# Accessing Social Support and Overcoming Judgment on Social Media among Parents of Children with Special Needs

**Tawfiq Ammari[1], Meredith Ringel Morris[2], Sarita Yardi Schoenebeck[1]**

[1]University of Michigan, [2]Microsoft Research

tawfiqam@umich.edu, merrie@microsoft.com, yardi@umich.edu

## Abstract

About 1 out of every 6 children has been diagnosed with a special need in the United States. For their parents, the economic and emotional costs can be overwhelming. Using a mixed methods approach, we show that parents of children with special needs rely primarily on Facebook pages, Facebook groups, and Yahoo! groups for accessing information and social support. Specifically, these groups offer geographic communities for local needs (e.g. school services) and case-based communities for specific conditions (e.g. autism). Promisingly, parents perceive less judgment online than offline when talking about their children's special needs; however, these perceptions are nuanced. In particular, posts containing humor, achievement, or treatment suggestions are perceived to be more socially appropriate than posts containing judgment, violence, or social comparisons. However, results show that social media generally fails at connecting special needs families over time and across the life span. We discuss implications for social media site design and for supporting special needs families.

## Introduction

About 1 out of 6 children in the United States is diagnosed with some kind of special need (Boyle et al. 2011). These disabilities range from speech and language impairments to autism, cerebral palsy, or attention deficit disorder. For parents, the economic costs of having a child with a special need can be overwhelming (Shimabukuro, Grosse, and Rice 2008). The emotional costs can be even more demanding. Caring for children with special needs requires more effort and resources than caring for a child with typical needs, and coping with a diagnosis and subsequent progress can be emotionally draining (Floyd and Gallagher 1997). Though studies are limited, reports suggest that parents of children with disabilities have higher rates of divorce or separation (Hodapp and Krasner 1994).

It is not surprising, then, that parents of children with special needs have increasingly turned to the Internet for information, resources, and social support. But they face many challenges. First, misinformation is pervasive and parents are challenged to discern credible information from myth (Crocco, Villasis-Keever, and Jadad 2002). Second, finding resources can be challenging—each child is unique, yet receives a broad diagnosis that collapses individual experiences into a single label (Dale 1996). Finally, trolling, judgment, and stigma are pervasive online and parents can be subjected to harsh critique and opinions related to their child's needs (Schoenebeck 2013). Problematically, parents who receive negative feedback may not return to a site, resource, or online social network (Burke, Marlow, and Lento 2009). Thus, while the opportunities for supporting parents of children with special needs online are vast, they come with risks and challenges that are not yet well understood. To better understand these issues and how we might support families, we investigate the following research questions:

*RQ1: What social media sites do parents of children with special needs rely on for information and social support?*

*RQ2: Do parents of children with special needs feel more judged online or offline, and how do they manage this judgment?*

*RQ3: What kinds of posts do parents of children with special needs perceive to be socially appropriate to post (a) on their own online profiles and (b) in shared online groups?*

*RQ4: How can we design social media sites to better support special needs families?*

To answer these questions, we use a mixed-methods approach combining 18 interviews with parents of children with special needs with a survey of 205 parents of children with special needs. Our contributions are threefold: first, this work is the first to report which social media sites parents of children with special needs find useful and why.

Second, we provide data-driven design implications for supporting parents of children with special needs on social media sites. Finally, understanding what kinds of posts are socially appropriate can help parents to better construct their own posts and understand how their posts will be received by their online audiences. This work lays the groundwork for new theoretical and design approaches to supporting parents of children with special needs—an important and growing demographic of social media users.

## Related Work

### Caring for Children with Special Needs

Researchers are increasingly beginning to consider approaches to designing interactive technologies for children with special needs (see an overview in (Alper, Hourcade, and Gilutz 2012)). Prior work has also explored computing approaches to supporting caregivers of special needs children such as automatically capturing behavioral data, supporting collaborative decision making, or wearable sensors for children (Kientz et al. 2007). Moncur investigates ways of providing support to families of babies in the neonatal intensive care unit based on the families' social networks, observing that parents are under considerable stress and their family and friend networks could be leveraged for emotional support (Moncur 2007). Technologies for caring for children with autism in particular are an emerging topic in the research community. For example, Hong et al. propose a SocialMirror concept that allows young adults with autism to seek advice from a trusted social network of family, friends, and professionals (Hong et al. 2012). Social network services are shown to have the potential to strengthen relationships between individuals with autism and their extended networks, mitigating their reliance on primary caregivers (Hong et al. 2013).

