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# Services and Supports for Families of Children with Special Health Care Needs: Rural vs Urban Settings

Jackie Johnson

*St. Catherine University*, [jackiejohnson148@gmail.com](mailto:jackiejohnson148@gmail.com)

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Services and Supports for Families of Children with Special Health Care Needs:  
Rural vs Urban Settings

By

Jacalyn Johnson, LSW

MSW Clinical Research Paper

Presented by the Faculty of the  
School of Social Work  
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St. Paul, Minnesota  
In Partial fulfillment of the Requirements for the Degree of  
Master of Social Work

Committee Members:  
Lisa Kiesel, MSW, Ph.D., LICSW (Chair)  
Jenny O'Connor, LSW  
Brittany Vlaminc, FNP-C

The Clinical Research Paper is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by the research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

### **Abstract**

The purpose of this qualitative study was to survey parents and caregivers of children with special health care needs (SHCN) to determine what they find important in the services they receive for their child with SHCN. A special focus was placed on if they live in a rural setting vs an urban setting and where they find the needed services. The results of the study indicate that parent and caregivers are willing to drive to an urban setting for services. They would rather keep their home community in place and drive up to an hour one way for the needed services.

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Services and support for children and their families who have Special Health Care Needs (SHCN) has gained increased interest, including interest regarding to how to best serve these children. As a result of this increased interest many of these families and children receive the services and support that they need to function in the best possible way. Support is defined as “resources and strategies necessary to promote the development, education, interests, and well-being of a person. Supports enhance the individual functioning. Supports can come from family, friends and community or from a service system” (thearc.org). Services can be defined by the dictionary as “the action of helping or doing work for someone” the services that the individual families need can also come from family, friends and from the community. Throughout the research the terms of service and/or support are used interchangeably.

Children with SHCN are a diverse group of children; the disabilities can become apparent at any time but typically before the age of 22 and can last the rest of their life (thearc.org). According to Jansen, van der Putten, and Vlaskamp (2012) on average parents who are able to receive services for their child with SHCN were satisfied with what services were offered to them. The age of the child when the services are provided can change the way parents felt about what services that they were offered and the type of services that they received for the child. The parents of older children up to the age of seventeen were more satisfied then the parents of younger children. If a child is diagnosed after age seventeen, there seemed to be more obstacles for the families to overcome when trying to access new services. (2012)

The children who have unmet needs face many barriers in the health care system; consequently, it is important for providers to know how to better serve these children and their families. It is also important to families so they know what services are available to their children. This can help both the provider and the family work together better, to ensure that

children needs are met. Based on the National Association of Social Workers (NASW) Code of Ethics there are two critical components regarding this population of people. In the NASW Code of Ethics, first is social justice, social workers pursue social change, particularly with and on behalf of vulnerable and oppressed individuals and groups of people. The second value of the dignity and worth of the person states that social workers respect the inherent dignity and worth of the person; both the families and the children with CSHCN need and deserve the respect from others.

Social workers need to know what services are available to children and their families. Seeking to understand the experiences of children and families that have unmet needs will be helpful in improving the services that are provided and coordinating what services should be provided to the child.

The purpose of this research is to better understand what parents of children with SHCN (a) find important in services that they receive, (b) what additional services they would like to see to help support their children, and also (c) finding services in a rural setting verse services in a urban setting. The research question that will be addressed: What effects does having a child with SHCN have in determining where the family chooses live.

## **Literature Review**

### **Who are Children with Special Health Care Needs?**

A special health care need is defined by the federal Maternal and Child Health Bureau as “those who have or are at increased risk for 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” (childhealthdata.org).

The list of conditions that define children with SHCN can include but not limited to Learning Disability, ADD/ADHD, Developmental Delay, Intellectual Disability, Cerebral Palsy, Bone, Joint, or Muscle problems, and Brain Injury (childhealthdata.org). This is in no way a complete list of some of the conditions that are considered when looking at children with SHCN. There will be differences in the diagnose of a child with SHCN depending on what research you examine.

