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Parental Attitudes of Immunization in Children with
Special Healthcare Needs: A Qualitative Study

Maren Topham

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Master of Science

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ABSTRACT

Parental Attitudes of Immunization in Children with Special Healthcare Needs: A Qualitative Study

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Background and Purpose: Just over 15% of children under 18 years of age in the United States, or approximately 11.2 million children, are estimated to have special healthcare needs. Although children with special healthcare needs (CSHCN) make up a small percentage of the pediatric population, they account for over one third of pediatric medical care. Parental attitudes regarding immunization play a significant role in vaccination rates among children. The purpose of this research is to explore parental attitudes regarding immunization of CSHCN.

Methods: This qualitative study focused on parental perceptions and beliefs about immunizations for CSHCN. Sixteen participants, who were parents of CSHCN from one pediatric specialty care clinic participated in focus groups. Institutional review board approval was received prior to data collection.

Results: While the purpose of this study was to determine the attitudes of parents of CSHCN regarding immunizations, analysis revealed parents simply wanted to share their life experiences rearing these children, with issues of immunization being secondary. Participants described the experience of caring for their CSHCN related to isolationism and the weight of responsibility as leader of their child's care. Additionally, the majority of parents that participated viewed childhood vaccinations in a positive light. Parents acknowledged that it was important for their own children to receive vaccines. Participants also recognized that it was important for the community to be vaccinated in order to protect their child. However, the desire for individualized care, at times, caused parents to disregard the immunization schedule recommended by Center for Disease Control and Prevention.

Conclusions: Health care providers can be effective and influential members of the health care team by engaging in community based education about vaccines, building trusting relationships with parents and helping parents understand the need to follow the recommended schedule for immunizations.

Keywords: child health services, chronic disease, immunizations, patient care team, patient-centered care

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Parental Attitudes of Immunization in Children with Special Healthcare Needs: A Qualitative Study

Approximately 11.2 million children in the United States have special healthcare needs (U.S. Department of Health and Human Services, 2013). The U.S. Department of Health and Human Services (USDHHS) (2013) defines this population as children "...who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (p. 5). Although children with special healthcare needs (CSHCN) only account for roughly 15% of the pediatric population, (USDHHS, 2013) these children account for over one-third of pediatric medical care (Bogetz, Bogetz, Rassbach, Gabhart, & Blankenburg, 2015). The significant amount of medical care is due to multiple visits to different providers and specialty care such as physical, occupational, and speech therapy, leading to increased healthcare costs.

Caring for these children is incredibly time consuming for parents and extended family members. The USDHHS (2013) reported that 13.1% of families with CSHCN spend 11 hours or more per week arranging and coordinating care for their child. The USDHHS (2013) also reported that having CSHCN greatly affects family finances, caregiver mental health, and employment status. Indeed, these parents face many challenges managing their child's special needs, including choices about immunizations.

Routine childhood immunization is one way to prevent disease and reduce healthcare costs in this vulnerable, yet steadily increasing (Cohen et al., 2011; USDHHS, 2013), population. Vaccines are one of the greatest public health advances in the 20th century. The Centers for Disease Control and Prevention (CDC) (2017) recommends vaccination for all children, with few exceptions. Therefore, immunizations can and should be given to most CSHCN. However,

parents decide if their children will be immunized. Parents of CSHCN often take into account the child's current health before obtaining immunizations, sometimes leading to delay or hesitancy.

In healthy children, previous research of parental immunization hesitancy has pointed to several themes including lack of perceived need of vaccinations, limited understanding of vaccine safety, lack of trust in healthcare providers and government, perceived lack of involvement in the decision-making process, erroneous link between vaccines and autism, immune system overload, lack of adequate time and resources, and religious objections to vaccines (Barrows, Coddington, Richards, & Aaltonen, 2015). However, in CSHCN, parental attitudes of immunizations are unknown. The purpose of this research is to explore attitudes regarding immunization among parents of CSHCN.