The stressors for parents of children with special needs are significant: income, time available for a child, and social support predict parenting stress better than the child's functional abilities (Smith, Oliver, and Innocenti 2001). Parents' major concerns center on how to promote the development of their children (Gowen, Christy, and Sparling 1993). Parents also express the need for information on dealing with the emotional and time demands of parenting, finding community resources, planning for their child's future, and understanding their child's rights (Gowen, Christy, and Sparling 1993).

### Judgment and Stigma

A major challenge faced by parents is the stigma and perceived judgment associated with special needs. Whether physical, emotional, or cognitive, children and their parents are subject to judgment, assumptions, and unfamiliarity from others (Green 2003). Special needs children may ex-perience a variety of types of stigma, ranging from actual biases based on their condition ("enacted stigma") to perceptions of stigma that may not actually exist ("felt stigma"). Parent also experience "courtesy stigma"—the stigma of affiliation that applies to people who associate with stigmatized groups rather than through any quality of their own (Goffman 1963). Mickelson's 1997 study of parents of children with special needs showed that parents' perceived stigma was related to their perception that less support was available to them (Mickelson 1997). When comparing offline support to electronic group support, they found that parents reported receiving less support offline than online. We build on Mickelson's studies and revisit social support questions in a context where social media use is pervasive, and where parents are one of the most active demographics online (Nielsen 2009).

### Health Information and Social Media Use

Over 70% of Internet users have looked online for health information in the past year (Fox 2013). Though most Internet users turn to doctors or established offline sources for medical advice, participants often share medical advice with one another, and in some cases the information can be accurate and rich (Hoch and Ferguson 2005). However, social support can go underutilized when patients fail to seek out information, assistance, and emotional support from family or friends or when family or friends fail to meet the needs of the patient (Skeels et al. 2010). When standard medical advice does not fit the experiences of patients with chronic illnesses, they turn to online communities for information and resources, developing new relationships and identities when doing so (Mankoff et al. 2011).

Parents are active users of social media: among new moms, 89% have posted a status about their child on Facebook and over 97% have posted a photo of that child (Morris 2014). However, for parents of children with special needs, the information and support needed can be complex and filled with unique kinds of challenges. A study of websites by parents of children with autism showed that stressed parents could forge ties among themselves and reduce their own isolation (Fleischmann 2005). A similar study of an email group among parents of children with autism showed that the group helped them find meaning, support, and shared experiences (Huws, Jones, and Ingledew 2001).

Many open problems exist. For adults with autism, online communities offer greater connectedness through support relationships, but intensify problems around knowing who to trust, who to disclose information to, and understanding online norms (Burke, Kraut, and Williams 2010). More generally, online question and answer forums can be limited by the lack of close ties and existing relationships, where users may not want to broadcast to an un-

| | Gender | Parent Education | Child Gender /Age* | Child's Special Need(s) | Method** |
|---|---|---|---|---|---|
| P1 | F | Graduate Degree | M/0-4 | Down's Syndrome | f2f |
| P2 | F | College Degree | M/5-10 | Heart Condition | S |
| P3 | M | College Degree | M/>=18 | Head Trauma, Psychological Impairment | f2f |
| P4 | F | Graduate Degree | M&F/0-4 | Autism | f2f |
| P5 | F | N/A | M/>=18 | Brain Condition | S |
| P6 | F | High School | F/0-4 | Spina Bifida, Brain Condition | S |
| P7 | F | High School | M/14,11,5 | Celiac, Asperger's, ADHD, Autism | S |
| P8 | F | Graduate Degree | M/10-14 | Mental Illness (undetermined) | S |
| P9 | F | High School | M/0-4 | Mitochondrial Disease, Cerebral Palsy | S |
| P10 | M | High School | M/(dec. 5-10) | Noonan Syndrome, Heart Condition | S |
| P11 | Both | High School | F/>=18 | Learning Disorder, Fatty Oxidation Disorder | f2f |
| P12 | F | College Degree | F/>=18 | Brain Tumor | f2f |
| P13 | F | Graduate Degree | F/5-9 | Down's Syndrome | f2f |
| P14 | F | Graduate Degree | F/5-9 | Cerebral Palsy | f2f |
| P15 | F | High School | M/0-4 | Cerebral Palsy | f2f |
| P16 | F | Graduate Degree | F/0-4 | Abnormal Brain Development | S |
| P17 | F | Graduate Degree | M/5-9 | Down's Syndrome | S |
| P18 | F | N/A | M/5-9 | Down's Syndrome | S |

*Table 1: Interview demographics. *Age ranges provided instead of ages to preserve anonymity. **f2f=in-person, S=Skype.*

defined audience (Tixier, Gaglio, and Lewkowicz 2009). On social networking sites, asking questions can bear high social costs (Brady et al. 2013) and a social networking site like Facebook may be too personal for some users to ask health-related questions (Brady et al. 2013; Morris, Teevan, and Panovich 2010). Facebook users feel that the site provides them with useful information, yet many report they are not likely to use Facebook to seek information (Lampe et al. 2012). Facebook users are also challenged to balance sharing information related to specific needs and the desire to manage self-presentation (Newman et al. 2011). Little work has explored what kind of judgment and social stigma people experience when they post personal health information online. Special needs families' experiences online are especially not well understood, despite being a large demographic in the United States and elsewhere. Our research begins to address these gaps in the literature.