### **Services in Urban Setting vs Rural Setting**

When looking at the differences between the urban health care setting and a rural health care setting and the services that each setting must offer can vary depending on the town and its proximity to a larger medical facility. Using a longitudinal study of 23 families Haring and Lovett (2010) gathered information on the perceptions and experiences that parents and other family members of babies that were identified neonatally in crisis or shortly after having been diagnosed with development disabilities. This study looked at families that lived in a rural setting. With the isolation of the rural setting, 74% or 17 out of 23, of these infants were sent by helicopter to the larger urban hospital because they were identified as being in neonatal crisis (Haring & Lovet, 2010). As part of the study done by Haring and Lovett (2010) there were four additional infants that were sent to the larger hospital by ambulance. The experience that the families had of the infants that were not transported was dramatically different. The families that stayed at the smaller hospital faced many unique difficulties in trying to get services for their infant. Authors Fulda, Johnson, Hahn and Lykens (2012) noted in their study that that there are geographic differences in unmet health care needs for children with SHCN.

### **Gaps in Services in the Rural Setting**

During the study done by Haring and Lovett (2011) one of the main complaints from the rural families were the availability of specialized medical care and development services were lacking also in the smaller rural area. The study looked at how to improve the way that services are delivered and access by families in the rural setting based on the experiences of the families that were interviewed. According to Haring and Lovett (2011) a family with a child that has a chronic illness or disability living in a larger metro or access to a larger metro area will have better access to the services that the family and children with SHCN needs.

According to research done by Axtell, Garwick, Patterson, Bennett and Blum (1995) a family that has a child with multiple impairments had more needs that were not being met. There needs to be more access to services for these families and the different service providers need to be helping the families find the resources that are needed. This study does not capture the needs of children that are not covered by some sort of health insurance. All of the children that were studied had health insurance coverage, which made receiving service easier for the family to obtain (Axtell, Garwick, Patterson, Bennett and Blum, 1995).

### **Key Variables for Families**

According to a study by Jansen, van der Putten, and Vlaskamp (2012) there is a very important partnership between the parents and the professionals in the support of children with disabilities. It is very important to acknowledge the key element of family centered care for these children. The study looked at what parents with children that had Profound Intellectual and Multiple Disabilities (PIMD) found important in support for their children. There were 100 total parents that completed an adapted version of the Measure of Processes of Care (Jansen, van der Putten, & Vlaskamp, 2012). The survey showed that parents on average were satisfied with the

services provided but the age of the child with the disability and the severity of the disability played a part in their satisfaction. The results of the study show that parents with children with PIMD find having family centered principles in the support of their children is important. Although the majority of parents are happy with the support that they received for their children, there are still some parents that are not able to access the services or the support that they feel they need.

### **What Resources Are Available to Families**

The study by DeCesaro and Hemmeter (2009) finds that a higher proportion of children receiving SSI have a higher rate of unmet needs, they have parents with a high school or equivalent level of education. One explanation for the unmet needs of these children is because the parents have jobs with poor health insurance or inflexible work schedules leading to the inability for the child to receive all the necessary services. (DeCesaro and Hemmeter,2009).

A study done by Jackson, Krishnaswami, and McPheeters (2011) states that some barriers to care for children with Cerebral Palsy (CP) and other CSHCN show the inability to afford health care or to afford to take the time off of work in order to take care of the child with the disability. Families had out of pocket expenses between \$1000 and \$5000, these families reported that the expenses associated with caring for a child with a disability caused significantly greater financial burden than did the families that had their health care needs met. (Jackson, Krishnaswami and MCPheeters, 2011).

### **Support**

In a study done by Nageswaran, Parish, Rose, and Grady (2010), they measured how difficult it was to use service for children with SHCN, their study showed that families with higher education are more likely to perceive health services as being difficult to use. According

to the study it suggests that families with higher education know more about the health care system and perceive the difficulties in using it. On the other side of this study there is a possibility that families with poor education could have other family and social supports systems in place that are unavailable to families with higher education. (Nageswaran, Parish, Rose and Grady, 2010).

### **Family Satisfaction for Services Received**

A recent study of Axtell, Garwick, Patterson, Bennett, and Blum (2011) uses data from 187 families with young children who have chronic illnesses and disabilities to determine if the parents are satisfied with the services that they receive and what additional unmet needs and services are available to the family. The results indicated that families were relatively happy with the services that they were receiving but 28% reported that they had additional unmet needs and services. Most of the unmet needs fell into the category of therapy: occupational, physical or speech; parents were also unable to get respite care for their children. Lack of money seemed to be the primary reason that the needs of the children were not being met. According to DeCesaro and Hemmeter (2009) a family with a higher medical out of pocket (MOOP) expense have a greater percentage of unmet needs compared to those families that have no unmet need.