Research Question

The following research question guided this study: what are the attitudes and perceptions of parents of CSHCN regarding routine vaccinations?

Methods

Setting and Sample

Parents were considered eligible for participation if they had at least one child with special needs who was a patient of a pediatric specialty clinic at Utah Valley Hospital.

Participants needed to be able to communicate in English and be willing to attend a focus group.

Procedure

After receiving institutional review board approval, a convenience sample of parents was established. Initial contact with participants took place when a parent responded to advertisements or word of mouth from another participant and expressed interest in this study. A member of the research team talked with each potential participant, asked inclusion/exclusion

questions, explained study purpose and procedures, and answered questions. Each participant was then scheduled for a focus group that best suited his/her schedule.

The principle investigator (PI) attended all focus groups and conducted the informed consent process with other members of the research team observing and assisting as needed. Participants read and signed consent documents. Each participant was given a copy of the consent to keep.

Once focus groups were formed, a mutually agreed upon time was determined. Participants met in a conference room at the pediatric specialty clinic. Participants and researchers were introduced over light refreshments while demographic data were obtained (see appendix A). Audio recording was centrally located on the table and was started after introductions were conducted and informed consent was obtained.

At the conclusion of each focus group, participants were thanked by a member of the research team and reminded to keep the discussion confidential. Participants were then given a 20-dollar gift card. Audio recordings were transcribed. Transcriptions were cleaned to assure accuracy. All findings were combined and reported in aggregate. No identifiable information was reported.

We conducted four, 45 to 90-minute, focus groups with three to five participants in each group. One focus group had six parents scheduled, although only three attended.

Instrument

Focus groups were led by a member of the research team following a semi-structured interview guide (see appendix B) that was created for this study. While focus groups were mainly discussions, the interview guide included questions about the parents' experiences having

CSHCN and questions about their thoughts regarding immunizations and schedules and how each pertained to their CSHCN.

Data Analysis

Data from audio recordings were transcribed verbatim by a member of the research team. Data were cleaned and verified by the PI and research team members. Clean data were analyzed for themes. Using content analysis methods, data were read and coded using open and in vivo coding. Codes were grouped into categories and themes.

Findings

Participants

A total of 16 parents participated. Females (n=13, 81.3%) were placed into three focus groups and males (n=3, 18.8%) into a fourth focus group. Of those reporting ethnicity, the majority of participants identified as Caucasian (n=15, 93.8%). Average age of female participants was 40.76 years (SD = 8.63). The average age of male participants was 43.33 years (SD = 16.19). All participants were married. The number of children in the home ranged from 1-11 (M = 4.4, SD = 2.6). The number of CSHCN in the home ranged from 1-9 (M = 2, SD = 2.2). The participant with nine CSHCN revealed they were all adopted. The average age of CSHCN was 8.2 years (SD = 5.9). Half of participants had completed education beyond high school. Approximately one-third of participants (37.5%) reported earning less than \$50,000 a year.

While the purpose of this study was to determine the attitudes of parents of CSHCN regarding immunizations, analysis revealed parents simply wanted to share life experiences rearing these children, with issues of immunization being secondary. Therefore, data obtained from these parents comprised two major overriding themes: life of caring for a CSHCN and decisions surrounding immunizations.

Life of Caring

In general, parents that participated in the focus reported that discussing their feelings with those of similar circumstances was helpful. Participants described the experience of caring for their CSHCN related to isolationism and the weight of responsibility as leader of the child's care.

