

# Networked Empowerment on Facebook among Parents of Children with Special Needs

Tawfiq Ammari, Sarita Schoenebeck

School of Information

University of Michigan

{tawfiqam,yardi}@umich.edu

## ABSTRACT

Theories of empowerment explain how people gain personal and political control to take action to improve their lives. However, empowerment theories were developed prior to the Internet and fail to account for the speed and scale that people can find one another online. One domain where empowerment is critical is caring for children with special needs, in which parents are required to navigate a complex maze of services and processes to access care for their child. We conducted 43 interviews with parents of children with special needs to investigate whether using social media sites helps them to perform this caregiving work. Critically, parents are able to do this through almost real-time access to other parents on Facebook. This work introduces the concept of *networked empowerment*, that describes how parents find other parents, access resources, and explore new ways for promoting health advocacy among caregivers at a local and national level. We conclude with design implications for facilitating faster and better access to information and support for caregivers.

## Author Keywords

Parents, special needs, disabilities, social media, empowerment, children.

## ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

## INTRODUCTION

Accessing support services can be time consuming and emotionally exhausting for parents of children with special needs [45]. Often newly diagnosed and in unfamiliar territory, parents are expected to fight for their children's needs amid a complex network of local, state, and federal requirements [30]. Furthermore, information tends to be

distributed across multiple websites and contain unfamiliar acronyms, rules, and hierarchies. Parents have to navigate medical and educational services that are splintered across organizations and hierarchies [31,50] while simultaneously coping with and adapting to their new identity as a parent of a child with special needs [18].

Not surprisingly, parents turn to the Internet to seek information and access social support related to raising their child [5,21,27]. Prior work suggests that parents find support in online groups (e.g., Facebook Groups, Yahoo Groups) where they can access geographic-based parents (e.g., to discuss local school services) or cased-based parents (e.g., to discuss autism) [5]. Promisingly, parents feel less judged online in these contexts than they do offline among family and members of their community [5]. However, it is not known whether social media supports parents in learning how to negotiate for services for their child—a complex and demanding activity that requires intensive and ongoing effort [17]. This is vitally important for understanding how to support the millions of children who are diagnosed with special needs each year in the U.S. and many more worldwide [9].

We conducted 43 semi-structured interviews with parents of children with special needs about their use of social media related to their children's needs. Results show that as parents need to access health and education services for their children, they turn to social media sites—primarily Facebook groups—to learn from other parents about how to access these services. We draw from empowerment theories to show how parents cope with and respond to receiving a diagnosis of a child with special needs [51]. We present a new concept of *networked empowerment* that describes how parents whose children have received a special needs diagnosis find other parents, mobilize resources, and become advocates. This work introduces new insights into the networked properties of social media sites for empowering parents of children with special needs. HCI researchers can leverage this information to design more supportive platforms for special needs families and to explore new ways of promoting health advocacy among caregivers at a local and national level. We conclude with design approaches for supporting faster and better support for caregivers on social media sites.

## RELATED WORK

### Empowerment Theory

Empowerment describes a process in which people gain understanding and control over personal, social, economic, or political forces in order to take action to better their lives [51]. When people face difficult situations, marginalized identities, or new environments where personal roles change, they can feel disempowered, no longer able to control their own outcomes [36]. Living in a cycle of disempowerment can lead to learned helplessness, where future outcomes continue to suffer because individuals no longer believe they can control and change their future and thus, stop trying [1]. In contrast, empowerment allows people to face challenges and adapt to new roles [36].

Zimmerman's model of psychological empowerment identifies three components: intrapersonal component, interactional component, and behavioral component [51]. The intrapersonal component describes "how people think about themselves" which includes self-efficacy, perceived competence, and mastery. Self-efficacy refers to the perception of a person's own ability to do the actions required to achieve a goal [6]. Greater feelings of competency correspond with the belief that other people have less control over oneself [44]. The interactional component describes people's awareness of social and political issues in their contexts, and how they can act on choices available to them to achieve their goals. Finally, the behavioral component describes "actions taken to directly influence outcomes" [51]. This includes behaviors to manage stress and adapt to change, and taking action to acquire help and resources. Together the interpersonal, interactional, and behavioral components come together to show how a person who believes that she can influence a given context (intrapersonal component) understands systems and processes located within that context (interactional component) and engages in behaviors to exert control in the context (behavioral component).

