.” Some Mama Days are filled with appointments since it is her only day off during the week, a post from August, 2015, demonstrated how often this happens, “A ‘mommy-day’ without doctor appointments...say whaaaaaat!?! Spent this beautiful day at the pool!”

Finally, my participant’s enjoyment of these days was evident in a post from October, 2015,

“The boys and I decided to take the light rail downtown for a fun little adventure. After 5 minutes of riding, Jay pointed out that there were two police officers that climbed aboard. Little did I know they were in the middle of a drug bust and had a lady in handcuffs. And leave it to my two year old to start screaming our ‘weeee-oooo weeee-oooo...no no bad guys. Go away bad guys!’ One of the police officers started to smile and almost started laughing, while I’m dying inside. #nofilter #ilovemyboys.”

- **Holidays.** The final sub-category in the Super Theme *Live Life to the Fullest* is Holidays. This sub-category contained references to holiday seasons, gatherings and preparations. My participant’s excitement for the holidays is evident in a post from December, 2015, “OMG, the movie Elf makes me so happy!!!! I can totally relate to Buddy-I LOVE all things sugar and Christmas!!” More excitement was expressed in a post from November, 2015, “The most magical time of the year has officially arrived in the Randall household! These Boys take their job very seriously!” Often, her posts mention the fun their family had on a holiday as noted in a post from July, 2014, “Best. 4th. EVER. ½ marathon, parade, fun in the sun, and a great BBQ. Both

kids were passed out by 6:30 pm and mom and dad got to enjoy a movie and ice cream in peace and quiet.”

Super Theme #6: Live Life to the Fullest—Descriptive Analysis

The sixth and final Super Theme that emerged from the data was *Live Life to the Fullest*. This Super Theme was comprised of five sub-categories. Of these five sub-categories, Routines emerged as the most prevalent reference in this Super Theme, at 5.8% of all references and fourth most referenced sub-category of all thirty identified sub-categories within my study. Family Adventures was the next most referenced sub-category at 4.2%. Family Adventures was noted as the most referenced sub-category in the Super Theme in 2011, dropping down to the fourth referenced in 2013, and emerged as a tie with Weather for second referenced as the most noted sub-categories in *Live Life to the Fullest* in 2015. Weather had previously been referenced in 0-2.9% before 2015. The sub-category of Holidays stayed relatively stable throughout the 5 years of posts, ranging from a low of 2.9% of references in 2014 to a high of 3.6% references in 2012. *Live Life to the Fullest* was identified as the third most referenced Super Theme of all six Super Themes, comprising 18% of all sub-category references in the five years of Facebook posts. The year 2011 had the lowest recorded references for this Super Theme, as the fourth of the six Super Themes. *Live Life to the Fullest* emerged as the number one Super Theme in 2015, the only Super Theme to surpass *Embracing the Positive* for any given year. Also, the year 2015 was documented as the only year that a sub-category other than Joy of Parenthood was the most referenced during that year, as Routines surpassed all other sub-categories to emerge as the most noted. Routines was identified as the third overall referenced sub-category at 5.8% of the overall 2722 references documented, following only Joy of Parenthood and Blessed.