When asked what it was like to have a child with special needs parents responded with “*challenging,*” “*hard,*” “*stressful,*” “*not fun,*” “*unpredictable,*” “*constant,*” and “*scary.*” However, the prevailing word used was “*isolating,*” or various synonyms of isolation. Foremost, it is very difficult for parents to leave home, stating trustworthy childcare is nearly impossible to find. One mother explained, “*I only can leave her home about an hour with my son, but any more than that, I'm scared to. I'm a stay at home mom because I can't trust anybody to take care of her.*” Another mother said, “*Nobody can babysit him because of his oxygen and his feeding requirements.*”

In addition to childcare problems, parents often stay home with their CSHCN to prevent illness. When asked how parents protect their children from contracting disease, one mother responded, “*...years of isolation in my home.*” She went on to say, “*People can't live like this.*” A father said, “*We isolate. We stay away from people.*” Finally, another father stated:

We have spent five of the last seven years with one of our kids in danger of illness and having to stay sequestered away from people we love. Not going to family reunions and not doing stuff [in order] to avoid illness.

The lack of respite from childcare and the need to prevent illness led many parents to experience severe social isolation. Participants were saddened by the loss of friendships and social interaction. A mother stated, “*There are weeks that the only other people I see, besides my*

immediate family, are therapists.” Another parent said, “What do I do all day? I sit in my house with my kids.”

Participants said their experiences related to rearing CSHCN were not completely understood by friends and family, which exacerbates feelings of isolation. *“It’s isolating because people don’t get it,”* a mother stated. She went on to say that her child looks perfectly normal on the outside, so others don’t understand her high level of anxiety. A father explained, *“It’s isolating for the obvious reasons, but then there’s friends that I had, and they’re not serious, and it’s kind of hard to maintain the friendship. It’s kind of like life has changed for me.”*

Feelings of isolation were even capable of negatively influencing marriages. One father spoke powerfully when he expressed feeling isolated from his wife, *“I feel lost. I feel like I don’t belong to her anymore, cause she’s always with my daughter, always talking, kind of leaving me out of the deal, and it’s kind of hard for me that way.”*

Leader of Care

In addition to feeling isolated, parents reported feeling an overwhelming weight of responsibility as they became the leader of their child’s care. Becoming the leader of care for CSHCN was a life-changing sacrifice for parents. This burden was not expected when the participants decided to have children, and there was a longing for normalcy. *“You never plan your life for these kinds of things,”* expressed a parent. *“It’s a lot on a family,”* said a father. One mother describes her personal sacrifice, *“I had to stay home. I had to quit my career, but the medical bills just keep growing higher and higher.”*

Parents explained their role as leader of care. The responsibilities include educating themselves about medications and treatments, becoming an expert in the child’s condition, bowing to the knowledge of providers, administering care, being flexible with uncertainty,

making difficult decisions, balancing the needs of other family members, being financially responsible, and a never-ending sense of duty to protect the child. These responsibilities affected careers, relationships, marriages, finances, and time. This father explained, *“It’s like everything that we do, in a lot of ways, is affected by it [caring for the child], because of it.”*

The majority of mothers identified themselves as leader of medical care for their child. Mothers supported this point by saying they are with the child more than anybody else. As one mother explained, *“I am the primary advocate for my child. I know my child first and foremost, better than anybody else.”* Another mother stated, *“I am my child’s expert, even if I’m not a heart expert or anything.”* For the most part, the group of fathers considered themselves to be co-leaders, with the respective mothers, of their child’s care.

Although parents expressed value in the expertise and knowledge of a provider, many parents viewed physicians or nurse practitioners as consultants, and the parents, especially mothers, made medical decisions after considering provider input. *“I value his [the provider’s] opinion immensely, but ultimately I make the decision,”* this mother explained.

A trusting relationship with the provider was imperative for a parent to listen to/follow a provider’s advice. Parents verbalized a desire for the provider to know and understand their child and his or her specific special need. Parents felt that trust in their provider, as well as feeling trusted and respected by their provider, were a priority. Mutual trust was cultivated when a parent reported feeling like a provider was already familiar with the child. One mother requested:

Recognize that my child is different...Take a couple of minutes before they come in and look over your information on the chart, and come in knowing a little about the child...I want to be confident that they know a little bit about my child. Come in already knowing him a little.