#### *Formal Empowerment*

*Proactive empowerment* refers to the pursuit of chosen and desired activities (e.g., environmental concerns) [24,49] whereas *reactive empowerment*—the focus of this work—refers to capacity acquired in response to a threat (e.g., disaster relief, health diagnosis) [24,49]. Reactive empowerment can be brought about in two ways: *formal empowerment* is brought forth by political decision-making systems when they allow some measure of meaningful citizen participation in policy making [37]. *Instrumental empowerment* is defined as the ability of an individual to affect the decision-making process outside of legal or policy infrastructures. Formal empowerment is usually enacted through laws mandating citizen participation, such as the Individualized Education Plan for special education, in which schools are legally mandated to take into consideration feedback from parents [45]. Though formal empowerment is designed to support citizens, Rich et al., note that "formal empowerment, by itself, is neither

sufficient nor necessary to give citizens the capacity to control their situation with respect to specific issues" [37]. They describe how "trappings of formal empowerment" could be employed by public officials to frustrate citizen engagement by using "pro forma hearings to consume the energies of the citizens" [37].

#### *Empowerment in HCI*

Empowerment is a core concept in many areas of HCI research. In 1990, Shneiderman penned a "Declaration of Empowerment" to incorporate social good into technology design and to attend to users' needs in the design process [38]. He proposed that HCI researchers and developers commit ourselves to "studying ways to enable users to accomplish their personal and organization goals while pursuing higher societal goals and serving human needs" [38]. Ladner emphasized user empowerment, especially in the context of empowering people with disabilities, to create or configure technologies on their own [22]. He presents the example of text-to-speech techniques that are used in screen readers that are optimized for blind users [22]. Malinverni, et al. have considered empowerment dimensions of participatory design as a means for improving the design results and for children with special needs [26]. Hook et al. extend these ideas to consider "interactional empowerment" that can help users to make sense of their emotions and make meaning through their use of a system.

Empowerment has also been incorporated into the "do-it-yourself" movement that suggests passive consumers can become active producers, though researchers question whether this is actually the case [4]. Empowerment is especially critical in marginalized communities; Shroff and Kam put forth a design model for empowering low-income women in India [39]. They propose aligning the technology design process with particular stages of women's lives. These prior studies place the user and user experience as central to the empowerment process; however, none of these have investigated social media use nor drawn from empowerment theory literature, an important gap we address in this work.

#### **Accessing Care for Children with Special Needs**

Approximately 1 in 6 children are diagnosed with a special need in the United States today [9]. Special needs is used as a diagnostic term to indicate a requirement of assistance; however, the severity of needs ranges widely, from mild cases of attention deficit disorder to severe cases of cerebral palsy. The special needs label tends to be inclusive, an approach we adopt in our work, and can refer to a range of needs including autism, down syndrome, visual disabilities, hearing disabilities, dyslexia, cystic fibrosis, cleft lips, learning disabilities, etc. When receiving diagnoses, the families of special needs children require new and often greater kinds of social, emotional, and instrumental support than they previously required [17,25]. Families also have

more information needs related to specialized educational and health resources [18].

#### Education Services for Children with Special Needs

About 6.4 million (13% of all public school) students receive special education services each year. Students with a special need are entitled to an Individualized Education Plan (IEP) [3], a document that ensures each student receive adequate and personalized services depending on her needs. However, many parents consider the IEP process to be a difficult process to engage with [3]. Although children are guaranteed provision of services by law [26], proving that they need such services is not easy. Parents experience a power imbalance with the school district, entering the negotiation process with little knowledge about organizational, legal, and disability issues [23]. Parents cannot typically determine when a proposed service is adequate or not, lacking what professionals call “judgmental knowledge” [42]. Finally, special needs laws are legislated on a federal level but enacted on a state and local district level, making it difficult for parents to know what to expect of their own district [42].

#### Health Support Online

Some of parents’ information and social support needs are met by offline support groups [2,7,40], a movement which grew in the 1980s with greater acceptance of special needs in American culture [40]. Caregivers also use online health communities and social media sites for information and social support [5,11,21,27,47]. Participation in health-related online support groups and communities can be empowering for patients, especially those who suffer from poorly-understood medical conditions [14] or lack of offline support [11]. They also provide support for caregivers [19], an increasingly important consideration as care, especially for chronic health problems, becomes part of the domestic home environment [16]. Online health communities also provide a platform for political activism relevant to participants’ conditions [43].

