

Chinese Immigrant Parents' Perspectives about Using the Internet to Access Health
and Education Related Information for Their Children with Special Needs

BY

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ABSTRACT

As parents rely more on the Internet for information, it provides a potentially more efficient and affordable format for directly reaching a large number of families with evidence-based health and education related information for their children with disabilities. Little is known, however, about Internet information seeking patterns for parents from culturally and linguistically diverse backgrounds. This pilot study explored Chinese-American immigrant parents' perspectives about using the Internet to access health and education related information for their children with disabilities. A survey was developed and conducted through a large community service center in the Western United States. Fifty two parents completed the survey and results suggested that challenges and barriers within the context (i.e., channels, culture) of the Internet limited parents from accessing meaningful and high quality information. Implications for research and practice are provided.

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TABLE OF CONTENTS

| | |
|--|-----|
| Abstract..... | iii |
| Acknowledgements..... | 1 |
| Table of Contents..... | 2 |
| List of Tables..... | 3 |
| CHAPTER I INTRODUCTION..... | 4 |
| Research Questions..... | 6 |
| CHAPTER II LITERATURE REVIEW..... | 7 |
| CHAPTER III METHODS..... | 18 |
| Survey | 18 |
| Recruitment..... | 18 |
| Participants..... | 19 |
| Data Analysis..... | 20 |
| Theoretical Framework..... | 21 |
| CHAPTER IV RESULTS..... | 25 |
| CHAPTER V DISCUSSION..... | 30 |
| CHAPTER VI IMPLICATIONS..... | 36 |
| References..... | 38 |
| Appendix A Literature Review Matrix..... | 44 |
| Appendix B Survey..... | 50 |
| Appendix C Poster for Survey Recruitment | 57 |
| Appendix D Parent Consent Form..... | 58 |

LIST OF TABLES

Table 1. Respondents' demographic information

Table 2. Disability diagnosis of respondents' children

Table 3. Respondents' frequency of Internet use for their children with disabilities

Table 4. Respondents' preference on information channels via the Internet

Table 5. Participants' trust level on information obtained from the channels

Table 6. Parents' online health and education related information-seeking behaviors

Table 7. Parents' trust level about health and education related information sources

Table 8. Participants' social support from friends with children with similar disabilities

Table 9. Parents' participation in offline social support gathering

Table 10. Multiple-regression model on participants' background and internet usage

CHAPTER I INTRODUCTION

Information can be defined as stimuli from a person's environment that contributes to his or her knowledge or beliefs (Brashers, Goldsmith, & Hsieh, 2002). Information that is accurate and reliable enables parents and other family members to make informed decisions and take an active role in their children's learning and development (Bemrose, 2003; DesGeorges, 2003). Parents' active involvement in their children's education can influence children's educational success (Cheatham & Santos, 2011). Providing family-centered services to support parents of young children with disabilities is a means to meet IDEA (Individuals with Disabilities Education Improvement Act, 2004) and accepted as recommended practice among early intervention/early childhood special education professionals (Sandall, Hemmeter, Smith, & McLean, 2005).

However, researchers indicate that parents of children with disabilities experience difficulties accessing timely and crucial information regarding their children (Blackburn & Read, 2005; Carter, 2009). Parents whose children are diagnosed with disabilities typically have little knowledge about the illness or available treatment (Porter & Edirippulige, 2007). While parents are emotionally vulnerable, they are required to gather and weigh information regarding issues such as health and special education services. Little evidence-based parenting information, despite its demonstrated effectiveness, is actually available to parents. On one hand, a traditional home visit approach has many obstacles, the most salient of which is its cost (Metzler, Sanders, Rusby, & Crowley, 2012). In addition, researchers indicate that evidence-based parenting interventions are not typically available on a widespread basis, especially outside of major metropolitan areas (Connell, Sanders, & Markie-Dadds, 1997). Traditional home visit services are not offered due to perceived

lack of staff time and resources (Baggett et al., 2010).

On the other hand, researchers indicate low parent participation rates in parenting interventions. For example, in a survey of parents of children with emotional and behavioral problems South Carolina, only 14% of parents reported involvement in a parenting program (Prinz & Sanders, 2007). Primary reasons identified for families' lack of participation included logistical difficulties such as scheduling conflicts, transportation, and child care; fatigue; and insufficient motivation to participate (Dumka et al., 1997; Spoth & Redmond, 2000). In short, research suggests that the provision of crucial information to parents of children with disabilities, at a time when they need it and in a form that they can use, can be problematic (Blackburn & Read, 2005).

While it is important to develop and maintain a wide range of information delivery systems that are sensitive to families from culturally and linguistically diverse backgrounds (Blackburn & Read, 2005), research in the past decade reveals that the Internet is one of the most prominent ways to increase the reach and impact of evidence-based interventions and enable parents to proactively access health and education related information regarding their children with disabilities. For example, Ferdig and his research team developed an online training system to educate fathers of children with autism and have been exploring the impact of solely using the online system compared to an in-home service model (Ferdig, Amberg, Elder, Donaldson, Valcante, & Bendixen, 2009). In addition, according to a U.S. Census report on internet and computer usage, "taking a course online," "searching about healthcare information," "searching for government services," and "searching for job" are four online activities that people aged from 15 to 65 years old most often mentioned. Among these four activities, "searching for health care information" is the one most

(35.5%) participants mentioned (U.S. Census, 2010).

Despite the fact that people are relying more on the Internet for information, little is known, about parents' perceptions about using the Internet to access health and education related information for their child with disabilities, especially for parents from culturally and linguistically diverse backgrounds. Young adults becoming parents today have probably been using the Internet for a large percentage of their lives, and it is likely that the demand for online information will increase over time (Porter & Edirippulige, 2007). Parent perspectives could inform special education service providers and website developers about this changing dynamic and allow them to accordingly adapt their information provision to ensure online information is meaningful and accessible.

This pilot study explores Chinese-American immigrant parents' perceptions about using the Internet to access health and education related information for their child with disabilities. Specifically, the following research questions will be addressed: (1) Is there a correlation between Chinese-American parents' background (age, education, income, and use of traditional media) and their frequency of using the Internet to access health and education related information for their children with disabilities? (2) What are Chinese-American parents' preferred ways to access health and education related information for their children with disabilities? (3) What kind of information sources do Chinese-American parents find most reliable and trustworthy? (4) What challenges do Chinese-American parents have when using the Internet to access health and education related information for their children with disabilities?

CHAPTER II LITERATURE REVIEW

Despite that fact that accurate and reliable information enables parents to make informed decisions for their children with disabilities, research indicates that parents frequently have difficulties accessing it in a timely manner (Blackburn & Read, 2005; Carter, 2009; Mansell & Morris, 2004). Therefore, this study aims to explore Chinese-American immigrants' perceptions about using the Internet to access health and education related information for their children with disabilities. To summarize the current research progress and trends related to the topic of parents and the Internet, this literature begins with a discussion of the following topics: (1) parents' information-seeking patterns; (2) knowledge about Internet usage for parents from cultural and linguistic backgrounds; (3) the impact of culture and language on information seeking for Chinese parents with children with disabilities.

Based on the research questions, this review was conducted using the following databases: PsycINFO, Eric, Health Wellness Resource Center, and Communication Abstracts, to identify peer-reviewed articles published from January of 2000 until March of 2013. Search terms consisted of "parents," "Internet," "information," "disabilities," "immigrant," "culturally and linguistically diverse," "children with disabilities." Most articles and books selected were primarily written in English. In addition, an ancestral search was conducted.

Parents' Information Seeking Patterns

The following section is a review of research investigating parents' perceptions and behaviors on finding information for their children with disabilities through the use of survey, interview, and focus group methods. Detailed information about the findings can be found at Appendix A, a Literature Review Matrix. Summary of the key findings across the literature are presented below.

First, the Internet is considered a key source for parents to access information for their children with disabilities, especially health and education related topics. For example, in a study about parents of deaf children seeking disabilities related information on the Internet, Porter and Edirippulige (2007) found that mothers search for health information on the Internet from the child's early years until the child left school and beyond. These mothers' use of the Internet for information gathering was unrelated to the age of the parent, the age of their child, geographic location, or their employment status. In another study, a survey of 788 parents with children with disabilities, results indicated that searching for information and seeking social support were their primary purposes for parents' use of the Internet (Blackburn & Read, 2005).

In a similar study, researchers found that, overall, 85% of parents of children with and without disabilities reported using the Internet to find information about children and families (Rothbaum, Martland, & Jannsen, 2008). Parents of children with autism reported that they used the Internet more than any other resource in seeking information about the disability (Department of Public Welfare, 2004). When parents of children with and without disabilities who had already searched for health information on the Internet were asked with whom they would consult the next time they need reliable information about health or medical conditions, 58% selected the Internet compared to only 35% of parents who selected a medical professional (Fox & Fallows, 2003). These findings indicate an increasing reliance on the Internet as a source of information among parents regarding their children's needs. Indeed, Parette and colleagues argued that as the importance of the Internet has grown, so has the participation of families of young children with disabilities across income, education, and age groups (Parette, Meadan, Doubet, & Hess, 2010).

