**Parents of Children with Special Needs**

**Survey**

### 1) Are you the parent of a child (or children) with special needs?

( ) Yes

( ) No

### 2) How many children do you have?

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### 3) How many of your children have special needs?

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### 4) What are the ages of your child(ren) with special needs?

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### 5) Describe the nature of your child(ren)'s special needs.

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### 6) Among parents you have first met online (e.g. on Facebook or in email groups), how often have you met them offline in face to face meetups?

( ) daily

( ) weekly

( ) monthly

( ) yearly

### 7) How often do you meet up with other parents of children with special needs  in social contexts (e.g. dinner, social support groups, playdates, etc)?

( ) daily

( ) weekly

( ) monthly

( ) yearly

### 8) How often do you meet up with other parents of children with special needs for advocacy, activism, or other special needs-focused discussions?

( ) daily

( ) weekly

( ) monthly

( ) yearly

#### 9) Indicate whether you use the following types of websites for the purposes described. If there are specific sites or types of sites that you use for these purposes that were not in our list, please use the comments field to tell us about them.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Seek social support | Seek information related to the health of my child with special needs | Seek information related to the education of my child with special needs | Seek information related to parenting my child with special needs | Share information about my the successes achieved by my child with special needs | Share information about the challenges encountered by my child with special needs | Share positive aspects about your experiences as a parent of a child with special needs | Share frustrating/stressful aspects about your experiences as a parent of a child with special needs |
| Yahoo! Answers |  |  |  |  |  |  |  |  |
| Quora |  |  |  |  |  |  |  |  |
| Meetup.com |  |  |  |  |  |  |  |  |
| Google Groups |  |  |  |  |  |  |  |  |
| Yahoo! Groups |  |  |  |  |  |  |  |  |
| CaringBridge |  |  |  |  |  |  |  |  |
| CarePages |  |  |  |  |  |  |  |  |
| Facebook (private groups) |  |  |  |  |  |  |  |  |
| Facebook |  |  |  |  |  |  |  |  |
| Facebook (public groups) |  |  |  |  |  |  |  |  |
| Babycenter |  |  |  |  |  |  |  |  |
| YBM |  |  |  |  |  |  |  |  |
| Other general-purpose Q&A/discussion forums |  |  |  |  |  |  |  |  |
| Other Q&A/ parenting forums |  |  |  |  |  |  |  |  |
| Other Q&A forums specific to special needs |  |  |  |  |  |  |  |  |
| Twitter |  |  |  |  |  |  |  |  |
| Google+ |  |  |  |  |  |  |  |  |
| Other social networking sites |  |  |  |  |  |  |  |  |

Comments: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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### 10) As a parent of a child with special needs, what (if any) types of online resources, networks, or services would you like to see created?

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### 11) Are you Facebook friends with any social workers who currently help or have helped in the past your child with special needs?

( ) Yes

( ) No

a) What made you decide to friend them or not friend them?

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### 12) Are you Facebook friends with any Registered Nurses who currently take care of or have taken care of in the past your child with special needs?

( ) Yes

( ) No

a) What made you decide to friend them or not friend them?

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13) To what extent have you felt judged about decisions you make related to special needs in each of the following contexts?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Never** | **Rarely** | **Sometimes** | **Frequently** |
| On your personal Facebook page |  |  |  |  |
| In a Facebook group |  |  |  |  |
| On an email listserv |  |  |  |  |
| On a different support group (e.g. Google Groups, Yahoo! Groups) |  |  |  |  |
| By family members either online or offline |  |  |  |  |
| By friends, colleagues or acquaintances either online or offline |  |  |  |  |
| In public settings by strangers |  |  |  |  |
| By social service workers |  |  |  |  |
| By doctors, nurses, or hospital administrators |  |  |  |  |
| By teachers, coaches, or other community leaders |  |  |  |  |
| Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |  |  |  |  |

14) How do you feel when you see parents of children without special needs posting about their child's accomplishments on Facebook?

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15) Have you ever increased or decreased the amount of time you spend on Facebook based on what other parents post?

( ) Yes

( ) No

1. If yes, why?

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16) Below is a list of actions that parents could take related to their child’s special needs. For each action, rate how appropriate you think each is on a scale from Very Appropriate to Very Inappropriate.

### Mr. and Mrs. Jennings have a child with special needs. They go to a restaurant and their child refuses to eat her burger because it is cut in half and therefore “broken.” They decide to post a status on Facebook making a lighthearted joke about having to ask the waiter for an unbroken burger.