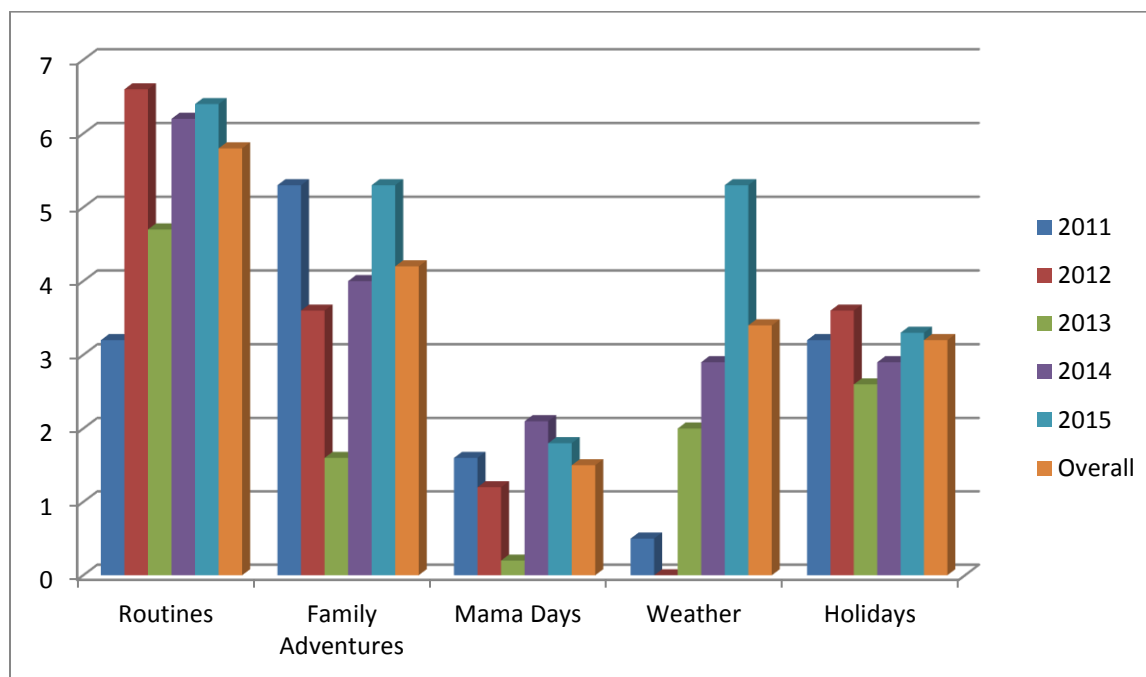


Figure 9. *Live Life to the Fullest* Sub-Categories Percentages by Year

Conclusion

In this retrospective case study of my participant's 5 years of Facebook postings, six Super Themes emerged as a basis for emotional support for a parent of a child with disabilities. *Embracing the Positive, It takes a Village, Our Team Rocks, Keeping it Real, We've Got This* and *Live Life to the Fullest* are the resulting six Super Themes. These findings became apparent through my participant's description of the events of her life, and her reaction to them, as they were happening. The results indicated clear fluctuations in themes as the events in her life change. In Chapter 5, I discuss the implications these results have for future research and for practitioners in the field and some limitations of this study.

Chapter 5: Discussion

Overview

The primary purpose of this study was to determine how social media, in particular Facebook postings, support parents in raising a child with a disability. The results demonstrated a wide-ranging variety of themes of emotional support. For this participant, posting on Facebook was utilized like a diary of events and her feelings about those events in real time. As events in her life unfolded, themes shifted and new themes emerged. In this chapter, I discuss what the emerging Super Themes and their sub-categories were and what they mean for my participant and for myself as a practitioner, limitations of this study, how my findings align with the current literature base associated with parental support, and the next steps in research for this topic.

Thematic Findings Interpretation

The six Super Themes to emerge from the data analysis procedures represented different emotional categories. They each held meaning for my participant, have implications for myself as a practitioner in the field of Early Childhood Special Education (ECSE), and also for other families with a child with disabilities.

The first Super Theme, *Embracing the Positive* and its five sub-categories, Joys of Parenthood, Blessed, Happy Kids, Boys Love for Others, and Laughter and Excitement, represented my participant's natural positive attitude. Although she may have been posting to her Facebook page about a challenging day, most often she ended the narrative with a positive phrase. The fact that this was the most documented Super Theme in all of her Facebook postings demonstrated that staying positive is very important to my participant. As a practitioner in the field of ECSE, it is beneficial for me to see the different sub-categories that emerged in this

Super Theme. I can now also recognize how a family may place priority on finding the positive aspects in the face of adversity with their child with disabilities. By remembering the emerging sub-categories in this Super Theme, I can help families to recognize and to focus on positive happenings in their lives to balance disappointments and challenges. Families with a child with a disability can read posts like my participant's posts on Facebook to learn to reframe their thoughts, embrace positive thinking themselves, and cease focusing on what may be going wrong for them. This positive approach seems to come very naturally for my participant in this study. Some families that we work with could benefit from ECSE teacher guidance in learning positive thinking strategies.