The anonymity afforded by some online communities related to health provides participants an opportunity to share their experiences without fearing concern about stigmatizing effects [47]. However, relationships formed in anonymous environments are usually short-lived [11] and might be impersonal [47]. In contrast, social media sites typically require the use of real names or identifications that are linked to a user profile [8]. Newman et al. [34] suggest that online health communities fall short of providing the support and accountability needed by participants to change their health behavior. Building on this prior work, our research explores the ways that parents learn how to access services and resources through social media sites.

#### METHODS

We conducted 43 interviews with a parent of a child with special needs in the United States. Our recruitment process embraced a broad definition of special needs. Thus, if

Parent Gender, Education*			Child Gender, Age, Diagnosis†				**
P1	F	GD	M	4	Down Syndrome	f2f	
P2	F	CD	M	6	Heart Condition	S	
P3	M	CD	M	21	Head Trauma	f2f	
P4	F	GD	M,F	4,4	Autism	f2f	
P5	F	NA	M	18	Brain Condition	S	
P6	F	HS	F	2	Spina Bifida	S	
P7	F	HS	M,M ,M	14,11, 5	Celiac, Asperger’s, ADHD, Autism	S	
P8	F	GD	M	13	Mental Illness, undetermined	S	
P9	F	HS	M	4	Mitochondrial Disease, Cerebral Palsy	S	
P10	M	HS	M	7	Noonan Syndrome	S	
P11	M/F	HS/ HS	F	18	Learning Disorder, Fatty Oxidation Disorder	f2f	
P12	F	CD	F	18	Brain Tumor	f2f	
P13	F	GD	F	5	Down Syndrome	f2f	
P14	F	GD	F	7	Cerebral Palsy	f2f	
P15	F	HS	M	3	Cerebral Palsy	f2f	
P16	F	GD	F	2	Abnormal Brain Development	S	
P17	F	GD	M	6	Down Syndrome	S	
P18	F	NA	M	6	Down Syndrome	S	
P19	M	GD	M	6	Prune Belly Syndrome	S	
P20	M	CD	M	6	ADHD	f2f	
P21	M	CD	M	8	Smith-Magenis Syndrome	S	
P22	M	GD	F	6	Autism	P	
P23	M	CD	F	9	Down’s	P	
P24	M	GD	F	9	Smith-Magenis Syndrome	P	
P25	M	CD	M	10	Autism	P	
P26	M	HS	M,M F,F	14,12, 9,9	Autism, ADHD	P	
P27	M	CD	M	5	Autism	P	
P28	M	GD	M,M	5,3	Autism, Fetal Alcohol Syndrome	P	
P29	M	HS	M	6	Autism	f2f	
P30	M	GD	M	5	Down Syndrome	S	
P31	M	CD	M	21	Autism	P	
P32	M	GD	F	9	Deaf, Blind	P	
P33	M	GD	M	7	CHARGE Syndrome	P	
P34	M	GD	M	6	Autism	P	
P35	M	CD	M	9	Wilson’s Disease	S	
P36	M	CD	F	7	Down Syndrome	P	
P37	M/F	CD GD	F	6	Sjogren-Larsson Syndrome	S	
P38	M	CD	F	5	Micro deletions	S	
P39	M	GD	M	12	Autism	P	
P40	M	CD	F	10	Marfan Syndrome	P	
P41	M	GD	M	5	Autism	P	
P42	M	GD	F	15	Cerebral Palsy	P	
P43	M	HS	F	6	Sturge-Weber	P	

**Table 1: \*GD: Graduate Degree; CD: College Degree; HS: High School. M: Married, D: Divorced, W: Widowed. \*\*f2f=face to face; P=Phone; S=Skype.**

parents responded to our recruitment messages and considered themselves parents of children with special needs, we invited them to participate in our interview. We recruited participants through hospital systems, community

organizations, Facebook groups, and snowball sampling. For Facebook groups, we asked permission of the group administrators before posting a recruitment message to the group. We conducted interviews until we reached data saturation, hearing consistent themes from participants. However, our first phase of interviews oversampled mothers, a phenomenon that has been frequently observed in research studies of parents. To address this imbalance, we recruited fathers in a second phase. We again conducted interviews until we reached data saturation, hearing consistent themes from fathers. The interview protocol with fathers was similar to the protocol in the first phase, with additional questions specific to fatherhood.