## Methods

### Interview Study

We conducted 18 interviews in early 2013, each with a parent of children with special needs (one was with a husband-wife pair). All participants lived in the U.S. Our definition of special needs was purposefully broad and inclusive: if parents responded to our recruitment message and said their child had a special need, we invited them to participate in the interview study. We chose this approach to understand the experiences of a broad range of special

needs families. Participants were recruited through local email lists, parent support groups, and by word-of-mouth. Interviews were conducted in-person or over Skype and lasted 40-70 minutes.

The interview format was semi-structured and began with general questions about what a day in their life looked like, their child's diagnosis and development, and about challenging and rewarding episodes with their child, spouse, and caregivers. The next set of questions focused on how participants used the Internet related to their child's special needs, such as what sites they visited and what purposes each served. Participants were also asked if they had felt judged on social media in relation to posts about their child. The final set of questions focused on aspirations parents had, including what sort of support or resources they wished were available both offline and online. The first author transcribed the interviews and coded the transcripts in NVivo using a qualitative inductive approach (Corbin and Strauss 2008). The research team discussed emerging themes iteratively throughout the coding process. After we began to see consistent themes in the data we drew on these themes to develop the survey questions.

### Survey Design and Recruitment

We created an online survey using SurveyGizmo. The survey contained 36 questions (mostly multiple choice, with a few free-response), and was called "Social Site Use by Parents of Children with Special Needs." The survey protocol was designed to expand and generalize findings from the interview study. It asked parents about their social media use and about perceived judgment from various rela-

tionships both online and offline. It also asked about how appropriate parents felt it was to post about different topics related to special needs on Facebook. This was done building off of social norm measurements techniques described in (Labovitz and Hagedorn 1973). Specifically, we developed three hypothetical scenarios where a parent posts a status to their own Facebook profile and three hypothetical scenarios where a parent posts to a Facebook group. The content of the scenarios was based on topics interview participants surfaced about special needs and judgment on social media sites. Thus, the first set of three scenarios measured posts that contained humor, judgment, or violence and the second set of three scenarios explored achievement, alternative treatments, and social comparisons (where parents compared their children with other parents' children). We focused the scenarios on Facebook because it is the most popular social networking site in the U.S. and interview participants reported that they used Facebook for special needs interactions.

We recruited participants using a professional recruiting service, Cint, which paid participants approximately $4 to complete the survey. Participants were sampled from across the United States, coming from 39 different states (see Figure 1a). Only parents of children with special needs were eligible to participate. 239 people completed the survey in July 2013; after filtering for invalid surveys (based on the free-text description parents provided about the nature of their child's special need, and on IP address information to ensure that participants really were within the U.S. as claimed), 205 valid responses remained for analysis. Although the survey was open to all parents, mothers completed the survey at a higher rate than fathers – 77% of respondents were female, and 23% male. Respondents' ages ranged from 22 – 65 years, with a median of 39 and a mean of 40 years old. Annual household incomes varied from less than $25,000 (20 participants) to over $150,000 (7 participants). Incomes in the $50,000 - $74,999 range were most common (62 participants) (see Figure 1b).

Parents used a free-response box to describe the "nature of your child's special needs." Many of the children described had more than one challenge. We coded the text responses into five broad categories of disabilities (more than one category could apply), and only applied a label if it was clear from the parent's description of their child's diagnosis. The most common category of special needs represented in our sample were cognitive and learning impairments (including attention deficit hyperactivity disorder (ADHD), Down syndrome, dyslexia, and speech delays), which affected 54%. Autism spectrum disorders (including Asperger's syndrome and pervasive developmental disorder not otherwise specified) were also prevalent, affecting 41%. Physical and motor impairments (including cerebral palsy, wheelchair use, and chronic physical ailments like arthritis, severe asthma, epilepsy, and type I di-
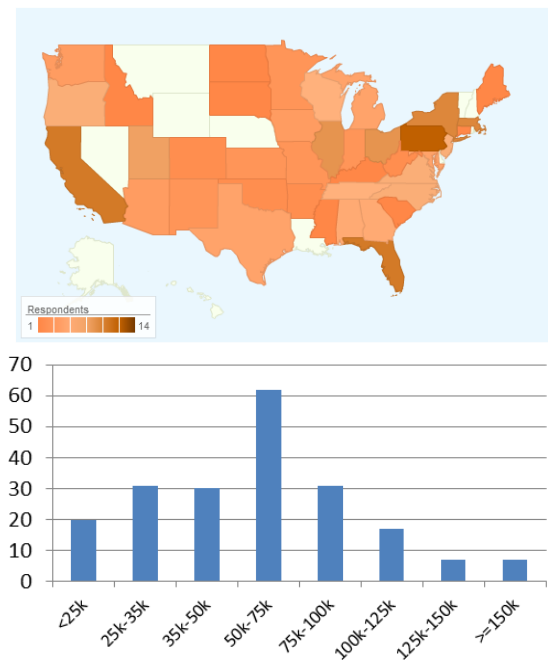