The findings of Jackson, Krishnaswami, and McPheeters (2011) look at children with severe health conditions such as cerebral palsy and what needs they have in comparison to other children with special health care needs (CSHCN). The data shows that children with CP have a greater occurrence of unmet health care as compared to other children with special health care need. The needs that with a growing child with CP prove to complicate the services and support required by the child and their family due to the fact that they must continually adjust as the child grows. Children with CP are similar to children with special health care needs in the fact

that they will all benefit from some sort of collaborative type of programs to help target the service they receive. To show the need for continue studies that focus on the complexity of the whole of a child with complex medical conditions. The goal according to this research is to provide more information about what children and families with complex medical conditions are missing from their care. Also, to make sure that there is some kind of universal care standards for these families. This continued research will help these families to get some of the additional needed health care. By recognizing that there are unmet health care needs of these families, both the policy makers and the health care providers can work at improving the lives of these children and their families. By working together with a family, a health care provider can be more informed as to what the additional needs these families have, such as easier access to the specialized doctors the children may need, less expensive health care so the family can afford the additional care the child needs.

### **Importance of Early Intervention**

According to Warfield and Gulley (2005) access to health care services are important to the development and well-being of all children, children with SHCN or chronic conditions are more vulnerable to becoming part of a poorer health outcome. Care coordination can be associated with the reduction of families with children that have SHCN having unmet specialty needs. (Boudreau, Goodman, Kurowski, Perrin, Cooley and Kuhlthau, 2014). The research that was done by Boudreau, Goodman, Kurowski, Perrin, Cooley and Kuhlthau (2014) found that care coordination is associated with a family reporting that the needs of the child are being better met. When DeCesaro and Hemmerter (2009) did their research, they found that children who had Medicaid insurance were less likely to have unmet health care needs on the other hand the children that did not have Medicaid insurance had a greater occurrence of unmet medical needs.

According to the study done by Boothroyd and Armstrong (2005) they found that there needs to be implemented comprehensive health policy's that emphasizes the importance of assessment, prevention and early intervention for all children with SHCN.

### **Conceptual Framework**

When reviewing the research that is available, regarding families that are receiving services for their children with special health care needs, a framework for understanding the research starts to develop. The ecological perspective was developed by the psychologist Urie Brofenbrenner in 1979, this framework tries to understand the larger system that is involved. This theory allows us to gain a better understanding of each family and how they function within their own environment and the various outside factors that influence the family.

The ecological model can become more specific and moves into systems theory in relation to the family. The systems theory as it relates to the families that have children with SHCN. According to Kerr (2016) "The Bowen family systems theory is a theory of human behavior that views the family as an emotional unit and uses systems thinking to describe the complex interactions in the unit" (Kerr, Michael E., 2000). Within this theory Kerr describes the thought that families are so profoundly affected by the thoughts, feelings and actions that when people are living under the same "emotional skin". This research leads to the connection that the child that has SHCN affects the entire family system. This contributes to the research that the entire family system is affected by the child with SHCN.

The ecological model and the system theory as it relates to the family system are what is most important when doing research that involves families that have children with SHCN.

## **Methods**

The methods section of this paper describes the research study to take place. It describes how the research questions will be address. The research questions this study aimed to answer are 1) How are parents with children that have SHCN accessing the medical needs of their children, 2) Is there a difference in the medical services provided to families that live in a rural setting verses a more urban setting and 3) Have these families made decisions on were to live depended on where they could receive the services. These questions were addressed using a survey which can be found in Appendix C.

### **Research Design**

The purpose of this study was to explore the ways in which families with children that have SHCN access medical services that their children need. The research design of this project used was a short response survey created by the researcher. This survey will be administered using an online survey on qualtrix. The survey recruitment message and survey link will be distributed by Special Education Teachers in both the Rochester Public Schools which will be considered the urban setting and in the Caledonia Public Schools which will be considered the rural school setting to the parents of children with special health care needs. The teachers will send out an email to the parents with a link asking them to complete the survey. The researcher sought to understand the parents' perceptions of the quality of medical care received by individuals with SHCN. This research study was submitted for approval to the St. Catherine University Institutional Review Board (IRB) before actual data collection began.

**Sample**

This utilizes the use of a convenience sample to establish a group of participants through a purposive snowball method. The reason for using this type of sample technique was to allow the special education teacher to identify which students' families fit into the research criteria. The sample this author will use includes parents (mothers, father, grandparent or other) who are caring for the child with a SHCN. The researcher included both families that live in the rural setting or in an urban (metro) setting.