Immunization

Along with discussions about personal experiences, immunizations were discussed in each focus group, and three themes were identified. Parents discussed their overall feelings about immunization, the desire for an individualized immunization schedule for CSHCN, and the need to rely on the community's immunization status in order to protect their child.

Overall attitudes. Participants expressed positive attitudes concerning childhood immunizations and knowledge of the importance of immunizations in their own children as well as in others in their communities. Many parents voiced these beliefs with conviction and passion. “*We are very strongly for immunizations.*” Another mother shared the following statement:

We vaccinate on time. We get the flu shot the second we can because she [the CSHCN] has a trach. She has chronic lung disease. Any tiny virus lands us in the hospital. If she got influenza, that would be it. She'd be toast.

One parent stated, “*I've kept him [the child] on a really tight schedule, and do the flu shot, because I love vaccinations. I think we're so lucky to live in a time that we have them. I think they are a huge benefit.*” One father expressed his feeling about vaccinations, “*No question about it. They're [all children in the family] immunized as soon as they're able to be immunized. They're immunized for the flu every year. There's no question about it. We immunize as much as we can.*”

Although most parents were pro-vaccination, some parents of CSHCN did voice slight apprehension about immunizing their children. One mother questioned the cause of her child's condition and considered vaccinations, among many other things, as a possible cause. However, she went on to say, “*If I ever had another baby, would I do immunizations again? Probably.*”

Individualized schedule. Because of slight apprehension, a few participants desired to choose their own immunization schedule. Because their children possess unique needs, parents felt that existing healthcare guidelines did not always apply to their children. Parents also felt they knew what was best for their child, even more than health professionals. Therefore, although participants admitted to understanding the importance of immunization in CSHCN, several parents expressed the desire for individualized vaccine administration schedules. One mother stated:

My baby is little. He's one, and we have been very slow on the immunizations, because I was worried...I was worried his body wouldn't be able to process the immunizations. So, we have been slow...I do believe in immunizations. I think we should do them, and I am doing them for him, but very slow...I'm hoping that I'm not hurting him by not doing them on schedule.

Another parent shared similar concerns about vaccinations and decided on an altered schedule for her children.

I worry about them [immunizations]. When he had his MMR [measles, mumps, and rubella vaccine] he got really sick. He was kind of different anyway, but he was more different after that. Then he started having seizures, and I don't know if it was from the MMR or not, but that's one shot I decided to wait on with my other kids... So, with my other kids I waited until they were four to give them the MMR...For the most part, all my kids are immunized.

Finally, one mother shared her experience with their provider regarding an individualized immunization schedule:

I brought in my opinion about how I wanted to stagger some of these immunizations better, and he [the provider] did not like that. We eventually moved. We found a different provider, and she's very respectful of the fact that I don't want to give him nine immunizations today. Let's give him three, and I'll be back in a month.

Relying on community. Not only did parents express their feelings about vaccinating their own children, they discussed their hope of others getting immunized and frustration at those who don't. Many participants reported having at least one child who is immunocompromised and explained the need to rely on others' immunization status to protect their CSHCN. *"I really hope all the healthy kids have had theirs [immunizations], to save mine,"* one mother stated. *"We really need people to get vaccinated,"* said another parent. A father, expounded on this by sharing the following:

It's scary. When she [his child] was going through cancer treatments, and she was super immunocompromised, and didn't have any ability to fight stuff, she got exposed to chicken pox [by an unimmunized child]. We read about chicken pox and immunocompromise. If she got it, it was really dangerous, and it could kill her. It was a decision of that mom not getting her kids vaccinated...It's annoying to get chicken pox, but in my family, it's more than annoying.

This father continued, *"With our kids being immunocompromised, we have really relied on other kids being immunized."*

Parent's voiced frustration about their need to rely on others for protection of their own children. *"You can't rely on other people getting vaccinations. It's even a larger reason for us to make sure he does get them [immunizations], because we can't ask. We can't ask if everyone's been vaccinated or not,"* a mother explained.