In total, we conducted 43 interviews with 17 mothers and 28 fathers (two interviews were with husband and wife pairs for a total of 45 participants). Nineteen participants' highest level of education was graduate degrees, 15 had college degrees, and 11 had high school diplomas (see Table 1 for participant demographics). Of the participants, 38 were married, 6 had been previously married but were now separated or divorced, and one was widowed. Participants had between one to four children, 18 of whom were female and 32 of whom were male, a distribution that reflects the more frequent rate of special needs among boys. Autism was the most common diagnosis (n=12); others ranged from relatively common conditions like Down Syndrome to rare conditions like Smith-Magenis Syndrome and Noonan Syndrome.

Interviews were conducted in-person, over the phone, or on Skype. In-person interviews were conducted in local coffee shops or the participants' workplace in a U.S. city. We conducted interviews in 11 states, including in the West, Midwest, South, and Northeast. In-person participants completed a paper consent form, and telephone and Skype participants completed a web-based consent form. The interviews ranged in length from 40 minutes to 2.5 hours (due to interruptions) and the median length was 53 minutes. We used a semi-structured interview protocol. We began with warm-up questions about the participant's family and daily life. The focus of the interview was split into two sections: the child's special needs and the parent's social media use. The first section asked about the child's needs, when she was diagnosed, and how the family's life was impacted after the diagnosis.

The second section focused on how parents used social media sites to learn about caring for their children's needs. We asked parents about what sites they visited, what recent interactions they had on the site, where they felt comfortable sharing information about their children online or not, and who they trusted on these sites. The interviews were transcribed and coded using NVivo. We coded each of the interview transcripts from the first phase using an inductive approach [12]. The research team discussed the codes then conducted a second pass of coding. After conducting the second phase of interviews, we conducted a

final pass of coding across all of the interviews. Discussing the themes iteratively resulted in 17 main themes. Table 2 depicts five of the main themes derived throughout the theme description process. Most respondents (n=38) described their use of Facebook; all of them discussed the use of social media.

### Limitations

Participants in this study identified as heterosexual and were currently married or had been married. This research oversampled participants with graduate degrees. Because we recruited parents through special needs organizations offline and online, we interviewed parents who were by definition engaged in empowerment processes. This is particularly important to note because studies suggest that low income families and single-mother families have higher rates of special needs children [33].

Theme	# interviews	# instances
Social media used by parents	43	448
Interacting with service organizations	32	112
Information seeking	36	95
Social support	32	95
Privacy and disclosure management	27	63

Table 2. Subset of key themes from interviews.

### RESULTS

Results are organized around three major stages observed in parents' stories raising a child with special needs: going online after receiving a diagnosis, learning about services from other parents, and becoming advocates for the child's needs. For each, we draw on empowerment theory to describe the challenges parents experience and the process of becoming empowered that they go through.

#### Going Online after Receiving a Diagnosis

As they adjusted to their new roles, participants felt overwhelmed by the amount of information they received after their child's diagnosis. They went home and searched keywords provided to them by their health care provider to better grasp their child's diagnosis.

There's a lot of medical terms that are thrown at us all the time... we just have to Google. Google these terms and what they mean and what things that it comes up with just to get an idea, because we don't always know and the doctor sometimes just throw it all on us. -P15

Some participants tried to educate themselves about their child's condition, oftentimes developing an understanding that helped them to steer their health care providers to a more specific diagnosis. P20's primary care physician had diagnosed their child with sensory processing disorder but his wife believed it was attention deficit hyperactivity disorder and was eventually shown to be right. Similarly, P24's wife found out about a genetic test "by doing research online" which they requested, and which led to their child's diagnosis. However, online information-seeking had downsides. Participants felt that the prognoses

they received through doing online research themselves was too negative. Searching online often returned the worst possible outcome, leaving participants feeling “anxious” and “depressed” after viewing negative prognoses online.