**Protection of Human Subjects**

This study was reviewed by a research committee and submitted to the St. Catherine University Institutional Review Board. Special education teachers were contacted and were asked to send an email out to the caregivers of the students that they had identified as fitting into the research criteria with a link to the survey. The special education teachers distributed the email with the survey's URL, and the researcher never had access to the teachers' names or emails. Upon distribution of the surveys, caregivers had the option to participate in the study or decline to participate in the study. Participants received a consent form in the form of an e-mail attachment (Appendix A) informing them of their protection and voluntary nature of participating in this study. Participants implied consent to participate in this study by completing the survey. There were no risks or benefits to participating in this study. The data was stored on a password protected computer belonging to the researcher. After the completion of this study, the data was destroyed from the computer.

## **Data Collection**

The method used to measure results was an online survey using the computer program Qualtrics. The questions on the survey (Appendix C) were developed by the researcher and based on the literature reviewed for this study.

## **Data Analysis**

Once all the data had been collected the researcher analyzed the data and used grounded theory to organize and interpret the data collected. The surveys were examined for reoccurring themes and grouped together. Using these categories, the theories were arrived at. This allowed the researcher to identify major themes across the data set. Grounded theory uses the data to develop a common theme, or hypothesis, from the collected data, rather than looking for information to support a pre-determined hypothesis, (Monette, Sullivan, and DeJong, 2010). Each survey was analyzed to find the common themes that went through out.

## **Research Bias**

This researcher has a child with special health care needs and been part of the community for over 15 years, thus it can be assumed that the research had some bias in developing the survey and the research questions. Committee members help the researcher avoid having questions on the survey that would be too leading or questions that would be too narrow in focus.

## **Findings**

### **Sample**

The purpose of this research is to examine the choices that a family makes when having a child with a special health care needs. The participants of this study were parents or caregivers of children diagnosed with SHCN, either living in a metro (urban) area or a rural (small town) area in Minnesota. There were 35 respondents that were offered the opportunity to participate in

the study. Fifteen chose to respond to the survey, six currently live in a rural setting and nine live in an urban setting.

There was a variety of respondents made up of mothers and grandparent of children with SHCN. Of the fifteen respondents, there were thirteen that were married and two that were divorced. The age of the children with SHCN ranged from five to twenty, all the children are currently enrolled in the public-school system. The families have children with various SHCN, some of the listed conditions are Autism, Emotional behavioral disorder (EBD), Nooans syndrome, Seizure disorder, Autism spectrum disorder (ASD), Cognitive impairment, Epilepsy and Cerebral Palsy (CP).

### **Themes**

For the purpose of this research, themes will represent two or more participant's response with the same core idea. Themes are the overarching words or phrases that come about from participant's responses to the survey questions. Five core themes were found from the fifteen participant's surveys.

**Access to Services.** When asked where the participants found or utilized services for their child with SHCN there were three different ways that the participants found worked for their family. Eight of the families lived in an urban setting and could access services close to home. Two of the families received their services in the rural setting where they lived. Four of the families would drive to a metro setting to access services, their drive would range anywhere from 30 minutes to an hour just to get the services that their children need. One participant does not receive services outside of the school setting. One participant acknowledged,

My husband is a pastor who is seeking a congregation. Last year he was not placed in a church because we had to tell the Conference (governing body of Methodist pastors) that

we could not be more than an hour away from our son's medical center". There were three families that continued to access services within the rural community that they lived. And there were eight families that accessed services in the metro setting, these were the same families that lived in the metro setting.

**Housing Location.** The participants were asked where they chose to live, if having a child with a SHCN determined where they lived because of the services that were or could be provided to the child with SHCN. Seven of the participants reported that they did not choose to live where they live because of the services that they need for their child with SHCN. Three of the participants said that they might have chosen to live in a different place knowing they would need different services for their child. Five of the participants said that they chose where to live based on the type of services that their child with SHCN required. One participant noted, "If we could go further out/rural, my husband would have had a job in his vocation last year. He currently works at a factory so he can tend our son."

**Drive for Services.** When asking the participants how far they travel to access the services that their child with SHCN needs, eight of the participants drive anywhere from five to thirty minutes for service. There were five of the participants that must drive more than thirty minutes for the services that they receive for their child that has SHCN. Two participants that do not receive any services outside of the school district.

**Services.** All the participants responded with some of the current services that their child with SHCN requires. That list of services include speech, occupational therapy, physical therapy, respite services, psychological therapy, IEP services, horseback riding and specialized medical. A parent commented, "Medical has saved his life. Physical therapy is saving his legs. Psychological therapy is helping us to help him cope".