The second emerging category, *It Takes a Village* includes five sub-categories as well. These five sub-categories are comprised of the personal relationships that my participant called upon when she needs help, struggles or just wants to have fun. She referred often to how grateful she is for her "village" and how blessed she is for everyone in her life. These sub-categories are made up of Extended Family, Friends, Spouse, Spiritual, and Animals. It is interesting to note that when my participant referred to those that make up her "village," she thanks them for always being emotionally present for her and for all that they do for her, but *It Takes a Village* ranked number five out of six categories in over all references. It appeared that she is very self-reliant, and that her positivity and "take charge personality" comes from a place of strong self-reliance. This finding is important because it points to a parent's possible sources of interpersonal support, which again is crucial for ECSE practitioners. When working with parents of a child with a disability, we can help them recognize their sources of interpersonal support and how to draw on those resources in times of need. Although self-reliance is a

valuable skill to cultivate, it is equally beneficial for a parent to recognize when they may need additional support, how to seek out sources of interpersonal support and then to learn to rely on those sources in a functional manner.

Another Super Theme that arose from my study's findings was *Our Team Rocks*. For my participant, this is an extension of her self-described "village," only expanded to include those in professional positions. Included in this Super Theme are their School District, Medical Professionals and Facilities, and Sports and Recreation Teams. As my participant's children became eligible to receive special education services, she began depending on her children's teachers and their local school district. She soon learned that their home visiting teacher was a great source of information, comfort and support. Additionally, with multiple medical visits and therapy appointments, she was able to also depend on their family's world renowned medical facility for information and necessary referrals. It is not surprising to discover that 2013 contained the highest frequency of posts for this Super Theme. This was the year when her older son became eligible for special education services and her younger son experienced multiple medical difficulties. The appearance of Sports and Recreation teams emerged later in the findings as a way for her son with Autism to acquire social skills. Interestingly, it also emerged as a means of social interaction for her and her husband that led to her husband coaching the t-ball team. It is important for practitioners in the field to recognize the impact that we have on families, particularly home visiting teachers. Early Intervention practitioners are often the first link to information and strategies for families once their child has an identified developmental delay or a disability. The medical community also carries this same responsibility when providing a diagnosis or making a referral to a school district or another medical provider. As

teachers then, we are accountable for developing a trusting relationship with a family and to ensure our reliability in providing resources and support. In one of my participant's examples, her son's special education team encouraged sports team participation as a way for him to develop social skills. She trusted her son's educational team to a point of empowerment resulting in positive outcomes for her son and their family. This is why she feels that *Our Team Rocks*.

Keeping it Real is the fourth Super Theme to transpire from my participant's Facebook posts. Although I have described her as a particularly positive person overall, she is also very human and is not afraid to reveal emotions that are negative. So although she may have ended a post on a positive note or used humor to illustrate a challenging day, she is not afraid to express other emotions. In this Super Theme, Grief/Frustration, Scared/ Worried, Exhausted, Diagnoses, Stress, Caring for Sick or Injured Children, and Flying Solo are all referenced as what she described as just *Keeping it Real*. She meant that, although she tried to be positive, even she cannot maintain this attitude all the time. Actually, this was what their life was truly like. As the results section showed, she did a great job of describing how challenging it is to be a mom of two children with disabilities and medical concerns. Her descriptions through her 5 years of posts described the journey she traveled seeking help and answers. This is crucial information for Early Childhood Special Education teachers. For ECSE teachers to get a glimpse of what a parent experiences, as they are experiencing it, is a priceless gift. This study is a window into their life, without interviewing them, where they may soften their emotions or need to rely on their recall of events. This type of study is a way to uncover what a family member may be feeling as they are going through it. This Super Theme in particular is most

likely to describe any concerns a parent with a child with a disability may have as well as the in the moment response to that concern. If a teacher has developed a trusting relationship with a parent, and that parent is willing to look through their social media pages with an ECSE practitioner, they could discover a lot of information about the child and develop parenting strategies that could benefit the entire family. This study has implications for use that could potentially aid Family Guided Routines Based Intervention, which is the basis of ECSE services from birth through age 2.