*Figure 1a, 1b. Survey participant location, income.*

abetes) affected 15%. Emotional disabilities (including depression, bipolar disorder, post-traumatic stress disorder, and oppositional defiant disorder) affected 14%. Sensory disabilities (including vision and hearing impairment) affected 6%. These different types of disabilities elicit a broad range of needs for the special needs family. However, some similarities exist: their parents are likely to have greater information and social support needs than parents of typical children, and the entire family may experience social stigma—either overt or discreet—within their communities. These shared experiences are the focus of this work.

In the Results section that follows, we first show what social sites parents use and what purposes those sites serve. We also describe experiences of judgment on these sites. We then show what kinds of posts are perceived as socially appropriate, first in the context of personal profiles on Facebook, then in Facebook groups. Finally, we describe design opportunities for supporting special needs families.

## Results

### RQ1: Social Media Use

Parents relied heavily on online support groups related to their children's special needs. Survey respondents indicated that they were most active on Facebook (89% were current active Facebook users) but a smaller minority of them used a variety of other groups and listservs (see Table 2). Older interview participants described a transition from listservs and discussion boards to Facebook use in recent

years. They usually did not leave existing groups, such as a Yahoo! group, but they found themselves joining Facebook and Facebook groups and spending more time there.

Among the 89% of survey respondents who used Facebook regularly related to special needs, 40% reported frequently posting status updates about their child with special needs (and 25% percent had never done so). 34% frequently posted photos of their child with special needs on Facebook (and only 17% had never done so). About half that number (18%) had posted video of their child on Facebook. A substantial subset of respondents reported frequently posting links or comments about each of the following: news articles (29%), medical studies (30%), or activism (27%) related to their child's special needs. The remainder of respondents were about equally divided between never having posted about these topics (26-35%) or posting infrequently about them.

Respondents reported differences in motivations for using Facebook. The most common uses of Facebook were seeking social support (44%), sharing positive aspects of experiences as a parent (41% vs. 33% sharing information about stressful/frustrating aspects of parenting, a significant difference according to a binomial test, $p = .01$), and sharing information about a child's successes (38% vs. 27% sharing information about a child's challenges, a significant difference according to a binomial test, $p = .002$). Other social media sites that were used included Yahoo! Groups and Twitter. Sites like CaringBridge and CarePages that are typically used for updating family and friends

| Platform | % | Most common uses |
|---|---|---|
| Facebook | 89% | seeking social support; sharing positive aspects; sharing stressful aspects |
| Facebook private groups | 51% | seek social support; share info about challenges; share stressful aspects; share positive aspects |
| Yahoo! Answers | 42% | seek health & parenting info |
| Facebook public groups | 35% | seek social support; seek parenting info |
| Yahoo! Groups | 28% | seek social support; seek health, education, & parenting info |
| Twitter | 27% | share positive aspects |
| Google Groups | 18% | seek information; seek social support |
| CaringBridge | 17% | seek social support; seek info about education and health |
| CarePages | 16% | seek info about child's health & education; seek social support |
| Quora | 16% | seek info about health, education, & parenting |
| BabyCenter | 14% | seek info about health, parenting |

Table 2: Percentage of survey participants who use each social platform and what they use it for.

about a serious health challenge (e.g. cancer) were not used very heavily among our participants.

Interview participants told us that the online sites they visited served two distinct purposes. We label these two types of participation as *geographically-based groups* for local services and *case-based groups* for shared conditions. Geographically-based groups are groups limited to a specific geographic area such as a city or a school district:

> The Facebook group, we just created a group for anybody that lives in [small town outside of a major metropolitan city] that has a child with special need. It is kind of like a help area as to, well I found this camp or I found this person helpful at the school. –P14

These groups were used primarily in tandem with face-to-face support groups and meet-ups to share advice and insights into local laws and educational services. In contrast, case-based groups were groups that provided information and support for case-specific healthcare needs related to a child's condition. Interviewee P14 continues:

> The Yahoo! group, I feel like is much more tailored because it's just cerebral palsy. So you can get a lot of information as to whose therapist is doing what or about special surgeries.-P14

Both kinds of groups offered an additional benefit beyond online interactions. While the majority of survey participants (57%) had never interacted face-to-face with parents they met online, a sizable minority had, with 29% engaging in face-to-face meetings monthly or more often with individuals they had first interacted with online.