**Needed Services.** All the participants also responded to the question asking what services go unmet for your child with SHCN. One participant noted, “it is not easy to quantify, doesn’t qualify on its own for service needs”. That list is much shorter but just as important, the caregivers would like to see more opportunities for their children to have social activities geared towards them or included more readily with typical children. They would also like to see more emphasis placed on vocational services for the children with SHCN. When a child reaches graduation from high school there is limited opportunities available for them as far as vocational services. One participant expressed, “Vocational-Olmsted Act has not been beneficial for people working below minimal wage. It has become a barrier for individuals with developmental disabilities to get a job”. Then the third and final area that was identified as needing additional services is in transportation. There are transportation services available to children with SHCN but it is very expensive and not very reliable. Another participant expressed, “We don’t qualify for help and transportation is too expensive”.

## **Discussion**

### **Sample**

The participants for this research are all from south eastern Minnesota. The sample recruited for this study was less than expected. The expected or hope for was between thirty and thirty-five respondents, however that did not happen there were only fifteen respondents. The respondents were from both the urban and rural settings. There were nine respondents that were from an urban setting and six respondents from a more rural setting. It was speculated that parents or caregivers would choose to live in a more urban setting so that they would have greater access to resources or services for their child with SHCNs.

The respondents were made up of mothers and a grandparent of children with SHCN. Within the sample of respondents there were parents that were both married and divorced. The age of the children with SHCN ranged from five to twenty, all the children are currently enrolled in their local public-school system.

### **Themes**

There are three themes that are common among the participants in the rural setting, they described the need to drive up to an hour to get the services that their child with SHCN. These themes relate to how and where the families access the services, where they have chosen to live (housing location) and how far they drive for services. The literature talked about a study that was done by Haring and Lovett (2011) within that study one of the main complaints from the rural families was the availability of specialized medical care and the development of services were lacking also in the smaller rural area. This theme was similar to what was found during the research that the families in a smaller more rural area had to drive to a larger urban area to receive their services.

The theme that was not similar to the literature was in relationship to what services the participants are receiving and what services that are needed by the families. What services that the participants feel would be beneficial to their children with SHCN. It is possible that these themes are not found in literature because the previous research was done in different regions of the country. These themes can be specific to each state and then even more specific to each area of the state. The current research was conducted in Southeastern Minnesota with the urban area being focused on the Rochester area and the rural area the participants lived minimum of a hour

from Rochester MN. The Rochester area has a large medical facility with in the community which has a great deal of services available to the participants living in the urban area.

### **Implications for Social Work**

The data gathered provides significant implications for professionals in the field of medical social work. The data gather could also be valuable to social workers who encounter families that have children with SHCN in various settings. Some of the information could also be valuable to special education teachers that work with children and families that have SHCN this data can help them better service their children and families. As discovered in the literature review, according to a study by Jansen, van der Putten, and Vlaskamp (2012) there is a very important partnership between the parents and the professionals in the support of children with disabilities. It is very important to acknowledge the key element of family centered care for these children.

At the micro level of practice social workers can work to ensure that families are receiving all the services that are available to them. If that means making sure that there is some sort of case management service in place to facility that nothing is getting missed. The case manager would also be able to ensure that all the service providers are working in the best interest of the child and family.

At a mezzo level this means education of social worker. Making sure that they can recognize what a family may be going through when they have a child diagnosed with a SHCN. As a social worker having the knowledge of the services that are available to the families both in the area they seek the medical care and if they live in a rural setting what services would be available to them locally. All the participants reported that the diagnose was given to them by a physician at an early age, most of the participants were diagnosed by the age of two. Helping the

parents cope with the loss that they are feeling can in turn help the parents educate the people around them about the differences in their child. This helping the child become better accepted by the large community that they live in. Also, social workers should be connecting parents or caregivers to support groups for children with SHCN, which gives them a sense of community and support from others that have similar experiences.

At the Macro level, social workers need to be advocating at both the state and federal levels to put more affordable programs in place for families. As children with SHCN get older parents are trying to find programs and activities for their child to attend. As one participant responded, “We don’t qualify for help and transportation is too expensive”. By advocating for a better transportation that is less expensive would allow for the children to continue to more activity involved in their community and continue gain social interaction with peers.