Participants recognized that, as a community, the consequences of vaccine refusal are shared. These parents reported feeling their families often bear the consequences for others' choices. Parents explained the decision whether or not to vaccinate is very different for their family compared to parents of a healthy child. One father said, *"It's hard to see other people make decisions that affect you, and you can't control them. It's scary and serious for some of us out there."*

Because of these frustrations and fears, parents stated that there needs to be more dependable education made available to the parents of healthy children. *"It would be nice if they [health care professionals] could do better at educating [the public] on vaccinations. There's a lot of misinformation and misunderstanding about vaccinations...It's like they're [the public] getting their information from all the wrong sources on what vaccines are."* This father also said, *"Even with the flu vaccine, though. I've told my extended family members about it and have pushed them to do it, and there's always a little bit of push back...It's hard to educate them about it."* In general, participants wished parents of healthy children more clearly understood the implications vaccine refusal has on fragile children, especially their own child and family.

Discussion

Parental attitudes about immunizations has been a topic of concern and research for healthcare professionals. Additionally, parents of CSHCN have been studied.

Life of Caring

Participants reported feeling as though they were guardians of their child's health, which many of them described as *"isolating."* Parents of children with disabilities (who are often children with special healthcare needs) experience poorer health themselves, and parental health is directly influenced by social support (Cantwell, Muldoon, & Gallagher, 2014). Indeed, parents

of children with mental and physical disabilities have reported lower social engagement than parents of healthy children (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). Similarly, parents in this study reported feeling a lack of social support. Studies suggest social support is especially important for success of families of children with special needs (McConnell, Savage, & Breitkreuz, (2014). Parents, particularly mothers in this study, reported feeling isolated and estranged from family and friends.

In their study detailing parental experiences with CSHCN, Woodgate, Edwards, Ripat, Borton and Rempel (2015) report parents of CSHCN often feel the overwhelming role as caregiver. This role involved guarding over the child's health status, medical treatments/procedures, safety, and psychosocial well-being. Woodgate et al. (2015) emphasize that the role of protector was something parents could not escape. As a result, parents were constantly at their child's side within the home. These parents also reported missing out on many social activities in order to keep their child protected from harm.

Leader of Care

Additionally, mothers in this study reported the burden of managing their child's health information. Health information is managed and kept primarily by mothers/wives (Zayas-Cabán, 2012). Although fathers reported sharing in the duty of making healthcare choices, mothers reported feeling like the team captain, when managing the health information and care of their child. Mothers reported feeling responsible for knowing when appointments were required, what information a healthcare giver needed, and coordinating information between healthcare providers, including current immunization status of self and child.

Woodgate et al. (2015) found that in a few cases mothers assumed the primary caregiver role, but fathers and mothers usually assumed a partnership or "tag team" approach when

providing care. This approach was necessary due to the amount of care required by CSHCN, which often exceeds that of a typical child. Paternal involvement can have a positive effect on the parent, the child, and his family (Swallow, Macfadyen, Santracroce, & Lambert, 2011).

Attitudes Regarding Immunizations

Parents of CSHCN reported an overall supportive attitude about immunizations. Current vaccination rates remain fairly high among the general public. Therefore, it could be assumed that most parents with healthy children have positive attitudes about immunizations as well. However, Kennedy, LaVail, Nowak, Basket, and Landry (2011) argue that high vaccination rates do not necessarily mean that parents do not have questions or concerns about immunizations. They report that only 23% of parents surveyed stated that they did not have any concerns about immunization (Kennedy et al., 2011). Although the majority of parents that participated in focus groups viewed vaccines positively, a small number voiced concern as well.

Community Implications

Parents identified the belief that their families often bore the burden for the immunization choices of others in their communities. Current literature regarding vaccine refusal validates these feelings.