Another important element regarding parents' information seeking is the "digital

divide.” In other words, differences in social economic status, gender, and level of education have a direct influence on parents’ Internet usability. In recent years this phenomenon has been well documented across socioeconomic status (SES) with greater accessibility by parents from higher SES backgrounds (Brandtzæg, Heim, & Karahasanović, 2011; Drori & Jang, 2003; Kvasny & Keil, 2006; Liang, 2012; Wei, Teo, Chan, & Tan, 2011; L. Wei & Hindman, 2011). It is worth noticing though, that Rothbaum and his colleagues (2008) observed a new phenomenon called digital skill divide (i.e., the ability to search for and evaluate credible Internet sites) in addition to the digital use divide (i.e., the growing gap in the ability of certain segments of the community to access information and communication technologies) (Porter & Edirippulige, 2007). In other words, even though people nowadays may have access to the Internet, they do not necessarily have the searching skills to find high quality information. Specifically, data indicated that the higher the parents’ SES level, the greater the use of the Internet, the more sophisticated the search skills (e.g., using advanced search options), and the greater the skills in evaluating the Internet information source (e.g., emphasizing the credibility of the sponsoring organization). Parents who have sophisticated search skills are likely to find an entirely different set of Internet sites than parents who lack those skills.

Another finding addressed gender differences during Internet searches (Stern, Cotten, & Drentea, 2012). It suggested that mothers were significantly more likely to feel frightened by the information they found online and they were more confident talking with a health care professionals. This is actually another dimension of the digital skill divide that fathers tend to be more adept at Internet searches and more skeptical than mothers about the information they found. Therefore, it is suggested that empowering parents with search skills in a more sophisticated manner (e.g., use of

combined key words to search information or use an alert function to receive updated information) could be an important part of the Internet use trainings (Rothbaum et al., 2008).

A third factor that influences parents' Internet usage is time. Despite the digital skill divide or technical related problems, lack of time can be another struggle for parents. Families have many demands placed on their time for caregiving, employment, and other typical daily routines and tasks. For example, in a study interviewing 60 parents employed at least 30 hours per week and caring for at least one school-age child with an emotional or behavioral disorder, the researchers found that child care arrangements could be varied and complex, with parents frequently making daily adjustments to design suitable care plans for all children in the families (Rosenzweig, Brennan, Huffstutter, & Bradley, 2008). Families of children with disabilities may have increased time demands compared to families without disabilities (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011)

Unfortunately, there is often a tendency for professionals who design Internet-based supports to assume that families are knowledgeable and have sufficient time for Internet searches. The reality is that families simply want timely "informed" answers or social supports from reliable organizations or social connections that can help their children (Rothbaum et al., 2008). To this point, Blackburn and Read suggested that seeking social support and directly obtaining information were the primary purposes of using the Internet (Blackburn & Read, 2005). However, Parette's (2010) study indicated that parent social support groups were actually less frequently used because they required a great time commitment. Such contradictory findings suggest that time is a key variable that influences parents' online social support group behaviors. In fact, contacting other parents of children with similar disabilities provides

parents with much needed emotional, social and practical support. Parents of children with special needs are uniquely qualified to help each other in many ways (Kerr & McIntosh, 2000), and professionals can develop technology to maximize the positive impact of social support and information empowerment. For example, Parette's study revealed that searchable features, organizing content by disability issues related to children, and bookmarking capability were parents' preferences when gaining information or support for their children with disabilities (Parette et al., 2010). More research is needed to advance our understanding about supporting parents in effectively finding parenting information through the Internet.

Finally, the fourth essential element regarding parents' information seeking is the quality of the information available on the Internet. For example, as Skinner and Schaffer (2006) found in their study, although 83% of parents of children with disabilities had used the Internet for some purposes related to their child's condition, the majority of the parents mentioned being anxious because online resources contained contradictory advice, failed to answer their questions, painted a dire portrait of their child's future, or made them feel as though they had to keep looking to find a missing piece or Internet link to information that would help their child. There have been some attempts to evaluate contents of the Internet; nonetheless, online information is largely not reviewed or approved by experts or professionals organizations before it is available for parents (Zaidman-Zait & Jamieson, 2007).

In summary, this section reviewed key issues about parents' online information searching behaviors. Information about a given disability and its implications for health and education for their children is often critical for parents as they try to identify strategies and resources to help their children (Smith & Meyen, 2003). Through the Internet, parents not only expand their understanding of their child's disability and the

special education process but also become further empowered in advocating for their child. Meanwhile, studies reviewed here suggest the existence of technical and time-related issues that result in a digital divide. Moreover, due to information quality concerns, parents may not have confidence about information from the Internet.

Importantly, participants of the studies mentioned above were mainly White parents from the United States. Actually, very little research focused on the Internet usage and parents from culturally and linguistically diverse backgrounds. Thus, the next section summarizes the findings of literature that sheds light on families of children with disabilities from culturally and linguistically diverse backgrounds and their use of the Internet.

Internet Use for Parents from Culturally and Linguistically Diverse Backgrounds

Though no survey study specifically focused on the perceptions of immigrant families regarding using the Internet to access information for their children with disabilities were found in this review, some reports related to this topic were salient. A summary of the key research findings are as follows.

First, the “digital divide”---the discrepancy of Internet accessibility due to disparities in income, ethnicity and education background(Rothbaum, Martland, & Jannsen, 2008)---has been pointed out as a primary difference between Caucasian parents and parents from cultural and linguistic backgrounds. Adults from culturally and linguistically diverse backgrounds tend to have less accessibility than their Caucasian counterparts. For instance, in a report analyzing digital technology use patterns among Latinos, Whites, and Blacks in 2010 with a sample of 1,375 Latinos adults, Livingston (2011) indicated that Latinos are significantly less likely than Whites to have a home Internet connection (55% vs. 75%); this difference persists even if the sample was limited to Internet users (85% vs. 96%).

In addition, although overall Internet accessibility for parents from different ethnicities was lower than that of Caucasians, parents with similar socio-economic background (i.e., income, education) tended to share online information-seeking patterns. For example, even if the gap between African Americans and White Americans was particularly pronounced in accessing the Internet at home, the difference tended to disappear once the two groups' income levels were controlled (Cotten & Gupta, 2004). In other words, some characteristics of Internet information searching patterns might be shared among parents from similar income and education levels regardless of their cultural and linguistic backgrounds.

Last, the use of mobile telephone technology might help close this digital gap. In a survey conducted by Pew Internet Project with 2,260 adults aged 18 years or older, Zickuhr and Smith (2012) argued that, although some groups' digital disparities still remain, both African Americans and English-speaking Latinos were as likely as Whites to own any sort of mobile telephone, and were more likely to use their telephones for a wider range of activities. Data indicated that groups that had traditionally been on the other side of the digital divide in basic Internet access were using wireless connections to go online. Among Smartphone owners, young adults, minorities, those with no college experience, and those with lower household income levels were more likely than other groups to say that their cellular telephone was their main source of Internet access. The use of cellular telephones might have had an even larger impact for Asian Americans; in a similar study, Rainie (2011) pointed out that using cellular telephones is the most popular way for English-speaking Asian Americans to go online compared to Whites, Blacks and Hispanic Americans. New mobile technology might be a promising Internet accessibility equalizer for some families from diverse backgrounds.

In sum, this section reviewed literature about the Internet usage for parents from

culturally and linguistically diverse backgrounds. Although a digital divide is still a dominant phenomenon, the use of mobile technology seems to be a promising way to minimize the gap between Whites and families from diverse cultural and linguistic backgrounds. However, this general information is not enough to obtain a deeper understanding on families from culturally and linguistically diverse backgrounds. Given that the Internet is becoming more prevalent for the younger parent generations, the research focus shall shift from the digital divide to specific Internet information-seeking behaviors. However, studies investigating Chinese parents' perceptions about using the Internet to access information for their children with disabilities are very rare in the current literature.

The Impact of Culture and Language

As stated above, some Asian American parents may have very different Internet information-seeking patterns and this might associated with aspects of their culture backgrounds, including the background of Chinese-American immigrants. In this section, literature related to Chinese language, culture and parents of children with special needs is reviewed to understand the needs of parents in the cultural context.

Since the early 1990s, Asian Americans and Pacific Islanders (AAPIs) have been the most culturally and linguistically diverse, as well as the fastest growing, racial and ethnic group in the United States (Lynch & Hanson, 2011). The Chinese-American community remains the largest Asian subgroup in the United States with a population of about 3.6 million in 2008 (U.S. Census Bureau News, 2010). Parenting children with disabilities requires specialized caring skills and knowledge. It is necessary for early childhood educators and service providers to know families' cultural and linguistic backgrounds so to develop a deeper understanding of their motivation systems, contexts, and other aspects of information seeking behaviors. Lynch and

Hanson (2011) argued that cross-cultural difficulties were not simply a matter of different language, but of different thought patterns, values, and communication styles.

First, evidence-based health and education related information about their children's disability is needed for Chinese parents. Wong, Martinson, Lai, Chen and He (2004) conducted four focus groups with Chinese parents of children with developmental disabilities. They found that although most of the parents accepted their children, Chinese parents felt guilty for having done something wrong, which led to the disability of the child. In facing the reality of having a child with disability, some of them made no attempt to make future plans for their children while others gave up their jobs and tried to seek alternative treatment in the hope of their child's total recovery. Information about practical parenting skills, child rehabilitation, teaching and training was the greatest need expressed by the Chinese parents included in this study. Wong concluded that the most important need of parents is to provide them with the correct information concerning developmental disabilities.

In another literature review, Lisa and Noorfarah argued that Chinese-American parents of children with learning disabilities tend to have unrealistic expectations for their children and the interventions (e.g., believing that their children will totally recover) and therefore, it is important to provide them with accurate information about their children's abilities and learning challenges so that they can understand and better support their children. In addition, professionals should respect parents' involvement in children's education, understanding cultural beliefs, and collaborate with Chinese-American parents during the intervention process (Tews & Merali, 2008).