Google is the worst for giving you like worst case scenario. So, I always talk to families, I'm like, “Don't Google stuff. Just don't do that.” That's what I used to kind of at the beginning of our journey with William [pseudonym] and it was just... You'll just read bad stuff and kind of the bad side to it about life expectancy and stuff like that. So, I always try and turn families away from going to Google. -P08

#### *Turning to Social Media Sites to Overcome Anxiety*

To help overcome feelings of anxiousness and depression resulting from these prognoses, participants sought out information from other parents on Facebook groups about topics like medications, hospital services, specially designed clothes, and special education services. Participants also valued the experiential information they could gather on Facebook:

You can search a website, you can Google things, you can glean or gather information on the web in millions of sites but to talk to someone that does it day-in-day-out, I think that probably the most informative and helpful way. And that's what I found on Facebook... If I needed a question answered, I have a couple of friends that I know I'd be able to just type in their name, ask a question and be able to get a response in a pretty timely manner. -P16

Such stories revealed other children's ages, severity of condition, and other details, enabling participants to believe that children could achieve the same outcomes.

[Facebook] is a great avenue to bring people together, you know, worldwide. And just say, “Wow, there's Janie. Her daughter did that? You know she didn't walk until 4? Mine didn't walk until 4.” You know, we feel better about it because we're not alone... And learning information takes that fear away because of the medical side doesn't always... They don't know how to connect with families. -P10

On Facebook groups participants followed other parents' stories about their children's progress, especially when their children were undergoing an operation, starting new medications, moving to a new school, or experiencing other transitions.

I've read [about] other kids... having a similar surgery to what we had... I read their day-to-day update, then I see what happens so that when my kid's in the hospital having surgery, I can [be prepared].... stuff like that, that I wouldn't have known if I hadn't read about other people's stories. -P02

Parents reported lurking online before posting, allowing them to identify individuals and communities with children with similar conditions. For participants whose children

experienced sensory challenges, narratives about navigating daily life were valuable. For example, some children with autism had negative reactions when sitting in a chair at the dentist office or the barber shop, and relied on local information about dentists and barbers who had more experience working with children with special needs. Parents also relied on local Facebook groups to access local services like accessible playgrounds (e.g., for children with Cerebral Palsy) and other appropriate activities.

#### *Role Changing and Coping Behaviors*

Diagnosis of a special need occurred at three different stages: 1) neonatal diagnosis, before the child was born (e.g., Down Syndrome, Spina Bifida); 2) diagnosis at birth (e.g., Cerebral Palsy); and 3) diagnosis when developmental milestones were not met (e.g., Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder). Each of these kinds of diagnosis introduced unique challenges and opportunities for participants. When participants first learned of a diagnosis, they recalled being in a state of shock and told us could not remember most of what their primary health provider said during the appointment where they received their child's diagnosis. Many participants indicated that their friends, colleagues, neighbors and at times, even family members, could not understand the conditions they were experiencing. During the early post-diagnosis stages, participants struggled to cope with the diagnosis and the impact it would have on the rest of their life. As one participant explained:

When [my son] was first born, I was extremely angry with how he was, and I didn't want to be around a lot of my friends that had perfectly normal children. Because all I heard was “oh, you know, little Johnny did this and did that” and my kid can't even eat. So it was extremely difficult the first couple of years. -P19

Participants noted that they experienced a role change from identifying as a parent to identifying as a parent of a child with special needs. Through this identification process, they started to comprehend that their children might not live a typical childhood and they began to go on social media as part of the coping process. Accessing other families of children with special needs helped them to learn how to cope with and adapt to their new roles and identities.

#### **Learning about Services from other Parents Online**

Participants told us that finding social workers and care providers who could help them find the resources and services they needed was an ongoing struggle and often a stressful and emotional one. Health and education systems were difficult to navigate and required learning how to manage multiple people, stakeholders, and obstacles. As one parent said:

The whole art of handling kids is learning how to navigate hundreds of people in your life. So you have a social worker from the school who ends up being useless. You have a social worker from the ventilation clinic. You have a social worker from the ICU. You

have a social worker from the Cardiac unit. You have the local county's social worker. And then you have a social worker from hospice. They were all from different organizations, but they're all trying to help give you resources. -P10

Most parents echoed this observation, lamenting that social workers did not have adequate or accurate information. One participant whose child has cerebral palsy said that most families were served by a children's services department for the state she lived in, but felt that this service was "clueless" when she tried to call them or go to their website for help. Participants emphasized that experiential information from families online helped them to overcome gaps in their knowledge about navigating health and medical care. Providers often did not have the time or ability to form strong social connections with a family and address all of their needs. One parent shared:

Our daughter, she's 15, it becomes a hard job to bathe her because she's so big and she's very clumsy. Physically, I can do it. My wife can't do it anymore. Through these discussions in this [Facebook] group, I discovered that there was a service that you can use, and it's actually free of charge, where twice a week somebody comes and bathes her. -P42

While parents had to deal with varying health resources depending on type and severity of their children's special need, almost all of them had to negotiate for special education services with government agencies.