Vaccine refusal is a danger to the public's health. We are living in a time when children and other vulnerable populations are contracting vaccine preventable illnesses years after these diseases were thought to have been eliminated in the developed world. (Dredze, Broniatowski, Smith, & Hilyard, 2016, p. 552)

Parents also expressed concern over the perceived lack of understanding from community members about the importance of immunizations. Participants voiced worry about the type of information community members receive about vaccinations. Kata (2011) found that at least

80% of Internet users search for health information. Sixteen percent of these users search for information on vaccination, and of this group, 70% state that what they found online influenced their decisions about vaccination. Turning to the Internet can be beneficial and may allow parents to be more involved in their child's care, but it can also lead to misinformation. Many anti-vaccination groups and self-proclaimed experts post content to social media, blogs, websites, etc. This content can be compelling without scientific evidence to support it, thus resulting in many misinformed parents and community members.

Implications for the Nurse Practitioner

Several parents identified that support groups were helpful for feelings of isolation. As patient advocates, nurse practitioners should refer parents of CSHCN to social media groups and other types of support groups so they can interact with others in similar situations.

Parents that participated in this study recognized the need for more community based education about vaccines. Education could be in the form of public service announcements, learning modules, or the use of social media. Because many parents turn to the Internet for guidance, it is crucial that it and social media are used to spread reliable data about vaccines in order to prevent future outbreaks of vaccine preventable diseases (Dredze et al., 2016). There are various ways this can be done. Kata (2011) summarizes some possibilities:

Some proposals include “immunizing” against misinformation through education, using emotional appeals, or even harnessing social media in return – such as by creating web-based decision aids about vaccination, using real-time Internet tracking to determine public attitudes, or launching social media campaigns. (p. 3784)

Although the Internet is a major source of information for parents, it does not replace the relationship with the child's provider, it merely supplements it (Kennedy et al., 2011). Parents

expressed the desire for a patient/provider relationship consisting of mutual trust and respect. Parents reported trust was increased when a provider relayed a personal relationship to the child and his/her parent. Providers should, therefore, take time to review the chart of CSHCN before entering the room. Specialty clinics may consider creating a one-page summary or face sheet for CSHCN, allowing the provider to quickly review the history, special needs, and chronic conditions.

Additionally, practitioners can increase the potential for quality relationships by utilizing electronic medical records. Primary care providers may identify a way to tag CSHCN on the electronic medical record. A tag would assist the provider in identifying a child that sees a specialist or that is receiving services such as homecare or any therapies. If the provider has a way to recognize these children in advance, he or she can adequately prepare before entering the exam room. Additional preparation and understanding of the child's unique needs will instill parental confidence in the provider.

Finally, parents emphasized their desire for personalized care for their child. However, providers need to teach parents the importance of keeping to the CDC's recommended immunization schedule. Kennedy et al. (2011) found that health care professionals continue to be the most important source of information when making decisions about vaccinations. This was followed by family, friends, and then the media. Therefore, nurse practitioners can be very effective when educating parents. Providers can acknowledge a child's vulnerability and emphasize the importance of strictly adhering to the recommended schedule in order to protect CSHCN from disease. Providers can also help parents understand that the recommended schedule is backed by extensive research and is recommended for nearly all children. With an

established relationship of trust, the provider can better educate and encourage the appropriate vaccination schedule for CSHCN.

Limitations

This study has limitations. The sample came from one small pediatric specialty care clinic. The sample for this study was homogenous and may not represent other cultures or ethnicities. This study also had small focus groups; especially notable is the limited representation of fathers. Findings can only cautiously be generalized to other parents of CSHCN. Additionally, although the purpose of the study was to explore parental attitudes regarding immunizations, parents spent a significant amount of time discussing the emotional stress of parenting a CSHCN. The findings from this study were therefore, at times, not directly related to the research question.