Secondly, despite their needs for information about their children's disability, Chinese-American immigrant parents may not find it easy to access the information from professionals. Jegatheesan (2009) conducted a qualitative study about perceptions

of Chinese (n = 11), Vietnamese (n = 6), Japanese (n = 4), Indian (n = 1), and Korean (n = 1) parents of children with developmental disabilities during parent-professional interactions. Results indicated that mothers endured significant hardships due to communication and cultural barriers with professionals, and levels of English proficiency and acculturation as well as other cultural barriers when interacting with the professionals. For instance, parents complained that some professionals directed them to Internet sites that were outdated. Jegatheesan (2009) suggested that professionals use simple, supportive, and respectful communication with parents while having knowledge of Asian culture. Meanwhile, parents need to actively increase their level of acculturation and knowledge of available services to advocate for their children through local community centers and other accessible channels.

Lai and Ishiyama (2004) investigated factors that inhibit Chinese parents' school involvement for their children with disabilities in Canada. Through interviews with 10 new immigrant parents who had children with disabilities and live in Canada less than 5 years, they learned that limited English proficiency was still a key barrier for parents to participate at school. In addition, different cultural values between parents and professionals also inhibited meaningful communication and information sharing. For example, parents in their study usually did not want to ask questions, because it would challenge the authority of the professionals and be impolite. Therefore, even though these parents had questions during the meeting, they would remain silent and rely on the Internet or other indirect ways to seek information afterward. Consequently, the parents' participation in school related activities and effective communication about their children's education decreased. Lai and Ishiyama (2004) suggested that active listening and self-reflecting from both parents and professionals was important to promote mutual understanding.

Thus, challenges from language and culture are very common for Chinese-American parents. These obstacles may decrease parents' involvement in their children's special education services. Although these studies commonly acknowledge that information about children's disabilities is tremendously important for the parents, little is revealed about their pattern and challenges in accessing information before and after the meeting with school and medical professionals. As an example, according to Stern et al., 2012, although a doctor provided one parent with important information about her child's disabilities, she found it frustrating because when she wanted to search more information through the Internet, she hardly remembered any key terms that the doctor mentioned during the appointment.

Literature Summary

In conclusion, the current literature provides insights on Caucasian parents' online information searching behaviors for parenting and health for their children's disabilities. On one hand, it indicates that the Internet was a key source for them to access health or education related information for their child with disabilities. But at the same time, challenges about searching skills, time, and information quality may prohibit them from benefiting from all that the Internet can provide. On the other hand, there is only broad and general information about the Internet usage by parents from culturally and linguistically diverse backgrounds. Very little is known about Chinese-American parents' Internet use to seek information for their child with disabilities. For example, when these parents go online, what kind of information do they look for? How do these parents perceive about the information they found? Do these parents trust and rely on the information they found? Do they also encounter language or cultural related barriers when they access to the Internet? This pilot study aims to advance knowledge related to these questions.

CHAPTER III METHODS

Survey

A survey (see Appendix B) was designed to capture Chinese-immigrant parents' demographic information, types of Internet searching preferences, ratings of information sources, and provided participants with opportunities for open-end feedback to specific questions regarding challenges and expectations to their use of the Internet to access parenting information about their child's disability. Survey questions were developed to address the research questions with reference to current technology trends and information gleaned through the literature review. To pilot the survey, five Chinese-American parents who met the inclusion criteria were asked to complete the instrument and provided feedback about survey content, clarity of individual questions, and ease of completion of the survey. Based on their feedback, the survey content and terminology were revised. In addition, survey design personnel at the Center for Research Design & Analysis Unit at the University of Kansas reviewed the survey and provided feedbacks and suggestions about survey content and implementation. This study was approved by Human Subject Committee at the University of Kansas before the survey was distributed to parent participants.

Recruitment

Participant recruitment was conducted through a community service center located on the west coast of the United States. This service center was established by 10 Chinese-American families who had children with autism. The objective of this organization is "to help individuals with special needs and their families to find love, hope, respect, and support through integrated community involvement." The majority of the children in this center were diagnosed with autism as it was primarily known as a Chinese community autism center until very recently when they expanded their

coverage to children with other disabilities and families from other cultures. Since its founding, this organization has rapidly increased its membership to over 800 multi-ethnic families, and now provides 44 comprehensive programs for thousands of individuals with special needs of all ages and their families.

To participate in this study, parents needed to meet the following criteria: (a) they were Chinese-American immigrant families; (b) they had at least one child with a disability; and (c) they were currently living with the child and acted as the child's primary care provider. This study was advertised to potential research participants in two ways: First information about this survey was disseminated to the members of the community service center through a weekly English-language newsletter. Second a poster was placed within the community service center (see Appendix C). Both the poster and newsletter advertisement explained the study, participant inclusion requirements, and contact information.

80 parents indicated (by providing their contact information through the e-mail address on the poster or reply to the newsletter e-mail) that they met inclusion criteria and were interested in participating in the study. The surveys, consent forms (see Appendix D), and self-addressed, stamped envelopes were sent to the interested parents. After filling out the surveys and signing the consent form, the parents returned the completed surveys by U.S. mail or turned them in at the organization's front desk. Of the 80 parents who expressed an interest in participating in this study, 65% (N=52) completed and returned completed surveys.

Participants

The socio-demographic characteristics of the parents who took part in the survey are outlined in Table 1. Given the sensitivity regarding immigration status, participants were simply asked whether or not they were Chinese-American parents without

reference to legal status. Being a Chinese-American immigrant was necessary to be included in this study. Therefore, all 52 participants self-identified as Chinese-American immigrants. The majority (96.2%) of them were mothers. Their ages ranged from 27 to 48 years with an average of 34.9 years ($SD=5.45$). 82.7% of them were employed as fulltime or part time workers, and 88.5% (46) had annual income of \$65,000 or above. 90.4% (47) of them held a university degree. 88.5% of them lived in a small sized (3-5) family. Most of them (98.1%) reported that the primary language they spoke to their child was English and all of the participants reported being comfortable using English to search for information through the Internet. In summary, the sample of this study was from a relatively high socio-economic status, and indeed many participants indicated choosing computer science, engineering, medicine, and law as their career.

In terms of the participants' child information, 42.3% (22) of the children were 4 to 6 years old and 57.7% (29) of them were 6 to 18 years old. The majority of them (80%) were diagnosed with autism; as stated above, the community organization from which participants were recruited was primarily known as a Chinese community autism center until recently when they expanded their coverage to children with other disabilities and families from other cultures.

Data Analysis

The data were analyzed to respond the research questions. For research question one, multiple regression was used to determine if parents' age, income level, education background, and use of traditional media correlated to parents' use of the Internet. For research questions two and three, descriptive statistics were employed to understand the participants' preferences and trust level on Internet information sources and channels. For research question four, data from participants' responses to the open-end

questions were categorized into themes regarding common challenges and expectations of using the Internet to access health and education related information for their children with disabilities. Feedback from the Center for Research Methods and Data Analysis at the University of Kansas was obtained and incorporated into the process of data analysis.

Theoretical Framework

To better conceptualize Chinese immigrant parents' perceptions on using the Internet to access health and education related information for their children with disabilities, the theory of information management (Brashers, 2001; Brashers, Goldsmith, & Hsieh, 2002) was employed as the theoretical framework. This theory was chosen for two reasons. First, compared to traditional communication theory which describes people's general communication patterns in all domains, Brashers' Information Management Theory specifically focuses on explaining patients' information-seeking patterns in the health context, which is closely related to the research questions of this study. Second, this theory has a strong concentration on context features and cultural influences on people's information-seeking behaviors, which is similar to the theme of this study.

Originally developed by Brashers and his colleagues (Brashers, 2001; Brashers, Goldsmith, & Hsieh, 2002) to explain the phenomenon of information seeking and avoiding in health context, the objective of this Information Management Theory is to understand what challenges and dilemmas are involved in information management in order to explain why some information management activities are more adaptive than others. According to this theory, the intention of information seeking is to meet multiple needs. Brashers and colleagues argue that people do not necessarily always want to seek out information. Rather, information management involves

communicative and cognitive activities such as seeking, avoiding, appraising, and interpreting those environmental stimuli. For example, information can be used to decrease uncertainty that is distressing, or to increase uncertainty that allows for hope or optimism, which some people have to rely on that for survival. In other words, information seeking and avoiding may be a balancing act for individuals who need to achieve multiple goals and suit their needs.

In the process of searching information, it is possible to encounter multiple challenges. Challenges and dilemmas of information management include psychological effect, relational demands (e.g., the need to coordinate the behaviors and goals of the information seeker) and contextual features (e.g., cross-cultural considerations and channels available for information seeking and providing).

First, psychological effect of an illness may affect information acquisition and processing. For example, when people experience extreme stress or anxiety because of illness or medical procedures, their cognitive capability might temporarily decrease and make it difficult to understand the information.

Second, challenges of information management might arise from the nature of collaboration and relationship of information seekers and information providers. For example, if the information seeker uses a passive style to access information and the information provider misunderstand and assume the information seeker is knowledgeable, it is possible that the information provider will overestimate the amount of knowledge that information seeker have, and provide less information or present the information in a way that is difficult for the information seeker to be understood.