#### *Learning about School Services*

Participants told us the school IEP was one of the most difficult and demanding processes they had to manage. They reported that school administration and specialists who took part in the IEP evaluation process acted as gatekeepers, limiting their children's access to resources. Each school district maintained different processes and requirements for serving special needs children and websites were under-maintained, if they existed at all. As a result, parents received little information about how to discover what services were available and what services their child was entitled to. Further, the cycle of requesting a service and being denied was an emotionally draining process that left them exhausted and angry.

Participants turned to social media sites to learn more about these services. In particular, they relied heavily on Facebook Groups to learn how they should advocate for needed services. Within these groups they could read other parents' stories about negotiating IEP processes in a particular school district. Drawing on these stories, participants were able to discover what services their particular school district typically provided, what services would be best suited for their children, and whether service providers were known to withhold mandated services.

Because my wife and I work in a tandem on a lot of stuff, she asked a lot of questions from the folks here

locally and I did a lot of research online, talking to some of the families that I noticed were sharing a lot [about] their IEP programs, the challenges... some of the tips to help improve in those areas. And my wife and I would share notes of how to approach IEPs more effectively. -P25

In cases in which other parents reported that they had experienced difficulty accessing services through the school, participants became aware that they might have to negotiate more forcefully for their own children's needs. Accessing other parents online prepared parents for a battle they might have to fight, mitigating the power imbalance parents experience when they face special needs providers by arming them with knowledge and insight about how the process will play out.

#### **Becoming Advocates for a Cause**

The process of trying to access services for their child with the support of other parents online pushed participants to embrace advocacy beyond the needs of their own child. Participants typically posted on their Twitter or Facebook timelines about legal, policy, and budgetary issues related to their children's condition. P01 used Twitter, saying that being an advocate was "part of [her] Twitter identity". P08 similarly said she preferred to use her Twitter for advocacy purposes, keeping it "pretty clean" while her Facebook feed was more personal and "quite a bit livelier and funnier." Other participants preferred Facebook over Twitter's character limit. P23 and his wife used their Facebook timeline to "out" the diagnosis of their child, saying:

I guess the biggest event for us was that we actually outed my daughter about a year and a half ago. So a lot of people in our network, even cousins and uncles and aunts, actually didn't know her diagnosis because we didn't want to use that to define who she was... [But] we really, really wanted to boost fundraising [for] this non-profit that we're organized with. -P23

#### *Facebook Groups for Advocacy*

Participants who had become advocates or had participated in the process of advocacy described two kinds of Facebook Groups: more private groups to organize and strategize and more public groups to advocate for policy change. Participants circulated online petitions in both of these platforms, especially when seeking change within local or national organizations or legal processes. Some participants also advocated in-person either in their local cities or by traveling to their local state capitols. P12 had traveled to Washington, D.C. to advocate in person and now used Facebook to recruit other parents to send letters to their congressmen. Participants such as P12, whose child was now 18 and had moved through the childcare system, not only had become advocates for the cause but also began to offer themselves as resources to help new parents. These "veteran" participants identified themselves as people who knew the system, and could help newly diagnosed parents who would be following in their footsteps. They took on the

responsibility of providing resources and practical advice for parents coping with a new diagnosis. P21 shared about the Smith-Magenis group he created:

It's mostly newly diagnosed people saying, "Hey, I just got this diagnosis and here's a picture of my kid and I'm glad that I know that we're not alone." Fifty people say, "Welcome to the group. Welcome to the journey. Here's some resources for you." It's a lot of that stuff. But also fundraising updates, research updates, conference updates, stuff like that. -P21

#### Addressing Rare Conditions

Participants whose children had rare conditions were especially likely to embrace and give back to their online communities. Because they typically could not find extensive resources online or in bookstores (and often, their healthcare providers knew less about the condition), they shared experiential information online with other parents worldwide. For example, P37's daughter was diagnosed with Sjögren-Larsson Syndrome (SLS), a rare syndrome, the symptoms of which intersect with other syndromes, making it hard to diagnosis and treat. P37 could not find offline support groups or organizations and there was no SLS Facebook Group so P37 created it himself:

So, right away, I just was thinking, "Well, this is rare. I've come to this growing huge social media site [Facebook] looking for information, and there is none. That means somebody else is somewhere doing the same thing, or will do, or has done the same thing I'm doing. So, I should create just some page with the name of that syndrome on it." -P37

At the time of the interview, the SLS Facebook page had 141 likes and had connected SLS families in the U.S., Jordan, Iran, France, and Sweden, among other countries. Participants also described interacting directly with families with rare conditions. When P40's daughter was diagnosed with Marfan Syndrome, they learned of another family who had this condition, contacted them through email and began Skyping with them. P21, whose son was diagnosed with Smith-Magenis Syndrome described "emergency Skyping sessions" that mothers organized on their Facebook groups if they had had a particularly difficult day. Though participants with less rare, high prevalent, conditions also engaged in these behaviors, they did not report having to work as hard to find online support groups for their children's condition.

Participants in densely populated urban areas could typically find local organizations and other parents to meet in person (e.g., through a hospital). However, participants in rural areas often did not have access to local organizations and thus, created and relied on Facebook Groups and other channels like Listservs that offered coordinating mechanisms. In some cases, these Facebook groups evolved into 501(c)(3) non-profits and other "real, formalized groups" as P19 termed them.

We've created a Facebook page for our group. It's a [state] non-profit, working on federal non-profit status. So, with other, a couple of other parents.... We all wanted to create something that was missing up in the [rural region], so we developed it sort of grass roots, so we're very much a grass roots organization. -P09

Creating an online identity and brand helped legitimize a particular cause or need, which was especially important among geographically isolated parents who might otherwise feel unable to access the support they needed.

## DISCUSSION

### Towards a Model of Networked Empowerment

Through their process of adjusting to their child's diagnosis, parents work to overcome the anxiety and uncertainty that follows a diagnosis, navigate the complex process of accessing services, and become advocates for their child's needs as well as for the special needs cause more generally. Results reveal categories of social media behaviors that map to components of psychological empowerment from prior work [51] (see Figure 1). Specifically, the intrapersonal component (how people think about themselves) involves reading other parents' stories, posting questions, developing cognitive models of how to care for one's own child, and developing the belief that one can care for their own child. The interactional component (people's awareness and ability to act towards goals) involves learning about health and education services, developing an understanding of these services, and learning how to access resources within them. Finally, the behavioral component (taking action to achieve broader outcomes) involves answering other parents' questions, welcoming newly diagnosed parents, creating groups for sharing information or advocacy, and campaigning and fundraising on social media sites.

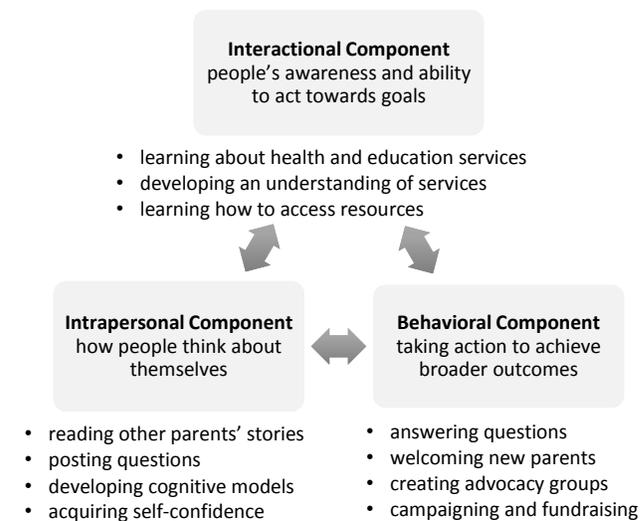


Figure 1. Model of networked empowerment on social media sites that builds on psychological empowerment theory [51].

Drawing on these social media behaviors and empowerment components we introduce the concept of *networked empowerment* that describes how social media sites help parents to find other parents, overcome power imbalances between parents and service providers, and mobilize resources to support the special needs cause. Unlike with offline groups, parents are now able to do this through almost real-time access to other parents on Facebook. boyd and Ellison describe social networking sites as public or semi-public profiles, with articulated lists of users, and an ability to traverse profiles and content [8,15]. Similarly, Wellman and Rainie [46] describe the web as a networked social operating system in which the “boundaries between producers and consumers are becoming blurred”, and “the boundaries that used to exist between public realms and private havens are no longer as rigid.” Prior empowerment theories insufficiently account for parents’ ability to find and “traverse” other parents’ profiles and/or content and access knowledge and resources to overcome health and education structures.