## RQ2: Perceptions of Judgment

A substantial challenge faced by children with special needs and their parents is the stigma of being different—whether cognitively, emotionally, or physically—and how families handle such differences (Goffman 1963; Hinshaw 2005). Survey respondents reported feeling more judged in their offline personal interactions and offline professional interactions than they did in their online interactions of any kind (see Table 3).

Most respondents did not find online social tools to be very judgmental (score of 4 "frequently" or 5 "constantly" on a five-point scale) – only 11% felt that way about their own Facebook page, 10% about Facebook groups, 7% about email listservs, and 9% about other support groups like Yahoo! or Google Groups. Rather than particular online forums being a source of negative judgment, instead "offline" relationships were the source of such issues, with 33% finding family members very judgmental and 28% finding friends and colleagues very judgmental. 33% also reported that strangers in public settings were very judgmental. Professionals who worked with their children, on the other hand, were in the middle – less judgmental than friends and family, but more so than those in online venues

| Personal Offline Interactions | Family members | 33% |
|---|---|---|
| | Strangers in public settings | 33% |
| | Friends and colleagues | 28% |
| Professional Offline Interactions | Teachers and coaches | 25% |
| | Doctors and nurses | 20% |
| | Social service workers | 13% |
| Online Interactions | Facebook | 11% |
| | Facebook groups | 10% |
| | Yahoo! or Google Groups | 9% |
| | Email listservs | 7% |

*Table 3: Percent of survey respondents who found each group to be very judgmental (where "very judgmental" is a score of 4 "frequently" or 5 "constantly" on a five-point scale).*

– only 13% reported social service workers to be very judgmental, 20% found doctors & nurses to be so, and 25% found teachers and coaches to be judgmental. These are significant differences in judgment between these sources according to a Friedman test $\chi^2(9, N = 76) = 76.1, p < .001$.

To gain insight into these differences, we combined the individual ratings into three groups: offline personal interactions, offline professional interactions, and online interactions (see Table 3) by averaging the component ratings on a per-user basis. There are significant differences in judgment across these kinds of interactions according to a Friedman test, $\chi^2(2, N = 163) = 77.5$ $p < .001$. Follow-up pairwise Wilcoxon tests confirm significant differences among all three groups, with online interactions being viewed as less frequent sources of judgment than interactions offline with professionals ($z = 4.8, p < .001$), which in turn are less frequent sources of judgment than offline personal relationships ($z = -6.0, p < .001$).

*Managing Online Judgment:* Parents reported a variety of approaches for mediating online interactions to reduce judgmental experiences: 25% of parents reported having changed their Facebook use in response to comments they received on a post about their child with special needs. Of these, the most common response was blocking or unfriending specific users (21%), reducing the frequency of posting about their child with special needs (15%), reducing time spent viewing others' posts (9%), and suspending or deleting their Facebook account (4%).

Interviewees told us that online judgment came in a variety of forms, including negative views of parenting philosophies, non-conventional medical choices, and sensitive politically-charged subjects such as abortion among mothers who are diagnosed prenatally. One interviewee told us:

> I got on[line] and I said, "I'm so excited. My daughter is gonna play in a soccer game and she's 37 days post-surgery." And we had cleared it through three doctors that she would be okay playing soccer. That's when one mom came on there and another mom and another

mom saying, "She can't play. That's too dangerous to her neck" and "How could you let her do that?" –P12

Some parents described how others in online groups would act in a rather judgmental manner even though their intentions were good, a behavior one participant labeled "benign judgment." Whether benign or maligned, a challenge parents face is the lack of shared norms, or not knowing what kinds of posts are likely to be subjected to judgment. The following section addresses this question.

## RQ3a: Socially Appropriate Posts on Facebook Profiles

The first set of scenarios we developed concerned status updates and comments that a parent of a child with special needs might post on their own Facebook wall. The survey results showed that scenarios where posts used humor to deflect a stressful special needs situation were viewed as appropriate (median=5, scale of 1-7 from Very Inappropriate to Very Appropriate, Figures a), but posts that contained judgmental information about an individual or described violence by a child were considered less appropriate (median=3, Figures 2b-2c).