Third, the channels of communication available for information seeking and providing may also initiate challenges. For example, despite the potential for

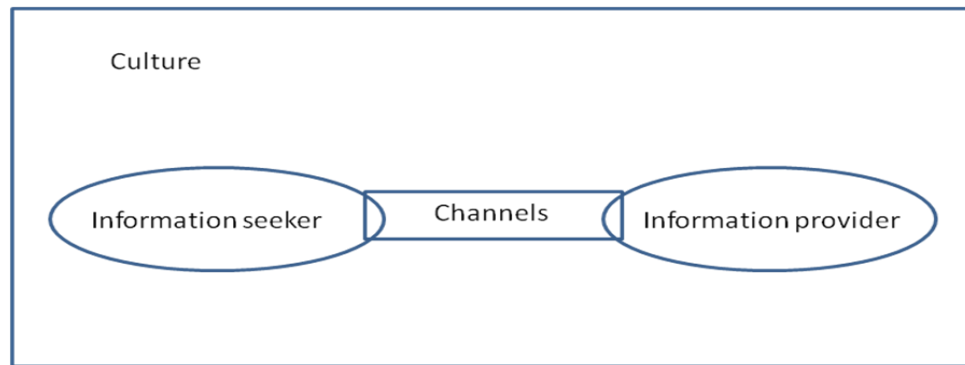
communication technology (e.g., the Internet) to improve systems of information delivery in health care context, it can be underutilized or ineffectively utilized. Part of the reason is that parents may lack the technology to use Internet resources. When they do have access to the technology, individuals may find the information confusing or contradictory and the volume of information overwhelming. Moreover, many credible sources provide website information that may be written in jargon and present minimal information, which may contribute to increased uncertainty about illnesses and treatment options. Meanwhile, less credible sources may offer miracle cures and claim themselves to be highly “reliable.”

Fourth, the challenge of information management might also have to do with the culture. When information is provided, Internet users’ sociocultural context may shape how specific behaviors are understood and interpreted, and thus create barrier in information transportation. For example, information control (information seeking, giving, and withholding) and decision making are assumed by family members rather than individual patients in some cultures (i.e., group-oriented or collectivistic cultures such as the Chinese, Vietnamese, and Ethiopian cultures). When individuals with these cultural backgrounds are involved in health and education system in the United States, their information seeking behaviors may be different compared to Caucasian families. For instance, family members may avoid information seeking if they believe asking questions challenges the authority of professionals, even when they express a desire for greater participation. Such indirect communication strategies may actually decrease the information acquisition (Brashers, 2001; Brashers, Goldsmith, & Hsieh, 2002).

In summary, Brashers’ Information Management Theory (Brashers, 2001; Brashers, Goldsmith, & Hsieh, 2002) reminds us that people might encounter internal and external challenges and decrease the quality of gathered information. This theory

can help understand parents' perspectives on using the Internet to access health and education related information for their children with disabilities, and the challenges that they may have during the process.

Chart 1. Information Management Theory



Note. Challenges during the information management process might result from (1) internal psychological effect; (2) collaboration nature between information seeker and information provider; (3) information channels; and (4) culture context. This chart is drawn based on the author's understanding of Information Management Theory (Brashers, 2001; Brashers, Goldsmith, & Hsieh, 2002)

CHAPTER IV RESULTS

This section reports on results for the current study by research question. Thus, each research question will be listed followed by data that addresses the question.

The first question, **Is there a correlation between Chinese-American immigrant families' background (age, education, income, and use of traditional media) and their Internet usage?** was addressed by the survey data. Results indicated that in general, the participants had used the Internet to access health and education related information for their children with disabilities but the usage frequency was fairly low (see Table 3). Specifically, 82.7% of the participants indicated that they used the Internet to search for health and education related information for their children with disabilities at least once a month while only 9.6% of them did at least once a week. In terms of specific Internet activities, "searching for special education or health related information and general parenting knowledge" was the most frequently selected activity. Results indicated that searching news and joining mailing lists were also employed as essential ways to access updated information related to their child's disability.

As reported in Table 10, multiple regression analysis indicated that the pattern of Internet use for information seeking was unrelated to the parents' education and income level. The respondents' age level, however, was related to the level of Internet use. Specifically, the standardized Beta Coefficients of the age variable was -0.46 with $t=-3.299$ ($p<0.05$), which meant the younger the parent participants were, the more frequently they used the Internet to access health and education related information for their children with disability.

An additional analysis, correlation between internet usage and traditional media (e.g., traditional TV program, newspaper, magazine, and book) usage was conducted;

however, results indicated there was no strong relationship between these variables (Standardized Beta = -0.15, $p=0.91$). Moreover, the overall R^2 change of this model was relatively weak (0.19), which means there was still 0.81 of the independent variables that had not been identified.

Next, the second research question, **What preferences Chinese-American parents have for information channels?** was also addressed via analysis of participants' survey response. The data (see Table 4) indicated that search engine (Mean=4.7, SD=0.5), professional organizations (Mean=4.4, SD=0.49) and books (Mean=4.0, SD=0.97) were the top three channels that parents preferred to use to access health and education related information for their children with disabilities. Meanwhile, I-pad app programs (Mean=1.9, SD=0.75), mini blogs (Mean=1.7, SD=0.63), and social portals (Mean=1.1, SD=0.38) were the least frequently used channels by which parents accessed health and education related information for their children with disabilities.

Interestingly, in analyzing the extent to which Chinese-American parents' preferred channels match up with trusted channels, results (see Table 5) indicated that only professional organizations (Mean=4.4, SD=0.61) were consistent with its high preference ranking, and the trust level of I-pad app programs (Mean=1.8, SD=0.57), mini blog (Mean=1.6, SD=0.68), and social portals (Mean=1.5, SD=0.53) were consistently low. However, the trust level of search engines only ranked No.7 compared to other channels (Mean=2.1, SD=0.81), which indicated that the participants had a large discrepancy between preference and trust level toward the use of search engines (i.e., search engines were frequently used but not trusted).

Furthermore, the third research question, **What information sources do Chinese-American parents find most reliable?** was also addressed via participants'

survey responses. For this research question, data (see Table 7) indicated that parents found professionals (personnel, organization, and network) the most trusted sources (Mean>4.3) for obtaining health or education related information.

Another key finding was that offline social gatherings with parents who had children with similar disabilities was a key way of information sharing for Chinese-American immigrants. Data suggested that 100% of the participants were actively involved in community parenting classes and 90.3% of them had parent friends who had children with similar disabilities (see Table 8 and 9). Despite the popularity for the younger generation of using the Internet to maintain social networks, immigrant parents in this study were still accustomed to offline face-to-face communication and considered their friends as relatively reliable for seeking information (e.g., parent friends were considered reliable information sources and were preferred after professionals, see Table 7 for more information).

Finally, survey results addressed the forth research question, **What challenges do Chinese-American parents have when using the Internet to access health and education related information for their child with disabilities?** To gather information for this research question, an open-end question asking parents' challenge and expectation on accessing information was included in the survey. Of the 52 participants who completed and returned the survey, 22 participants completed the open-end questions, which were analyzed and are summarized by below key themes.

First, Chinese-American parents were expressed difficulty identifying information (via the Internet) that they thought matched their child's needs. Many of them mentioned that the information they found was very basic. Or parents were told not to trust the information found on the Internet. For example one parent indicated the following:

“I know national autism organizations such as Autism Speaks. But I remembered when I tried to look into their website and see if there is any resource I can use, I find it very confusing. I mean, when I get deeper into their website, I find the information too broad for me.”

Another parent wrote the following:

“I like to search on the Internet and I do accumulate lots of knowledge about Autism through reading the articles. But sometimes I find it hard to employ what I learn to the daily practice, you know, every child is different.”

One parent wrote:

“Sometimes it makes me stressful to learn too much. I feel so privileged to have my daughter and me engaging with other moms and their children at the community agency. I don’t think I need the information from the Internet. It is just I don’t know whether I should trust or not.”

Professional organizations that are well known by the Caucasian parents may not necessarily be recognized by Chinese-American immigrants. Even though there are some highly credential organizations, if the parents are not aware of its existence, it is possible that they cannot get access to the reliable information provided by the organizations. Results for Question 3 indicated that parents care about the credibility of the parenting and health-related information and they tended to trust information from the professionals, but they may not trust the same information when it was found on the Internet. In other words, communication channels (i.e., face-to-face versus the Internet) can distort the credibility of the information source.

In addition, although most of the participants indicated that they were comfortable using English to read online information, language differences still represented a challenge to their use of the Internet to obtain health and parenting information. For example, one parent shared the following:

“I hope there would be more Chinese autism website. I used to search with Chinese. But the websites I found were all from China and I don’t get much information from that. I mean I don’t trust them sometimes.”

In addition, some parents suggested that they tended to be stressed with too much parenting information and, consequently, they tended to avoid information even if the information was highly reliable. For instance, one parent wrote the following:

“For me I don’t use the Internet a lot. I just think there is too much information for me at the moment.”

In summary, the participants’ responses to the open-end questions provide insight on challenges that Chinese-American immigrant encounter when using the Internet to access information for their children with disabilities. Chinese-American parents in this study expected to effectively find individualized and reliable information through the Internet. However, lack of research skills and background knowledge are preventing them from benefiting the advantages that the Internet could provide. In addition, cultural barriers and language differences make it even harder to do so.

In the Results section, results related to the research question were presented. Specifically, parents’ age was statistical significant to predict parent participants’ frequency of Internet usage for their children with disabilities. In addition, it seems that parents have a discrepancy between their preference and trust level of information found on the Internet. Data also indicated that professionals and parents’ friends are considered the most reliable sources to gain health and education related information for their children with disabilities. Moreover, parents encountered several challenges which may prohibit them from effectively gaining meaningful information from the Internet.

CHAPTER V DISCUSSION

This pilot study aims to explore Chinese-American immigrant parents' perceptions on using the Internet to access health and education related information for their children with disabilities. In this chapter, four main points will be delineated by comparing the results of previous studies, and interpreting the results in light of the framework of Information Management Theory. Specifically, this section highlights the following discussion points: (1) Chinese-American immigrant parents use the Internet to access information; (2) Information providers need a deeper understanding on the online information-seeking patterns for the younger parent generations; (3) Service providers need to address the discrepancy between their preferences and their trust level for using search engines; and (4) it is important for educators to address culture and language challenges for Chinese-American immigrant parents when using the Internet.