The fifth Super Theme to emerge from the 5-year retrospective study of my participant's Facebook page was *We've Got This*. The sub-categories in this Super Theme spoke to the resiliency of my participant. Super Jennifer, Self-Care, Relief/Hope, Advocacy, and Team Randall made up the five sub-categories in this Super Theme. My participant prided herself on her take charge attitude, as was demonstrated in the examples in chapter four under the sub-category Super Jennifer. It is a personality trait that served her well as a parent of two children with disabilities because she was able to meet challenges head on and did her best to meet the needs of her children. This self-assured attitude also supported a great advocate for her children. This emerged more strongly each year of her posts, as the challenges of her children's delays increase. It was a journey for her from learning of her children's delays to researching everything she could, to fitting all the pieces together and starting to educate others. Although these challenges made my participant research more, advocating more for her sons and seeking out other services, which is not always true of the general population. Therefore, as practitioners in the field of Early Childhood Special Education, it is important to understand and learn from my participant's journey. We need to remember that when we meet a family for the first time, it

may be the first time they have learned that their child has a developmental delay. Early Interventionists need to develop a relationship with them, understand their learning style and help them best discover how to help themselves on the journey. This study helps practitioners by demonstrating one parent's 5-year learning curve, reminding us of the process families go through. Hopefully we can begin to recognize at what point on the path a family may be, and can meet them where they are with our support, resources and programming.

The last of the six Super Themes to emerge from the data is *Live Life to the Fullest*. This Super Theme contains five sub-categories, Routines, Family Adventures, Mama Days, Weather, and Holidays and referred to my participant's deceased father's mantra of "living large." My participant carried on his perspective of making the most of everyday by placing a high priority on schedules, events, and activities. The fact that she was highly organized and prioritized routines was evident in the fact that the sub-category Routines placed fourth overall in references for the 30 sub-categories. This is beneficial to her child with Autism as he felt the most comfortable with a predictable routine. Additionally, placing a focus on making the most of every day helped the family to treasure each other and create lasting positive memories, rather than focusing on evaluations and medical diagnoses. This family loves their "adventures" and it's a way for them all to look forward to the day ahead even in the midst of multiple doctor, therapy and school appointments. For Early Childhood Special Education practitioners like myself, it is important to learn from this study that each family that we work with has their own priorities, routines and life philosophies—even if they are not able to put it into words. It is our job to help them determine what their priorities and routines are so that we can best provide services for them, particularly in early intervention home based services. It is important to pay

attention to what they talk about and how they describe their days so that Family Guided Routines Based intervention is truly that, *their* family guided and *their actual* routine based intervention, not what ECSE teachers feel would be the best for them.

Study Limitations

As is true for all research studies, this study had some limitations. To begin with, it only had one participant, so that this single case is only one perspective on how Facebook postings can serve as support for parents who are raising children with disabilities. Generalizing the results of this one participant's Facebook posts is not possible in that every person that posts to Facebook does not do so in the same way. This participant happens to be a very positive person in general combined by highly expressive communication style, sometimes posting several times a day. This would not necessarily be true for the general population of parents of a child with a disability. Even though I was able to create six Super Themes from my participant's 5 years of Facebook posts, another parent may have only posted a few times with entirely different emotional responses. Conducting a qualitative categorical analysis may not be possible or, at the very least, would yield very different results.

An additional concern with my participant's overly expressive social media personality was that there was simply too much data for the scope of this project. I was unable to place each post into a single theme or sub-category; they were placed into several due to the length and content of each post. Therefore, using total number of posts as a denominator was not possible, rather total number of references within all posts had to be used. Key-words and a second read through were utilized for intra-rater reliability, but this too could have been improved with specific inter-rater reliability processes.

A third limitation noted with this study is that it only took into account posts to the social media network Facebook. It did not look at any other type of social media, such as Instagram, Snapchat, or Twitter. Generalizing Facebook posts to all social media is neither valid nor reliable because people use each type of social media a little bit differently. Therefore, conclusions reached apply to Facebook users more so than other social media users.

Another concern with Facebook came during the data collection phase, when it was discovered that Facebook will allow you access to only a certain number of posts each calendar year. This was an issue for my study because my participant posts to Facebook nearly every day, and sometimes several times a day. For this study, I was unable to access any posts between January and April for 2011, 2012, 2014, and 2015, and none between January and May in 2013. The intent was to collect data from March, 2011, to May, 2016, but the data collection dates were less than that. Missing several months of posts per year, even if they were generally the same months each year, did alter the results in my opinion because the birth of both of her children were not included, including the premature birth and NICU stay of her younger son, which could have potentially added content in several sub-categories.

Verifying Current Literature

Overall, my participant's Facebook postings resulted in six emotional support Super Themes that mostly align with the current literature representing positive emotional support, interpersonal or informal support, professional or formal support, a shared community, optimism and self-confidence, and coping strategies.