### **Conclusion**

The purpose of this study was to gain the perspective from parents and caregivers about the services that they receive for their child with SHCN, what services that they would like to receive for their child and finding services in a rural setting versus services in an urban setting. Looking particularly at the effect of having a child with SHCN have on where the family chooses to live. The overall findings of the study were that parents and caregivers did not make the decision as to where to live based on the needs of the child with SHCN. These parents would continue to live in the rural setting and drive for an hour to receive the services that their child needs. It was just as important to these families to have their preferred community around them as long as they were still able to get the services that the child needed. Social workers can play a key role in helping the families navigate the services that are available to them both in their home community and the community that they travel to for the needed services.

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## Appendix A

### Email Letter to Parents/Caregivers

January 5, 2015

Dear Parents and or Caregivers,

I am a student at St. Catherine University pursuing a Masters of Social Work. As part of my graduation requirements, I need to complete a research project. My research project involves how you as a caregiver of a children with special health care needs access the services and supports that your child needs.

The purpose of this email is to ask you to take 15 to 20 minutes and participate in a short survey

In order to help you make an informed decision, please note the following:

- I am working with a faculty member at St. Kate's to complete this project.
- The potential risk to participating in the survey could come from answering questions about difficult family situations which could cause possible emotional upset.
- Your responses to this survey will be anonymous and results will be presented in a way that no one will be identifiable. Confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties.
- I will be writing about the results that I get from this research. However, none of the writing that I do will include the name of this school, the names of any students, or any references that would make it possible to identify outcomes connected to a particular student. Other people will not know that you were part of my study.
- The final report of my study will be electronically available online at the St. Catherine University library. The goal of sharing my research study is to help other social workers who are also trying to improve their work with families.

If you have any questions, please feel free to contact me, [john2193@stthomas.edu](mailto:john2193@stthomas.edu).

Thank you,  
Jackie Johnson

## Appendix B

### Survey Consent

You are invited to participate in this research project because you have been identified as having a child with special health care needs. This project is being conducted by Jackie Johnson, a student in the Masters of Social Work program at St. Catherine University. The purpose of this survey is to find out how you as a caregiver for a child with special health care needs access services and supports for that child. It will take approximately 15 to 20 minutes to complete. I anticipate that there will be approximately 45 people that will respond to this survey.

Your responses to this survey will be anonymous and results will be presented in a way that no one will be identifiable. Confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties. The only people that will have access to the de-identified data will be myself and my faculty advisor Dr. Lisa Kiesel, Ph.D., MSW, LICSW.

Your decision whether or not to participate will not affect your relationships with the researcher, your child's school, or St. Catherine University. If you decided to stop at any time you may do so. You may also skip any item that you do not want to answer. Your participation in this survey is strictly voluntary. If you have any questions about this project, please contact Jackie Johnson at [john2193@stthoms.edu](mailto:john2193@stthoms.edu), the Factuality advisor Dr. Lisa Kiesel, Ph.D., MSW, LICSW at [Kies0954@stthomas.edu](mailto:Kies0954@stthomas.edu) or John Schmitt, IRB Chair at [jsschmitt@stkate.edu](mailto:jsschmitt@stkate.edu); (651) 690-7739. By responding to items on this survey you are giving us your consent to allow us to use your responses for research and educational purposes.

As a Participant, you may wish to keep an electronic copy of the consent form for your record.

Appendix C

Research Questions (Suvery)

Services and Supports for families of Children with Special Health Care Needs

Instructions:

Please fill out the following questions completely and to the best of your ability.

1)What is your relationship to the child:

Mother

Father

Grandparent

Other: please explain \_\_\_\_\_

2)What is your current relationship status:

Single

Married

Divorced

Widowed

In a Committed Relationship

3)How old is the Child with the Special Health Care Needs:

\_\_\_\_\_ (age of child in years)

4) Where do you currently live:

Urban area (including - metro area, city, Suburb)

Rural area (small town, township, etc.)

5) How did you or the family become aware of the child's medical condition or illness?

6) What is the child's medical diagnoses?

7) What services are you currently receiving? (example – medical, OT, PT, Speech, respite, etc.)

8) What services have you used in the past? (example – medical, OT, PT, Speech, school, respite, etc.)

9) Of the services that you have utilized/received, which would you consider the most beneficial? (example – medical, PT, OT, Speech, school, respite, ect)

10) Where do you currently access the services?

Rural Area (small town)

Urban Area (including - metro area, large city, suburb)

Drive from the Rural area into an Urban area

11) How far do you travel to access the services you need?

12) Have you chosen where to live because of the services that your child needs?

13) What service needs do you feel go unmet for your child?

14) Why do you think that these services are unmet?

Thank you for your time! Your contribution has made this research possible.