First, the current study confirms that Chinese-American immigrant parents use the Internet to access health and education related information for their children with disabilities, although the frequency is not very high due to challenges when using the Internet. Specifically, 82.7% of the participants indicated that they used the Internet to search for health and education related information for their children with disabilities at least once a month while only 9.6% of them would do so at least once a week. In addition, results also indicate that younger parents rely on the Internet to access information more frequently. This finding is commensurate with studies of Caucasian parents in that they also considered the Internet as a key source for parents to access information for their children with disabilities, especially health and education related topics (e.g., Porter & Edirippulige, 2007). From a theoretical viewpoint, as suggested by Information Management Theory, the motivation of health information seekers is to

reduce uncertainty of illness and other goals. Parents need information to reduce uncertainty about parenting their children with disabilities and makes informed decisions about health and education for their children. Thus, Chinese immigrant parents may seek information about their children's disabilities to help inform their decisions regarding education and support. As a consequence, the need of accurate and reliable information appears prevalent across different ethnicities for parents.

Second, it is imperative to advance our understanding about information-seeking patterns for the younger parent generations. As indicated in the current study, age is a negative-correlated predictor for the frequency of Internet usage. This finding is different from the conclusion of previous studies. For example, in Porter and Edirippulige's (2007) study with Australian parents of children with deafness as survey participants, they tried to explore if the parents' backgrounds (i.e., education, income, job status, and age) were correlated to their frequency of Internet use to search for hearing loss-related information. The result of Porter and Edirippulige's study indicated that parents' online information seeking pattern was unrelated to their age and employment status but the level of education was related to the level of Internet use. They concluded that parents with a university education were more frequent users of the Internet for information seeking.

However, this finding may not simply mean that only parents' age is correlated with frequency of internet usage. Participants' age and their children's age may be related; that is, younger parents in this study may have had newly diagnosed children and younger parents in this study tend to have newly diagnosed children and thus rely more on the Internet to access information for their children with disabilities. Meanwhile, older parents have been parents longer and their children may have had a disability diagnosis longer ago, and have more experiences with the children. Thus, the

difference of frequency about Internet usage could be because older parents know more about their children and do not need that much information from the Internet.

In addition, in explaining this discrepancy of results between studies, participants in the current study have a high education level and tend to be older than those of Porter and Edirippulige's (2007) study. Culture, traditional ways of information seeking, personality, and other factors may prohibit the older immigrant parent generation from using the Internet in a broader way. As implied from Information Management Theory (Brashers, Goldsmith, & Hsieh, 2002), information seeking is influenced by the interaction process between information seekers and information receivers. Younger parent generations may have different interaction pattern with information providers than the older parents. Younger parents may rely more on Internet for daily life even though they do not necessarily have a high education background or income level. For example, a recent study investigating young Caucasian parents' parenting information-seeking patterns found that they had a strong preference for self-administered parenting intervention delivery in the form of video, online programs, and written materials; the least preferred formats were home visits, therapists, and multi week parenting groups (Metzler, Sanders, Rusby, & Crowley, 2012). In short, parents' information seeking patterns appear to be changing as technology evolves. Information providers may find that the preference of information receivers differ across parents' age.

Third, it is important to realize the discrepancy between parents' preferred Internet usage and their trust levels, particularly for parents from culturally and linguistically diverse backgrounds. Search engines are considered a preferred channel to access information given parents' busy daily schedule. It is a common theme in participants' response to the open-ended survey questions that parents may not know

how to effectively access professional information online, a place where information is not reviewed by experts. The quality of the information available on the Internet is a concern for parents. For example, Skinner and Schaffer (2006) pointed out that online resources may contain contradictory advice, fail to answer the parents' questions, paint a dire portrait of their child's future, or make the parents feel as though they had to keep looking to find the missing piece or link to information that would help their child. Information that is too broad or too in-depth, despite its quality, may discourage parents from accessing to it. According to Information Management Theory (Brashers, 2001; Brashers, Goldsmith, & Hsieh, 2002), information channels available for information seeking and providing can influence the information management processes and outcomes. In other words, even though a source might be considered highly reliable for professionals, it might not be the case for parents if they access the information from a low creditability channel, or the information seekers do not have the required skills to decode or evaluate the information. Therefore, it is important that information channels match sources so as to balance accessibility and reliability when parents from culturally and linguistically diverse backgrounds are provided with parenting information (Brashers, 2001; Brashers, Goldsmith, & Hsieh, 2002).

Last, culture and language challenges for Chinese-American immigrant parents are important to better understand their Internet use to access health and education related information for their children with disabilities. Based on Information Management Theory, when information is provided, people's social cultural context may shape how specific behaviors are understood and interpreted (Brashers, Goldsmith, & Hsieh, 2002). The current study indicates that culture and language barriers are important context features that influence parents' information-seeking behavior. A common theme mentioned in the open-end questions is that Chinese-American

immigrant parents cast doubt on Internet information sources and found Internet information overwhelming. This outcome may not necessarily mean that the online information itself is low quality, but parents may not be familiar with the medical and educational professionals in their own culture. In other words, reliable information sources, which are well known by western parents, might not be known by Chinese-American immigrant parents. When parents in the current study commented that they did not know whether to trust the information, it may be because they have cultural conflicts: In the era in which information is freely available online, too much information can be overwhelming, especially when parents have not learned ways to critically evaluate the credibility of website information and still use passive or indirect information seeking strategies that illustrate respect to authority figures. Hence, the degree of information acquisition for Chinese-American immigrant parents may actually decrease if too much information is available for them. In short, when examining Chinese-American immigrant parents' perspectives and Internet-related behaviors, the source and channels are important, so too are cultural and linguistic contexts.

When interpreting the findings, several limitations of the current study should be kept in mind. First, the small sample size and convenience sampling method make the findings difficult to generalize to other parent populations. In addition, the participants of this study have high SES backgrounds, therefore, information-seeking patterns identified in this study might not be the same with Chinese-American immigrant parents from low income backgrounds. Also the study only included as participants parents who read and spoke English. Those who could not use English as daily communication language were excluded in this study. Additionally, most of the parent participants are female; thus, the extent to which the findings apply for fathers of

young children with disabilities are unknown. Finally, the use of survey limits the depth of information participants could provide.

Despite the limitations, this pilot study is a first attempt to investigate Chinese-American immigrant parents' perceptions about using the Internet to access health and education related information for their children with disabilities. Some of the original findings contribute to the literature and provide knowledge to inform parenting information design and dissemination. As a generation that has grown up seeing the Internet as a source of information, their information seeking habits would probably remain. Therefore, it is imperative to conduct more research to advance knowledge toward this new phenomenon in the field of early intervention/ early childhood special education.

CHAPTER VI IMPLICATIONS

Implications for Research

This study has several implications for research. First, research focusing on this topic can gather more in-depth information by using interviews, focus groups, and observations or mixed-methods research methodology. For example, interviews within families could provide more in-depth information about parents' common challenges when using the Internet to gather information about their children with disabilities. Similarly, observations of ways in which families search for information could provide narrative descriptions on their information seeking patterns of which parents may not be aware.

In addition, it is important that further research investigates Chinese immigrant parents who only access health and education information in Chinese. It would be equally imperative to conduct more research regarding perspectives of families from the low income backgrounds as a means to increase the reach and impact of evidence-based information for this population. Gathering this information is important given the large number of families from low-income backgrounds who have children with disabilities and likely need health and education related information for making informed decisions. If parents cannot afford the expense of Internet equipment or have limited information searching skills, researchers could determine the extent to which parents would educate themselves to effectively use the Internet?

Moreover, to advance insights regarding on information-seeking patterns for families from African American, Hispanic and other backgrounds who may suffer from the disadvantage of digital divide, more research can be conducted. This information is important because parents from different cultural backgrounds may have

different parenting belief systems and that influence parents' perceptions about what information channels work best.

Implications for Practice

This study also provides several implications for practice. As identified in this study, parents are relying on the Internet to access information. It is important that leaders of traditional home visiting service programs to become aware of and incorporate the Internet and mobile technology into their service components and information dissemination systems. For instance, Parents as Teachers has a rich online curriculum; however, only internal staffs can access to the content and it is not available for parents or public due to copyright issues.

In addition, more effective online searching skills should be identified and taught to parents so that they can benefit from available, effective and meaningful online information to support their involvement in the development and learning of their children with disabilities. Developing training that counteracts SES differences in Internet skills is especially important in bridging the current digital divide in the quality of online information about childrearing (Rothbaum et al., 2008). For example, educators can provide trainings on topics such as how to choose alternative keywords, how to evaluate search results, and how to evaluate the credibility of Websites. In addition, it is also important to provide parents with a list of online information sources and a brief introduction so that they can access effectively.