( ) very appropriate

( ) somewhat appropriate

( ) somewhat inappropriate

( ) very inappropriate

### Alicia’s parents are having a birthday party for their 6-year-old child, Alicia, who has special needs. Alicia gets upset during the party and throws her birthday cake on the floor. Alicia’s Aunt suggests ways that Alicia’s parents could discipline her better. Alicia’s parents post on Facebook about how upset they are at Alicia’s Aunt for saying this.

( ) very appropriate

( ) somewhat appropriate

( ) somewhat inappropriate

( ) very inappropriate

### Mr. and Mrs. Harrison are trying to get personalized help for their child with special needs in the elementary school. They believe that under the ADA and state rules, their child should be allowed access to a particular service. After many discussions, they are blocked from accessing the service by the school district. They post a status about their frustrations on Facebook where many school administrators and teachers can see the status.

( ) very appropriate

( ) somewhat appropriate

( ) somewhat inappropriate

( ) very inappropriate

### The Smiths have four children. Their second oldest child has special needs. At times, he    acts violently and damages physical objects in their home. He is also capable of physically hurting his siblings. After a difficult episode, Mrs. Smith posts an account of a violent outburst he had on her Facebook page.

( ) very appropriate

( ) somewhat appropriate

( ) somewhat inappropriate

( ) very inappropriate

### Mr. and Mrs. Stevens live in a small college town. They like to go to the popular local coop to buy groceries and eat dinner in the cafe. Many of their friends also go to this coop. They go to the cafe for dinner one day and the waiter is particularly impatient with their child. They decide to post a status on Facebook complaining about the coop and its staff.

( ) very appropriate

( ) somewhat appropriate

( ) somewhat inappropriate

( ) very inappropriate

17) Imagine you are a member of a Facebook support group for parents of children who have special needs similar to those of your own child. Below is a list of actions that members of the Facebook group might take. For each action, rate how appropriate you think each is on a scale from Very Appropriate to Very Inappropriate.

### A parent whose child is higher functioning than most other children in the group frequently posts about their child’s latest achievements.

( ) very appropriate

( ) somewhat appropriate

( ) somewhat inappropriate

( ) very inappropriate

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.

( ) very appropriate

( ) somewhat appropriate

( ) somewhat inappropriate

( ) very inappropriate

A parent who uses non-traditional approaches that are not typically recommended by doctors frequently comments on group posts with suggestions using these alternative treatments.

( ) very appropriate

( ) somewhat appropriate

( ) somewhat inappropriate

( ) very inappropriate

### A parent who is an activist and advocate for special needs rights frequently posts news stories and updates about state and federal rules.

( ) very appropriate

( ) somewhat appropriate

( ) somewhat inappropriate

( ) very inappropriate

### A parent who is an activist and advocate for special needs rights frequently posts political updates about special needs rights.

( ) very appropriate

( ) somewhat appropriate

( ) somewhat inappropriate

( ) very inappropriate

### 18) Do you have a Facebook account?

( ) Yes, I have a Facebook account

( ) No, I have never had a Facebook account

( ) No, I used to have a Facebook account, but have disabled/deleted it

#### 19) Indicate how often you do each of the following on Facebook.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | A few times per day | Once per day | A few times per week | Once per week | A few times per month | Once a month or more rarely | Never |
| View friends' posts in your Newsfeed |  |  |  |  |  |  |  |
| Like a friend's post |  |  |  |  |  |  |  |
| Comment on a friend's post |  |  |  |  |  |  |  |
| Post a status update |  |  |  |  |  |  |  |
| Post a photo |  |  |  |  |  |  |  |
| Post a video |  |  |  |  |  |  |  |
| Post a status update about your child with special needs |  |  |  |  |  |  |  |
| Post a photo of your child with special needs |  |  |  |  |  |  |  |
| Post a video of your child with special needs |  |  |  |  |  |  |  |
| Post relevant news articles |  |  |  |  |  |  |  |
| Advertise online |  |  |  |  |  |  |  |
| Post relevant new studies |  |  |  |  |  |  |  |

### 20) Our research team might contact some survey participants for a follow-up interview. May we include you in our potential interview pool?

( ) Yes, enter my name in the pool of potential interviewees (requires providing an email address)

( ) No, I would prefer not to be considered for an interview

### 21) What is your gender?

( ) Male

( ) Female

### 22) What is your age?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

### 23) What is the highest level of education you have completed?

( ) 12th grade or less

( ) Graduated high school or equivalent

( ) Some college, no degree

( ) Associate degree

( ) Bachelor's degree

( ) Post-graduate degree

## Thank You!

### Thank you for taking our survey. Your response is very important to us.