Echoing survey participant responses, interview participants reported using humor as an outlet for coping with day to day episodes and challenges. The kinds of humor parents reported were usually light-hearted updates, reporting an episode or change in condition, where readers could both laugh at the story and support the poster.
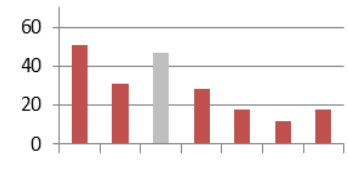


2a. Humor
A parent posts a light-hearted joke about a special food request in a restaurant for their child with special needs.
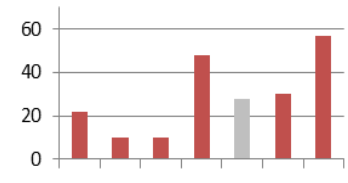
2b. Judgment
A parent posts about being upset with an aunt who suggested better ways of disciplining their daughter.

2c. Violence
A parent posts about a difficult episode by their child who is capable of violent outbursts and physical harm.
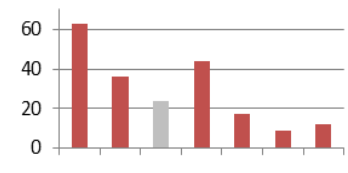
*Figure 2a-2c. Appropriateness of scenarios where parents post a status on their own Facebook wall describing an episode involving their child with special needs. The x-axis ranges from "Very Inappropriate" (1) at left to "Very Appropriate" (7) at right (median in gray), and the y-axis indicates the number of survey respondents.*

Usually, if I think [my Facebook post is] gonna be received as funny… like my primary motive for coming here is reading and seeing funny things, and giving funny things back to other people… Knowing that I have a sounding board [online] makes me feel braver about going out in the community, because if it goes spectacularly wrong, I can come back and tell about it in a way that makes people laugh, in a way that makes me laugh, in a way that gets sympathy. –P4

Being able to rely on online support as a sounding board for offline events helped parents to cope better, and to have an outlet to share experiences.

### RQ3b: Socially Appropriate Posts in Facebook Groups

The second set of scenarios concerned posting behavior in case-based Facebook groups devoted to parenting children with specific special needs. Results showed that posting about a child's achievement and posting about alternative treatments were perceived as more appropriate (median=5, Figures 3a-b) than posting about a lower functioning child facing harder challenges than other children were ("one-upping", median=4, Figure 3c).

Interview participants similarly reported being concerned about posting too negatively, telling us that they "try to share more positive things" (P11) and "I don't share many negatives. I might share a funny situation, but I don't share negative things" (P13). P8 explained that she only shared positive content because:

People don't like negativity. They just don't. You know? Yeah, I think we've all read those cries for help or whatever they are. That's not how I wanna be known. -P18

Participants also expressed an aversion to what one participant called "pain Olympics" where parents try to "one-up" one another with how difficult their child's own issues are:

It makes me really angry when something big is going on and another parent says, "Oh, mine did that too. They'll be over it in a day." It's like, you don't seem to realize this is not what you dealt with. One of my friends talks about this term she calls "the pain Olympics" where... "Oh, I'm going through this hard time," and another person says, "Oh, I went through something a lot harder." I don't wanna take the chance of putting out there something that I'm really struggling with, only to have somebody minimize it. –P4

Parents were similarly sensitive to how their own posts might be perceived by others. Parents whose children were doing well worried that their posts might come across as bragging:

I struggle with knowing what to post because, knock on wood, my daughter is doing very well and so many of the comments that come up are people whose children aren't doing so well. So, I have to find that bal-

ance of helping people find hope but not feeling like my kid is doing so much better than theirs. So I don't post when I should because I think there could be some hope but I feel badly about posting those things for other people reading and saying, "Well, why is my kid not doing that well?" –P12

Participants typically had Facebook friends who had children with similar conditions as their own, and they were sensitive to the challenges their special needs networks were facing.

### RQ4: Design Opportunities

Interview and survey participants indicated that current social media sites failed to support their needs in four ways. *Across-The-Lifespan Groups*: First, participants wanted a site that could connect younger parents with more experienced parents which we refer to as *across-the-lifespan* groups. Younger parents wanted to connect with older parents and their grown children to see where their own children might end up:

I guess I'd like to see a place where I could... I wanna see where people with Down syndrome end, like people with disabilities, their life span. You know, where they end up, a place where... Eventually I'd like to see a place for my son to have a community among him because I think that's gonna be important for him. -P1

This desire was echoed by many participants. Interestingly,



3a. Achievement
A parent whose child is higher functioning than most other children in the group frequently posts about their child's latest achievements.

3b. Alternative Treatments
A parent who uses non-traditional approaches that are not typically recommended by doctors frequently comments on group posts suggesting these alternative treatments.