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Appendix A Literature Review Matrix

| Article | Method | Participant | | | | Inclusion criteria | Findings |
|-------------------|-----------------|-------------|----------------|---------|--|--------------------|--|
| | | N | Age | Gender | SES | Ethnicity | |
| Stern et al. 2012 | Phone interview | 1349 | 46.3 (SD=16.7) | F=57.8% | 18.1% >100,000; 13.3% range from 75,000-100,000; 17.9% range from 50,000 to 75,000; 30% range from 10,000 to 50,000. 69.6% were employed; 47% are college graduate or higher | NA | 1. Male and female parents are actually quite similar in Internet usage but female parents are more likely than male parents to put the health information they have found online into use. 2. Parents regardless of sex, felt more relieved by the information they found online. 3. Women, regardless of their parental status, were significantly more likely to feel frightened by the information they found online. They are more confident with a health care professional. |

Matrix (continued)

| Article | Method | Participant | | | | Inclusion criteria | Findings |
|---------------------|---|-------------|---|--|--|--|---|
| | | N | Age | Gender | SES | Ethnicity | |
| Parette et al. 2010 | Survey | 144 | Most of the participants were 31-40 years old (35%) or 41-50 years old (39%). Only 9% of were younger than 30 years old and 16% were older than 51 years old. | The majority of the participants (76%) were mothers of children with disabilities. | The participants had a diverse educational background. Thirty three percent of the participants reported that their annual household income is smaller than \$45,000, 31% reported that their annual household income is between \$45,000 and \$85,000, and 36% reported that their household income is greater than \$85,000. | 93% were white | <p>Families of children with disabilities</p> <p>1. As the importance of the Internet has grown, so has the participation of families of young children with disabilities across income, education, and age groups.</p> <p>2. Seeking information about their children (treatment, intervention, and disability-specific information) is the primary purpose. Social support groups were less frequently used as it require more time commitment.</p> <p>3. Searchable features, organizing the content by disability issues related to children, and bookmarking capability are parents' preferences when gaining information or support for their children with disabilities.</p> |
| Dillard et al. 2010 | Pre survey and post telephone interview | 38 | 30 (SD=8) | M=17 F=20 | 2 had formal education of less than high school, 18 completed high school, 8 had vocational or technical training, 7 attended college, and 3 held a post-graduate or professional degree. | <p>Caucasian (35)</p> <p>Native American (2)</p> <p>not to answer</p> <p>(1)</p> | <p>1. Among seekers, the most common sources of information were the Internet and pediatricians/family physicians.</p> <p>2. The medical establishment needs to take a more active role in the dissemination of information to parents at this critical moment in their child's life.</p> |

Matrix (continued)

| Article | Method | Participant | | | | Inclusion criteria | Findings |
|----------------------|-----------|-------------|---|---------------------------|---|--|---|
| | | N | Age | Gender | SES | Ethnicity | |
| Rothbaum et al. 2008 | Interview | 120 | The two levels of age of participants' children were middle childhood (6–12 years) and adolescence (13–18 years). | 60 mothers and 60 fathers | 39 low SES parents (high school degree but no college courses and income less than \$45,000), 39 middle SES parents (at least some college courses but no graduate degree, and income between \$45,000 and \$85,000), and 42 high SES parents (bachelors or graduate degree and income above \$95,000). | <p>The ethnic representation of the sample was 92 Caucasian, 21 African-American, 5 Hispanic-</p> <p>All participants had used the Web at least once and had Internet access (i.e., at home, work, school or library).</p> <p>(e.g., selecting one's own search engine rather than relying on a default; changing keywords); and (c) the greater the skills in evaluation (e.g., emphasizing the credibility of the sponsoring organization).</p> <p>3. In contrast to the digital divide in Web use and skills, there was no evidence of greater satisfaction among higher SES parents. We find a digital skill divide in addition to digital use divide.</p> | <p>1. Overall, 85% of parents reported using the web to find information about children and families</p> <p>2. The higher the SES level (a) the greater the use of the Web; (b) the more sophisticated the search skills (e.g., selecting one's own search engine rather than relying on a default; changing keywords); and (c) the greater the skills in evaluation (e.g., emphasizing the credibility of the sponsoring organization).</p> <p>3. In contrast to the digital divide in Web use and skills, there was no evidence of greater satisfaction among higher SES parents. We find a digital skill divide in addition to digital use divide.</p> |

Matrix (continued)

| Article | Method | Participant | | | | Inclusion criteria | Findings |
|----------------------------|--------|-------------|--|---|---|--|---|
| | | N | Age | Gender | SES | Ethnicity | |
| Porter&Edrrip pulige, 2007 | Survey | 157 | Two thirds were aged between 34 and 49 years of age. | 89% of the respondents were mothers of a deaf child | 77% living in the three most populous states, New South Wales, Victoria, and Queensland. Over half (56%) were located in the city. 50% hold a university degree | 94% of them are comfortable speaking and reading English from birth to 21 years, and living in Australia | <p>1. This study confirms primarily mothers search for health information on the Internet. They are searching for information from the early years until the child leaves school and beyond. Their use of the Internet for information gathering was unrelated to the age of the parent, the age of their child, where they live, or their employment status.</p> <p>2. People with a university degree reported that the information they find on the Internet has a major influence on decisions they make about the management of their child's hearing loss.</p> <p>3. Parents do need to be directed to quality information by health professionals.</p> |

Matrix (continued)

| Article | Method | Participant | | | | Inclusion criteria | Findings |
|---------------------|----------------------------------|-------------|--|--------|---|---|--|
| | | N | Age | Gender | SES | Ethnicity | |
| Skinner et al. 2006 | Longitudinal, ethnographic study | 106 | The average age of this group of young children was 30 months. | F=106 | Families represented a full range of income and education levels. Forty-seven percent had annual incomes of less than \$30,000, while 21% had annual incomes of more than \$75,000. Only 7% of the mothers had less than a high school education, 26% had a high school diploma or GED, 34% had some college or an associate's degree, 23% had a bachelor's degree, and 10% had advanced degrees. | Parents of young children with suspected or known genetic disorders. African American, 62 European American, 13 American, 13 Latino, and 8 Native American. | <p>1. 83% had used the Internet for some purpose related to their child's condition. Overall, families of any ethnicity with lower income and lower education levels were less likely to use the Internet.</p> <p>2. For the majority of users, the Internet merely supplemented what they learned from their healthcare providers. But for those who felt they did not receive adequate information about their children's diagnosis and treatment options, the Internet became a primary source of information and support.</p> <p>3. the anxiety caused by online resources that contained contradictory advice, failed to answer their questions, etc.</p> |

Matrix (continued)

| Article | Method | Participant | | | | Inclusion criteria | Findings |
|------------------------|--------|-------------|--|---------------|--|--|--|
| | | N | Age | Gender | SES | Ethnicity | |
| Blackburn & Read, 2005 | Survey | 788 | Two thirds (67%) were in the age range 30–44 years | M=55 F=732 | Over half (56%) were not in paid employment and 75% lived in owner-occupied accommodation. | The majority (96%) identified themselves as being of White British or European origin. | <p>1. Relatively high proportions of the parents in this study had access to the Internet and were using it at home.</p> <p>2. Directly obtaining information related to their role as parents of children with disabilities and social support are the primary purposes of using internet.</p> <p>3. Technical (difficult to navigate) and time-related (takes too much time to get information) problems.</p> <p>4. A range of information delivery is necessary to accommodate the needs and circumstances of families.</p> |

APPENDIX B Survey

Survey of Immigrant Parents' Perspectives about Using the Internet to Access Health and Education Related Information for Their Children with Special Needs

| | |
|--------------------------|--|
| Questionnaire No. | |
|--------------------------|--|

Dear Parent/Guardian,

Thank you for your participation in this study. Your feedback and suggestions are important and valuable to improve the provision of parenting interventions and development of parent-professional partnerships. The purpose of this survey is to explore Chinese-American immigrant parents' perspectives about using the Internet to access information about health and education related issues for their child with special needs. Please follow the instructions and select the answer(s) that best describe your thoughts. We appreciate your time and effort on completing this survey.

Songtian Zeng and Greg Cheatham

University of Kansas, Department of Special Education

Section A. Background Information

Instructions: In this section, you will be asked to provide demographic information about you and your child with disabilities. The information you share will be kept confidential and no one other than the investigators will access your individual information. If you find any question that you are uncomfortable to answer, please leave it blank and move to the next question.

A1. How long have you lived in U. S.?

_____Year(s) _____Month (s)

A2. What is your highest level of education?

- ☐ Elementary school or below
- ☐ Junior high school graduate
- ☐ High school graduate
- ☐ Associates degree
- ☐ Bachelors degree
- ☐ Master degree
- ☐ Doctoral or equivalent degree (e.g., M.D, Ed.D)

A3. What's your annual household income?

- ☐ Less than \$15,000
- ☐ \$15,000-25,000
- ☐ \$25,000-35,000
- ☐ \$35,000-45,000
- ☐ \$45,000-65,000

☐ \$65,000 or above

A4. How many people are supported by this income in your family?

A5. Are you currently employed?

☐ Yes full time

☐ Yes part time

☐ Yes freelancer

☐ No

A6. What is the year of your birth?

_____ Year (example, 1975)

A7. What is the target child's clinical disability diagnosis? (You may choose more than one that apply)

☐ Autism

☐ Specific learning disability

☐ Speech or language impairment

☐ Developmental delay

☐ Hearing impairment

☐ Deaf-blindness

☐ Deafness

☐ Visual impairment, including blindness

☐ Emotional disturbance

☐ Intellectual disability

☐ Traumatic brain injury

☐ Orthopedic impairment

☐ Multiple disabilities

☐ Other health impairment

A8. What is your child's date of birth?

_____ Year(s) _____ Month (s)

A9. What is your child's gender?

☐ Male

☐ Female

A10. What is the relationship between you and the target child?

☐ I am the child's biological mother

☐ I am the child's biological father

- ☐ I am the child's step mother
- ☐ I am the child's step father
- ☐ I am the child's adoptive parent
- ☐ I am the child's grandparent

Other, please specify _____

A11. How often did you use the Internet to search for health and education related information for your child with disabilities in 2012?