We find that parents engage in what Huh and Ackerman [20] referred to as “illness trajectory alignment” as they looked for parents whose children suffered from similar conditions and who maintained similar illness “medical models” [28]. Parents collectively engage in collaborative sensemaking [35] of their children’s medical conditions. When they found such parents, they might communicate with them in other means (e.g. form a closed Facebook group, communicate through Skype, or meet in person). Specifically, when advocating for change through, parents often use Twitter and public Facebook Groups while opting to use closed or secret Facebook groups when discussing potentially stigmatizing conditions related to their children’s needs. The next section presents design recommendations for supporting networked empowerment for families online.

### **Design Approaches for Networked Empowerment**

#### *Needs-Based Search: Finding Other Parents*

Parents feel anxious after looking up a diagnosis online, a phenomenon described as “cyberchondria” by White and Horvitz which they define as unfounded escalations of concerns about symptom [48]. After this point, parents turn to social media sites, where they can access information, resources, and advice from other parents. Prior work suggests that chronic disease patients reverted to online health communities for support, especially family and friend support is lacking, [28,41]. Participants described health and education special needs services as complex and confusing, a sentiment documented in prior literature (e.g., [45]). Echoing Davis et al. [13], participants reported that they relied heavily on veteran parents on social media sites to learn about IEPs and to prepare for their IEP meeting.

Though Facebook groups for special needs are pervasive (searching for “[city name] + autism” typically returns a variety of results), searching Facebook groups for a

particular condition returns a list of groups that has little apparent structure or order. As a result, parents may join groups that are not the best fit for their needs, and may miss groups that are relevant. Prior work suggests that parents of children with special needs use groups either based on location or on diagnosis [5]. One design solution is for sites like Facebook to index groups by diagnosis and region, allowing parents to more quickly find relevant groups to them.

An additional challenge facing online platforms is how to provide summaries and visualizations of content to a newcomer. This need is especially pressing in the context of health concerns (and indeed, researchers are looking to address this problem [32]). Integrating join dates, profile information, and content shared could provide a unique kind of profile that allows parents to find other parents in similar stages of a diagnosis. However, a challenge would be balancing privacy considerations for parents who may not want their families’ healthcare needs indexed online (though, it is worth noting that participation in any of these groups makes this information already stored in Facebook’s servers). In addition, parents may eagerly welcome new parents who fit the demographics of the group, but may want the content (and perhaps even existence) of the group to remain private to everyone else, making findability of such groups for newly diagnosed parents an important challenge for social media designers.

#### *Network Structure for Resource Mobilization and Advocacy*

Empowerment models have typically described community involvement in organizations and neighborhoods [51]. This research extends that work into online spaces, highlighting community involvement on social media sites, primarily Facebook. Extensive prior work has shown how information spreads through social networks (e.g., [10]). Our work explores how parents access information in the context of special needs care. Parents learn to navigate service providers and negotiate for services with these providers, transforming what might be an isolated, stigmatized process of seeking access to services to a networked process. Indeed, veteran parents also began to advocate on a broader level than their child’s own needs, educating other parents, community members, and sometimes lawmakers in both their online and offline environments. By tapping into online groups and gaining critical awareness, participants learned how to mobilize resources to negotiate for their children’s needs, a process that requires bringing together a collective group of people and organizations [29]. However, translating networked activity among parents to collective movements that impact policy at a local and national level is more challenging. One approach is to use automated techniques to understand what policy challenges are expressed by parents, which kinds of services and organizations are over- or under-delivering necessary services, and how services and parents might work together in collaboration rather than opposition towards shared goals. While we find that parents turn to

social media sites for mobilization and advocacy, there is little evidence that such efforts have resulted in change on a local or global scale. Future work in HCI should investigate the effects of mobilization for accessing health services and should explore ways of designing social media sites that better support parents and caregivers to perform this advocacy work.

### CONCLUSION

We introduce a new model of networked empowerment that highlights how social media facilitates the process of empowerment through access to other parents at various stages of the special needs trajectory. These results can be translated to other contexts where individuals need to overcome structural boundaries to access services, especially related to health and education needs. Future research should investigate the experiences of parents who do not learn how to access care for their child and how they might be better supported to do so. Future work should also explore crowdsourcing techniques for collecting and aggregating information about how to navigate and access education and health services.

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