3c. "One-upping"
A parent whose child is lower functioning than most other children in the group frequently posts about how their child faces harder challenges than others.
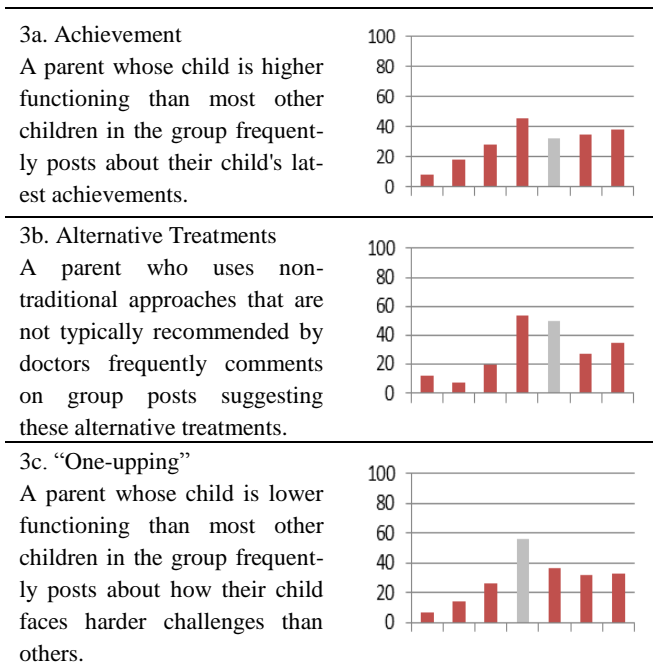
*Figure 3a-c. Appropriateness of types of posts parents might post to Facebook case-based groups about their child with special needs. The x-axis ranges from "Very Inappropriate" (1) at left to "Very Appropriate" (7) at right (median in gray), and the y-axis indicates the number of survey respondents.*

the older parents among our participants suggested that they were indeed willing to fill that need. Older parents whose children were now teenagers or young adults told us that they still returned occasionally to the sites that they used to visit regularly specifically to help younger parents. P5, whose son was 18 and had been "through the system" for a long time told us:

> But a lot of us, our children are further out. So, our discussions are on our special ed programs and school so we share a lot of information especially for those... We're a little further ahead of the game, so a lot of the parents just coming in, getting their kids back enrolled in school. We can help them in situations. -P5

P5 emphasized that they were still active in their son's community, even though their son was now an adult. Like many of the interviewees, their advocacy became a cause beyond their own child's particular special needs and one focused on the needs of the entire community.

*Connecting Special Needs Children*: A second area where current social media sites failed was in connecting special needs children together. Many parents expressed a desire for their children with special needs to be able to connect to other children with a similar age and diagnosis profile. One survey respondent noted the benefits that such a site might offer:

> Sites for the child to participate in to see that their [sic] are other children like them, and that they are not alone. Where there are things to do, that slowly help them and encourage them, and raise their self-esteem.

Other survey participants made similar requests, such as for a "page in which my son can talk to other kids about the social difficulties he has" or "something that the older kids can go to [to] help them with their feelings." Though our results show that online spaces are generally perceived as less judgmental than offline ones, judgment still exists and one parent said she would "like my son to be able to chat with online games without having to worry about being made fun of or ridiculed."

*Connecting Siblings*: A third area where social media sites fell short was in connecting siblings of special needs children together. Parents wanted online sites to help support younger family members, specifically, siblings of special needs children. Some requested sites focused only on connecting siblings while others suggested sites that connected siblings and parents together.

*Centralized Information*: Finally, parents also expressed a desire for a single online platform that served as a hub for information:

> There are so many groups and so many products on the market geared to special needs. I would love for there to be one forum that compiles reviews from end users about the best. For example, Rett Syndrome has

one www.rettgirl.org. While this is fantastic, there is not the same for things for my other children's needs.

Other parents requested a network that "encompasses all issues" that would allow them to go to a single source then choose the options they need, such as social interactions, health information, and access to a specialist.

## DISCUSSION

To summarize, our interview and survey results showed that special needs parents use Facebook (and to a lesser extent Yahoo! Groups and Twitter) to find information and social support. Interactions on these sites tend to be less judgmental than offline interactions. Posts with humor, achievements, and alternative treatments are perceived to be more socially appropriate than posts with judgment, violence, or social comparisons. Though social media sites succeed in supporting parents through geographic and case-based groups, they fail to connect newly diagnosed families with experienced families, or to connect special needs children and their siblings to other children with similar experiences. These results suggest that online spaces are functioning relatively well as a safe space for parents of children with special needs to discuss parenting issues in a supportive setting, but limitations in site design exist.