- ☐ Never
- ☐ Sometimes not very consistent
- ☐ At least once a month
- ☐ At least once a week
- ☐ At least once a day

A12. What language do you primarily speak to your child with disabilities at home?

- ☐ My own native language (other than English)
- ☐ English
- ☐ Sign language
- ☐ Other, please specify _____

A13. What language do you prefer or feel most comfortable with when searching online health or education related information for your child with disabilities?

- ☐ My own native language (other than English)
- ☐ English
- ☐ Both my native language and English

Section B. Communication Preferences

In this section we would like to know your preferred ways to access parenting interventions through **the Internet**.

B1. How would you prefer to receive health or education related information for your child with disabilities?

Note: please circle the number representing your degree of preference

| Channel | Not Prefer | ←-----→Prefer | | | |
|------------------------|------------|---------------|---|---|---|
| Traditional TV program | 1 | 2 | 3 | 4 | 5 |
| Newspaper | 1 | 2 | 3 | 4 | 5 |
| Magazine | 1 | 2 | 3 | 4 | 5 |
| Book | 1 | 2 | 3 | 4 | 5 |
| Brochure | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|--|---|---|---|---|---|
| Video website (e.g., You Tube) | 1 | 2 | 3 | 4 | 5 |
| Searching engine (e.g., Google) | 1 | 2 | 3 | 4 | 5 |
| I-pad app program | 1 | 2 | 3 | 4 | 5 |
| Mini Blog (e.g., Twitter) | 1 | 2 | 3 | 4 | 5 |
| Social Portal (e.g., Facebook) | 1 | 2 | 3 | 4 | 5 |
| Professional network (e.g., Autism Speaks) | 1 | 2 | 3 | 4 | 5 |

B2. In terms of online information quality, which media type(s) do you TRUST most for health or education related information for your child with disabilities?

Note: please circle the number representing the extent to which you trust each information source.

| Channel | Not Trust | ←-----→Trust | | | |
|--|-----------|--------------|---|---|---|
| Traditional TV program | 1 | 2 | 3 | 4 | 5 |
| Newspaper | 1 | 2 | 3 | 4 | 5 |
| Magazine | 1 | 2 | 3 | 4 | 5 |
| Book | 1 | 2 | 3 | 4 | 5 |
| Brochure | 1 | 2 | 3 | 4 | 5 |
| Video website (e.g., You Tube) | 1 | 2 | 3 | 4 | 5 |
| Searching engine (e.g., Google) | 1 | 2 | 3 | 4 | 5 |
| I-pad app program | 1 | 2 | 3 | 4 | 5 |
| Mini Blog (e.g., Twitter) | 1 | 2 | 3 | 4 | 5 |
| Social Portal (e.g., Facebook) | 1 | 2 | 3 | 4 | 5 |
| Professional network (e.g., Autism Speaks) | 1 | 2 | 3 | 4 | 5 |

If you have ever used the Internet to access health or education related information for your child with disabilities, please answer B3-B6. Otherwise, please skip and go to section C.

B3. What is your average amount of time using the Internet to search for health and education related information for your child with disabilities each day in 2012?

- ☐ 30 minutes or less
- ☐ 30 minutes to 1 hour
- ☐ 1-3 hours
- ☐ 3-5 hours
- ☐ More than 5 hours

B4. When did you use the Internet to access information for your child in 2012?

(Note: you can select more than one answer according to your experience)

- ☐ Morning (6:00-12:00)
- ☐ Afternoon (12:00-18:00)
- ☐ Evening (18:00-23:00)
- ☐ Late night (23:00-6:00)

B5. How do you use the Internet to obtain information for your child with disabilities?

Note: please circle the number representing the frequency of your online activities

| Online activities | Never | ←-----→Always | | | |
|---|-------|---------------|---|---|---|
| Search for health or education knowledge | 1 | 2 | 3 | 4 | 5 |
| Search for general parenting knowledge | 1 | 2 | 3 | 4 | 5 |
| Online shopping for your child with disabilities | 1 | 2 | 3 | 4 | 5 |
| Consult or share information with a friend about your child with disabilities | 1 | 2 | 3 | 4 | 5 |
| Access videos (TV show) related to your child's disabilities | 1 | 2 | 3 | 4 | 5 |
| Receive e-mail about your child's disabilities | 1 | 2 | 3 | 4 | 5 |
| Search news related your child's disabilities | 1 | 2 | 3 | 4 | 5 |
| Other, please specify () | 1 | 2 | 3 | 4 | 5 |

B6. Have you ever used I-pad app programs to obtain health or education related information for your child with disabilities in 2012?

☐ Yes frequently

☐ Yes sometimes

☐ No never

Section C: Parenting Information Sources

Instructions: In this section, you will be asked to share your thoughts about information sources about children with disabilities. Please choose answer(s) that best give to your perspectives.

C1. What source(s) do you TRUST most in terms of providing health or education information for your child with disabilities?

Note: please circle the number representing your degree of trust-worthy

| Information Source | Not Trust | ←-----→Trust | | | |
|--|-----------|--------------|---|---|---|
| Grandparents | 1 | 2 | 3 | 4 | 5 |
| Your wife/husband | 1 | 2 | 3 | 4 | 5 |
| Friends who have a child with the similar disability | 1 | 2 | 3 | 4 | 5 |
| Professionals (e.g., pediatricians or professors) | 1 | 2 | 3 | 4 | 5 |
| Professional organizations (e.g., Parents as Teachers, Head Start program) | 1 | 2 | 3 | 4 | 5 |
| Parent self-help organization (e.g., FCSN) | 1 | 2 | 3 | 4 | 5 |
| Other, please specify () | 1 | 2 | 3 | 4 | 5 |

C2. Who do you first contact for information when you encounter health or education issues for your child with disabilities?

| | |
|--------------------------|---|
| <input type="checkbox"/> | Grandparents |
| <input type="checkbox"/> | Your wife/husband |
| <input type="checkbox"/> | Friends who have a child with a similar disability |
| <input type="checkbox"/> | Professionals (e.g., pediatricians or professors) |
| <input type="checkbox"/> | Professional organizations (e.g., Parents as Teachers and Head Start program) |
| <input type="checkbox"/> | Parent self-help organization (e.g., FCSN) |
| <input type="checkbox"/> | Other, please specify () |

C3. Do you currently know parent of children with similar disabilities with whom you regularly share health and education information?

| | |
|--------------------------|---|
| <input type="checkbox"/> | Yes I have and we share information with each other regularly |
| <input type="checkbox"/> | Yes I have but I do not share information with them |
| <input type="checkbox"/> | No I do not engage in parent group |

If you chose the first answer in question C3 (Yes, I have and we share information regularly), please answer question C4. Otherwise please skip to question C5

C4. In what way do you prefer to share information with other parents of children with disabilities?

| | |
|--------------------------|---|
| <input type="checkbox"/> | Through telephone |
| <input type="checkbox"/> | Through online communication tool (e.g., Facebook, Skype) |
| <input type="checkbox"/> | Through regular parent gathering |
| <input type="checkbox"/> | Other, please specify_____ |

C5. Currently, how do you consult with professionals (e.g., special education teachers, pediatricians, school psychologists) about your child?

Note: you can choose more than one response

| | |
|--------------------------|---|
| <input type="checkbox"/> | Through telephone |
| <input type="checkbox"/> | Through one-on-one clinical consultation |
| <input type="checkbox"/> | Through online communication tool (e.g., Facebook, Skype) |
| <input type="checkbox"/> | Through home visit |

Other, please specify_____

C6. If you could choose, which consultation methods with professionals do you prefer the most?

Note: you might choose more than one response

☐ Through one-on-one clinical consultation

☐ Through online communication tool (e.g., Facebook, Skype)

☐ Through home visit

Other, please specify _____

C7. Have you ever participated in group-based parenting classes?

☐ Yes very often

☐ Yes sometimes

☐ Yes but only once

☐ No

Note: Please answer question C8 if you chose “only once” or “No” for question C7.

C8. Why do you seldom participate in group-based parenting classes?

Note: you might choose more than one answer

☐ The location is far from my house

☐ I am not aware of these programs in my community

☐ I don't have time

☐ I don't think it will work for my child

☐ I am not interested in these types of classes

Other, please specify _____

Section D: Challenge

In this section, we would like to ask some open-end questions. Please briefly provide your response to questions D1-D3.

D1. What is your biggest challenge to access information about health or education issues for your child with disabilities?

D2. What changes do you think are necessary to improve your access to information for your child with disabilities through the Internet?

D3. Are you willing to participate in follow-up interviews or surveys?

☐ Yes I will

☐ No I won't

-----This is the end of the questionnaire, thank you for your time!-----

Media and Parenting Interventions Study

Participants needed through February 30th 2013

Nowadays media and new technology enable us to access parenting interventions (programs aiming to empower care givers with special education knowledge and parenting skills.) more conveniently and effectively. The purpose of this survey is to explore U. S. Chinese immigrant parents' perspectives about using media to access parenting interventions. Please consider participate this study if you:

- **Are Chinese-American immigrant parents or family members;**
- **Use Chinese or English for daily communication at home;**
- **Have or take care of at least one child with a disability;**
- **The child is less than 18 years old;**
- **Are currently living with the child and act as the child's primary care provider.**

Your participation in this study will help provide a better understanding on parents' needs and consequently, more effective provision of parenting information can be provided. The survey will take 10-15 minutes and the information you provided is confidential.