My literature review resulted in no research in the area of parents with a child with a disability and the support they receive from Facebook postings. However, studies focused on the

benefits of support in general for parents of a child with a disability and, in regard to support on the Internet, they focused on online support groups. My research study supported the current literature on the benefits of informal and formal support. Both types of support earned their own Super Theme in my research from my participant's references, *It Takes a Village* and *Our Team Rocks*.

In terms of online support groups, this project did not focus on responses from other Facebook users, therefore it did not look into the give and take of a dialogue that online support groups would offer. However, this study does support the sense of community that one would find in an online support group. Both the Super Theme, *Embracing the Positive* and *Keeping it Real* carry concepts of emotion, both positive and negative, that would be likely be shared in an online support group as well as social media.

Another way that this project supports current literature is in the area of coping. Literature in the field demonstrates that parents of a child with a disability that have learned resourcefulness and an optimistic attitude are more self-confident and are better able to seek out resources. This is definitely true of the participant in my study. She prides herself on her positive outlook on life and has used that to drive her ability to advocate for her children, and soon for other children and their families as she has been accepted into an Early Childhood Special Education graduate program. These concepts were well represented in my participant's Facebook posts through the Super Themes, *Live life to the Fullest*, *Embracing the Positive* and *We've Got This*.

New Ideas for Current Literature

Since there were no studies looking at how social media is used by parents of a child with a disability, only that it is used by 47% of one study's participants, this research project is important in this area of study. Social media is becoming ever more present and, as ECSE practitioners, we need to be aware of its impact on the families we work with and the potential usefulness of it in our programming. Additionally, this study is a retrospective look at one parent's thoughts and stories in the moment, a live interactive diary, that is giving us a more accurate look at thoughts and feelings than a study that asks a parent of a child with a disability to recall events, or to answer a survey with a numerical value that represents an emotion.

Next Steps in Research

There are several next steps in research for this topic. To begin with, adding several participants to the study would provide more reliability to the results. Researchers could add variables such as different disabilities, different socio-economic statuses, different social media sites and different cultural or ethnic backgrounds to get a more thorough look at a true population of parents with a child with a disability and their social media posting habits.

Another next step in research became apparent to me as I was analyzing data. My participant, perhaps inadvertently, documented the development of her children, concerns she had about that development and her reactions to those concerns as a parent. This is a great tool for educators. If our families are using Facebook, we should be studying how we can use that information in the field, for instance parenting strategies, tracking child development or as a self-reflective tool for parents.

A final and important suggestion for future research would be to track the responses to my participant's posts. It would be fascinating to determine what supports my participant actually received in the comments to her posts, whether it was simply pushing the "like" button, getting sympathy, relaying information or providing a pat on the back. In other words, did those responses fulfill my participant's expectation?

Conclusion

The results of this study will help guide Early Childhood Special Education practitioners in their practice by a retrospective look at five years of Facebook postings from a parent with children with disabilities. This study will help support practitioners in learning how to meet parents where they are at emotionally on their journey through the process of their child's disability and delay. This will help the practitioner to empower parents toward growth and advocacy for their child as well as to help them to realize that they are their child's best teacher.

This research will also help ECSE practitioners recognize that every family has their own routines and priorities, which is the foundation for Early Intervention services for Part C, birth through age 2 of IDEA (Individuals with Disabilities Education Act). This study supported the importance of routines in a family's life, but we also need to be aware of our biases in this area in practice.

Finally, this study supports the use of social media posts of a parent of a child with a disability as a teaching tool. Teacher and parent could consult reflectively about a parent's posts to search for developmental concerns or parenting strategies or even—to spark general conversations that strengthen trusting relationships between Early Childhood Special Education

teachers and the families with whom they work. As a final concluding Facebook post, my participant reflected:

As I put both our boys to sleep, I can't help but think of this journey we have been on so far. This chapter in our life has been far from easy; there are weeks it feels like we have been at the doctor more than we have been home, we have had extra appointments, labs, and tests done with every type of specialist imaginable, and there are days we wish we could have just one "normal" day. But then I think, this is our normal, this is the life we know, and our boys are perfect in our eyes. It's the way God made them, and I wouldn't want it any other way because then we wouldn't be blessed with Jay and Thomas. Life isn't supposed to be easy...it's supposed to make you happy, and my three boys bring me all the happiness in the world. Jennifer Randall, 7.27.2013

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