### Design Implications
#### Social Media across the Special Needs Lifespan
Parents reported that social media was useful for connecting them with parents of children with similar cases and those residing in proximate geographic areas (e.g. same school district). However, social media generally failed at helping them find long-term perspectives. What emerged from our interview participants was a desire for a sense of long-term outcomes: what would their child's future look like 5 years, 10 years, and 50 years down the road? Parents wanted to know how they could better prepare their children now, and struggled with anxiety about what parenting an adult child with special needs (especially for low functioning individuals) would be like. These results suggest that there are design opportunities for connecting parents across a child's special needs lifespan. We envision special need-specific social networking sites that contain profile features including diagnosis information, child age/gender, location, and interests (treatment, advocacy, information, support). However, privacy concerns exist, especially in relation to health insurance pricing structures or job discrimination. Parents are already sharing health information online, and the benefits may ultimately outweigh the risks, but the risk/benefit tradeoffs of a social network providing aggregated persistent information with more structured (and therefore searchable) metadata need to be better understood.

**Social Media for Special Needs Families**
Gibson and Hanson (2013) found that Facebook was important for mothers to connect with other mothers but also to maintain their own identities and relationships. Special needs families may similarly need sites that connect them to other special needs families, but that allow family members to maintain their own individual identities. Parents expressed interest in involving other family members in the use of social media as their children grew up. There was a desire to enable siblings of children with special needs to meet other people with very similar situations (e.g., diagnosis and age of the child with special needs, and age/gender/interests of the sibling); such situational matching may be unlikely in a given geographic community, and rich meta-data on a specially designed social network could make connecting with the right people easier. However, current legal policies regarding the use of social networks by youths under the age of 13 (COPPA) present challenges to realizing such technologies in the near-term, and warrant re-examination in light of the benefit they might provide for specialized situations such as this.

**Implications for Theory**
Our results contradict Mickelson's results from 1997 (Mickelson 1997); our participants reported that online interactions were *less* judgmental than offline interactions. One hypothesis to explain these differences is that people may be able to better manage online social interactions than they can offline ones. Privacy controls on a site like Facebook allow for active and discreet management, such as unfollowing certain friends' posts or hiding them from your own posts without having to unfriend them. Other features like asynchronous communication, friend groups on Facebook, lists on Twitter, or circles on Google+ may allow more fine-tuned cultivation of content sharing and audience. Computer-mediated communication theory suggests that the lack of verbal or visual cues online can inhibit communication (Kiesler, Siegel, and McGuire 1984). Though this is often portrayed as a negative or constraining feature of online interactions (e.g. miscommunication; flaming on anonymous discussion boards), for families who may experience social stigma as a result of their special needs, the lack of visual or auditory cues might offer a more safe and comfortable forum for interacting.

We see other differences emerge in how parents of children with special needs use social media. Participants relied on humor as a coping strategy and perceived it to be socially appropriate to share. Humor has been found to be useful in other boards like cancer support boards (Skeels et al. 2010). In these contexts, people are often looking for a way to share deeply personal and emotional content in a manner that is not overly negative. Thus, humor becomes a valuable social outlet. Though bragging on social media is generally not well-received (Hutto, Yardi, and Gilbert 2013), parents of children with special needs perceived posting about achievements to be appropriate. This may reflect a broader trend towards more positive self-presentation, suggesting that social media sites may be less effective for eliciting social support related to negative topics. Parents who go through greater challenges than parents of typically developing children may be more likely to support each other's accomplishments, having shared an uncommon set of experiences, challenges, and needs. Our findings speak to a unique set of theoretical frameworks and design ideas for supporting achievement, humor, and connectedness online for special needs families.

**Limitations**
The interview study likely oversampled parents who were more engaged in their children's needs. Although the survey population is quite diverse, it has some limitations. Fathers are represented in smaller numbers than mothers in both studies. Not all special needs are represented, and some may be over-represented (e.g., ADHD and autism spectrum disorders). Participants who chose to fill out the survey may be more comfortable sharing information about their special needs child online or offline. Finally, this work documents only a parent-centered perspective; future work could focus on social media use and attitudes among health care, social service, or education providers.

## CONCLUSION

We show that social media, particularly Facebook, play an important role in providing case-based and geographically-based information to parents of children with special needs. We find that online interactions are perceived as less judgmental than offline ones. This work reveals new insights into what kinds of content parents find appropriate to post about a child with special needs. This can help parents be better informed about how posts might be received by others, and illustrates difference in posting norms for this community (e.g., the appreciation of posts about a child's achievements). In some cases, there may be a tension between what a parent wants to post and what their audience wants to see—helping parents to negotiate this tradeoff can help them to elicit the kinds of support they want. Computational approaches could help parents find service recommendations and feedback from other like-minded parents, but privacy challenges exist. Similarly, new kinds of across-the-lifespan social networks could help young parents envision their child's future and help older parents give back to a shared cause.

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