Please contact Songtian Zeng at s815z148@ku.edu or (785)424-5160 for more information. We appreciate your time and effort. ☺

Songtian Zeng, Graduate Student

Greg Cheatham, Assistant Professor

University of Kansas Department of Special Education

Media and Parenting Intervention Study
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APPENDIX D Parent Consent Form

INFORMED CONSENT STATEMENT

PROJECT TITLE

Immigrant Parents' Perspectives about Using the Internet to Access Health and Education Related Information for Their Children with Special Needs

INTRODUCTION

The Department of Special Education at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You may refuse to sign this form and not participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with the Department of Special Education, the services it may provide to you, or the University of Kansas.

PURPOSE OF THE STUDY

The purpose of this survey is to explore U. S. immigrant parents' perspectives about using the Internet to access information about health or education related issues for their child with special needs.

PROCEDURES

You will be asked to fill out a survey regarding to your experience and perceptions about using media to access special education knowledge and interventions. Parents will also be asked to report demographic information and general use of media. The questionnaire is only used by the researchers and will be stored in a locked cabinet.

RISKS

Your participation in this study has no known or anticipated risks. Your participation or non-participation in this study will not in any way impact your relationship with Friends of Children with Special Needs (FCSN).

BENEFITS

Your participation in this study will help provide a better understanding on parents' needs. Consequently, more effective provision of parenting information can be provided.

PAYMENT TO PARTICIPANTS

There is no payment for participating in this study.

PARTICIPANT CONFIDENTIALITY

Your name will not be associated in any publication or presentation with the information collected about you or with the research findings from this study. Instead, the researchers will use a study number or a pseudonym rather than your name. Your identifiable information will not be shared unless (a) it is required by law or university policy, or (b) you give written permission.

Permission granted on this date to use and disclose your information remains in effect indefinitely. By signing this form you give permission for the use and disclosure of your information for purposes of this study at any time in the future.

REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you refuse to sign, you cannot participate in this study.

CANCELLING THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose further information collected about you, in writing, at any time, by sending your written request to: Songtian Zeng, 2905 Crestline drive, Lawrence, KS, 66047. (785)424-5160. E-mail: tim19851231@gmail.com.

If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

WHAT THE DATA WILL BE USED

The data obtained from this survey will be used for scholarly presentation and publications. It will also be used to support teacher professional development regarding ways to provide parenting information and special education information to families of children with disabilities.

QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to the researchers listed at the end of this consent form.

PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429 or (785) 864-7385, write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7568, or email irb@ku.edu.

I agree to take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

Type/Print Participant's Name

Date

Participant's Signature

Researcher Contact Information

Songtian Zeng
Graduate Student
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Table1. Respondents' demographic information

| | n | % |
|---|----|-------|
| Relationship to child | | |
| Father | 2 | 3.8 |
| Mother | 50 | 96.2 |
| Respondents' age (in years)* | | |
| 27-34 | 24 | 46.15 |
| 35-49 | 28 | 53.85 |
| Child's age (in years)** | | |
| 4-6 | 22 | 42.31 |
| 7-18 | 29 | 55.77 |
| 18-21 | 1 | 1.92 |
| Child's gender | | |
| Male | 46 | 88.5 |
| Female | 6 | 11.5 |
| Employment status | | |
| Employed (full time/part time) | 43 | 82.7 |
| Freelancer | 6 | 11.5 |
| Unemployed | 3 | 5.8 |
| Household annual income | | |
| \$65,000 or above | 46 | 88.5 |
| \$45,000-65,000 | 6 | 11.5 |
| Highest level of education | | |
| Vocational degree | 5 | 9.6 |
| University degree | 47 | 90.4 |
| Family size | | |
| 3 | 7 | 13.5 |
| 4 | 30 | 57.7 |
| 5 | 9 | 17.3 |
| 6 | 5 | 9.6 |
| 7 | 1 | 1.9 |
| Language primarily spoken to the child | | |
| English | 51 | 98.1 |
| Language other than English | 1 | 1.9 |
| Language comfortable to use for searching information | | |
| Both my native language and English | 40 | 76.9 |
| English | 12 | 23.1 |

Note. *the SD of respondents' age=5.45

**the SD of the children's age=3.81

Table 2. Disability diagnosis of respondents' children

| | Frequency | Percent |
|-------------------------------|-----------|---------|
| Autism | 42 | 80.8 |
| Speech or language impairment | 3 | 5.8 |
| Deaf-blindness | 3 | 5.8 |
| Hearing impairment | 2 | 3.8 |
| Developmental delay | 1 | 1.9 |
| Emotional disturbance | 1 | 1.9 |
| Total | 52 | 100.0 |

Table 3. Respondents' frequency of Internet use for their children with disabilities

| | Frequency | Percent |
|--------------------------------|-----------|---------|
| At least once a month | 43 | 82.7 |
| At least once a week | 5 | 9.6 |
| Sometimes, not very consistent | 4 | 7.7 |
| Total | 52 | 100.0 |

Table 4. Respondents' preference on information channels via the Internet

| | Sum | Mean* | SD |
|--|--------|-------|------|
| Searching engine (e.g., Google) | 248.00 | 4.76 | 0.50 |
| Professional network (e.g., Autism Speaks) | 229.00 | 4.40 | 0.49 |
| Book | 211.00 | 4.05 | 0.97 |
| Video website | 182.00 | 3.50 | 0.93 |
| Brochure | 178.00 | 3.42 | 0.82 |
| Magazine | 141.00 | 2.71 | 0.80 |
| Newspaper | 107.00 | 2.05 | 1.05 |
| Traditional TV program | 103.00 | 1.98 | 0.95 |
| I-pad app program | 101.00 | 1.94 | 0.75 |
| Mini Blog (e.g., Twitter) | 93.00 | 1.78 | 0.63 |
| Social Portal (e.g., Facebook) | 61.00 | 1.17 | 0.38 |

Note. *for all the tables in this study, the scale of Mean is between 1 and 5. Larger numbers indicates the level of preference or trust is higher.

Table 5. Participants' trust level on information obtained from the channels

| | Sum | Mean | SD |
|--------------------------------|--------|------|------|
| Brochure | 233.00 | 4.48 | 0.57 |
| Professional network | 233.00 | 4.48 | 0.61 |
| Newspaper | 226.00 | 4.34 | 0.55 |
| Book | 224.00 | 4.30 | 0.67 |
| Traditional TV program | 223.00 | 4.28 | 0.72 |
| Magazine | 207.00 | 3.98 | 0.93 |
| Searching engine | 111.00 | 2.13 | 0.81 |
| I-pad app program | 96.00 | 1.84 | 0.57 |
| Video website (e.g., You Tube) | 96.00 | 1.84 | 0.69 |
| Social Portal (e.g., Facebook) | 86.00 | 1.65 | 0.68 |
| Mini Blog (e.g., Twitter) | 82.00 | 1.57 | 0.53 |

Table 6. Parents' online health and education related information-seeking behaviors

| | Sum | Mean | SD |
|---|--------|------|-----|
| Search for health or education knowledge | 228.00 | 4.38 | .56 |
| Search for general parenting knowledge | 227.00 | 4.36 | .56 |
| Receive e-mail about child's disabilities | 207.00 | 3.98 | .69 |
| Search news related child's disabilities | 195.00 | 3.75 | .86 |
| Access videos (TV show) related to child's disabilities | 145.00 | 2.78 | .57 |
| Consult or share information with a friend | 134.00 | 2.57 | .95 |
| Online shopping for your child with disabilities | 84.00 | 1.61 | .56 |

Table 7. Parents' trust level about health and education related information sources

| | Sum | Mean | SD |
|--|--------|------|------|
| Professional organizations (e.g., Parents as Teachers, Head Start program | 251.00 | 4.82 | 0.38 |
| Parent self-help organization (e.g., community parenting service agency) | 237.00 | 4.55 | 0.50 |
| Professionals (e.g., pediatricians or professors) | 224.00 | 4.30 | 0.50 |
| Friends who have a child with the similar disability | 174.00 | 3.34 | 0.88 |
| Your wife/husband | 163.00 | 3.13 | 1.18 |
| Grandparents | 62.00 | 1.19 | 0.39 |

Table 8. Participants' social support from friends with children with similar disabilities

| | Frequency | Percent |
|--|-----------|---------|
| No | 4 | 7.7 |
| Yes but do not share information with them | 25 | 48.1 |
| Yes and share information regularly | 22 | 42.3 |
| Total | 52 | 100.0 |

Table 9. Parents' participation in offline social support gathering

| | Frequency | Percent |
|----------------|-----------|---------|
| Yes sometimes | 24 | 46.2 |
| Yes very often | 28 | 53.8 |
| Total | 52 | 100.0 |

Table 10. Multiple-regression model on participants' background and Internet usage

| Model Summary | | | | | |
|---|-------------------|----------|-----|-----|---------------|
| Model | Change Statistics | | | | |
| | R Square Change | F Change | df1 | df2 | Sig. F Change |
| 1 | .193 ^a | 2.206 | 5 | 46 | .070 |
| a. Predictors: (Constant), use of traditional media, highest level of education, respondents' age, employment status, household annual income | | | | | |

| Coefficients ^a | | | | | | |
|---------------------------|----------------------------|-----------------------------|------------|---------------------------|--------|------|
| Model | | Unstandardized Coefficients | | Standardized Coefficients | T | Sig. |
| | | B | Std. Error | Beta | | |
| 1 | (Constant) | 4.059 | 1.215 | | 3.340 | .002 |
| | Highest level of education | .016 | .071 | .032 | .224 | .823 |
| | Household annual income | -.152 | .201 | -.117 | -.753 | .455 |
| | Employment status | -.054 | .060 | -.140 | -.906 | .370 |
| | Respondents' age | -.035 | .011 | -.460 | -3.299 | .002 |
| | Use of traditional media | -.003 | .028 | -.015 | -.112 | .911 |