Recommendations for Future Research

Additional research would further our understanding of this unique and growing population. Future research is warranted on the use of electronic medical records to increase provider preparation prior to clinic visits. Research on tagging, tracking, and personalizing care for CSHCN has the potential to enhance provider/parent relationships, thus increasing the likelihood for greater immunization compliance. Additionally, similar studies with large sample sizes should also be conducted. Of special note is the need for additional research on the perception of fathers of CSHCN.

Conclusion

CSHCN are a key portion of the pediatric population in the United States. The responsibility of caring for these children requires massive amounts of time and resources from family members, resulting in increased parental stress and feelings of isolation. Therefore, many

parents of CSHCN would benefit from additional social support, particularly by interacting with those in similar circumstances through support groups and social media groups.

Contributing to high levels of stress and isolation, mothers of CSHCN usually assume the burdensome role of medical team leader and decision maker. Although mothers considered themselves to be the medical team leaders and main decision makers, they valued the knowledge and expertise nurse practitioners. Trusting relationships with providers were essential for parents, especially mothers, when making medical decisions, including decisions about immunizations.

The majority of parents in this study viewed childhood vaccinations in a positive light. Parents recognized it was important for their own children to receive vaccines. Parents also recognized that for their own child(ren)'s protection, community members need to be vaccinated. However, the desire for individualized care, at times caused parents to disregard the immunization schedule recommended by the CDC. Healthcare providers must deliver reliable and trustworthy education to families of healthy children as well as CSHCN to improve childhood vaccination rates and compliance with the recommended administration schedule.

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Appendix A

Demographics Questionnaire

1. What is your gender?
 - a. M
 - b. F
2. What is your age? (in years)
3. What is your current marital status?
 - a. Now married
 - b. Widowed
 - c. Divorced
 - d. Separated
 - e. Never married
 - f. Don't want to answer
4. How many children do you have living in your home?
5. What is the placement of the child with special health care needs in your family?
(e.g. oldest of 3, 3 of 7)
6. How old is your child with special healthcare needs? (in years)
7. What is the gender of your child with special healthcare needs?
 - a. M
 - b. F
8. What medical resources are you currently using to help care for your child with special healthcare needs? (e.g. OT, PT, Home health, respite care)
9. What are you currently using for social support?
(e.g. family, blogging, community programs, social media)

10. Do you currently have children under 2 years of age living with you?
 - a. Yes
 - b. No
 - c. Don't want to answer

11. Do you currently have health insurance (self, employer, or parent sponsored)?
 - a. Yes
 - b. No
 - c. Don't know
 - d. Don't want to answer

12. What is the highest level of education you have completed?
 - a. Less than high school graduate
 - b. High school graduate
 - c. Technical school training
 - d. Bachelor's degree
 - e. Master's degree
 - f. PhD, or other doctoral degree
 - g. Don't want to answer

13. What was your total household income before taxes during the past 12 months??
 - a. Less than \$25,000
 - b. \$25,000 to \$34,999
 - c. \$35,000 to \$49,999
 - d. \$50,000 to \$74,999
 - e. \$75,000 to \$99,999
 - f. \$100,000 to \$149,999
 - g. \$150,000 to \$199,999
 - h. \$200,000 or more
 - i. Don't want to answer

14. What is your ethnicity?
 - a. American Indian or Alaska Native
 - b. Asian
 - c. Black or African American
 - d. Native Hawaiian or other Pacific Islander
 - e. White
 - f. Other
 - g. Don't want to answer

15. Do you consider yourself Hispanic or Latino?
 - a. Yes
 - b. No
 - c. Don't want to answer

Appendix B

Focus Group Interview Guide

1. What have been your experiences of having child with special healthcare needs?
2. What are your thoughts or opinions about immunizations for children with special healthcare needs?
3. Why are immunizations important for children with special healthcare needs?
4. Why would you have your child with special healthcare needs receive routine immunizations?
5. Why would immunization not be appropriate for children with special healthcare needs?
6. Why would you not have your child with special healthcare needs receive routine immunizations?
7. What should healthcare professionals consider when discussing immunizations for children with special healthcare needs with you as a parent?