FORT HAYS STATE UNIVERSITY
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INSTITUTIONAL REVIEW BOARD FOR HUMAN SUBJECTS RESEARCH

NEW IRB SUBMISSION

I. Project Title and Research Team Members

Project Title:

Factors Affecting Daily Stress in Siblings of Children with Special Needs

Principal Investigator Name:

Sheldon Cooper

Faculty Research Supervisor (If student is the PI):

Dr. Howard Wolowitz

Additional Team Members:

N/A

This form must be used to submit an application through the IRBNet system.
No other methods of submission will be accepted.

Access the system here: www.irbnet.org
Student and Adjunct Faculty researchers: Please note that Faculty Research Supervisor approval is required prior to submission to IRB. The Faculty Research Supervisor signature in IRBNet indicates approval and agreement with section XII.
For faster processing, ensure all research team members have completed all required CITI training through https://www.citiprogram.org/ prior to submitting this application.

II. Type of investigator and nature of the activity: (Check all appropriate categories.)

A. Faculty/Staff at FHSU:
- ☐ Submitted for extramural funding to:
- ☐ Submitted for intramural funding to:
- ☑ Project unfunded
- ☐ Quality improvement/program evaluation
- ☐ Quality assurance
- ☐ Other (Please explain)

B. Student at FHSU: ☑ Graduate ☐ Undergraduate ☐ Independent Study
☑ Thesis ☐ Specialist Field Study ☐ Graduate Research Paper

C. Class Project (Course Number and Course Title), explain activity:

N/A

D. Other than faculty, staff, or student at FHSU (Unaffiliated with FHSU)
Please explain:

N/A

III. Human Subjects Research Ethics Training: The IRB will not review submissions without verification of appropriate CITI training. The Principal Investigator and all members of the research team must complete the appropriate CITI training modules. Faculty Research Advisors, when listed above, must also complete CITI training. If the PI is not affiliated with FHSU, documentation of CITI or other comparable training must be provided.
Date completed CITI training:

Sheldon Cooper: July 2017; Dr. Howard Wolowitz: April 2017

IV. Project Information

A. Expected study period from: 8/21/2017 To: 8/20/2018

B. Describe the purpose of the research. Explain what is intended to be discovered, including goals, aims, and objectives and/or state the hypothesis to be tested. Background: provide a brief scientific or scholarly rationale for the research activities, and address gaps in current knowledge.

Children who have siblings with disabilities often take on responsibilities that are beyond anything their peers experience. With these extra responsibilities, comes more daily stress. Currently, the public schools and mental health facilities in our area provide no specialized support for this specific population. This project is intended to bring attention to this form of stress, bring attention to these experiences, and promote awareness of the need for family and schools to seek out various forms of support services.

☐ Investigators NOT currently affiliated with FHSU will collaborate on this project.

C. (If checked above) Identify any cooperating institutions by name.

N/A

D. This study is being/has been reviewed by another IRB. Yes ◯ No ◉
If yes, please attach relevant documentation.

V. Subject Information

A. Number of subjects:

Approximately 50 participants ranging from 7-18 years of age that have a sibling with a disability will participate. Both genders and any ethnicities will be allowed to participate.

B. Subject Age (Check all that apply):

- ☐ 1-7
- ☑ 8-17
- ☐ 18-65
- ☐ 65+

C. Special Populations (Check all that apply):

- ☑ Minors
- ☐ Non-English speaking
- ☐ Prisoners
- ☐ Individuals with impaired decision-making capacity
- ☐ Individuals who are economically or educationally disadvantaged
- ☐ Individuals with Legally Authorized Representatives
- ☐ Individuals who are vulnerable to coercion or undue influence

D. Describe target demographic of proposed subjects; explain how you will ensure that selection is equitable and that all relevant ethnic groups, genders, and populations have access to the study.

To participate in the study, the child must have a sibling that qualifies for support services under the Individual with Disabilities Education Act (U.S Department of Education, 2004) 20 U.S.C. 1401(3); 1401(30). It also will be required that parents are willing to participate, and that the participant be 8 to 18 years old, so that they can fully understand the survey content. The siblings do not have to be genetically related or live in the same household, however, the participant must have regular monthly exposure to their sibling with a disability to participate in the study. As the child with a disability will not be participating in the study, this child's age will not be used as a qualifying factor in participating in research. Children who are wards of the state, as well as non-English speaking student and parents will be excluded from the study.

E. Describe any specific populations targeted for inclusion or exclusion: Justify criteria based on age, gender, race, ethnicity, sexual orientation, or origin.

Only students who fall within the 8-18 age range with monthly exposure to their sibling with a disability will be able to participate.

VI. Recruitment

A. Describe the recruitment process for the study. Explain in detail how you will gain access to and recruit participants for participation in this project. Upload scripts, emails, letters, advertising, and all marketing materials with your application. Provide a step-by-step description of how potential participants will be recruited.

Four different methods will be used to recruit participants. The first method will be through contacting local school administrators. I will be asking for consent to talk with parents of children receiving special education services. The research will be conducted at times and places at the discretion of the parents and school administrators.

The second method of recruitment is through a snowball procedure. Parents of participants will be asked to provide my contact information to other families they believe would be willing to participate in my study or provide me with the contact information for the family they believe may be willing to participate. Parents will be called or contacted through e-mail and read or sent the attached recruitment script.

The third method of recruitment is through Fort Hays State University's Herndon Clinic. The clinic provides speech pathology services for children with disabilities. I will call, e-mail, or personally talk to parents of perspective families. Handouts will also be supplied to the clinic to be sent home with families who have not been previously contacted. Research will be either conducted on the Fort Hays State University campus or an alternate location chose by the participants' parents.

The fourth proposed method of recruitment is through local summer day camps, after school programs, support groups, and Head Start programs. Procedures will be similar to the procedures for schools. The administrators will be contacted for permission to conduct the study. Written permission will be obtained prior to the conduct of any recruitment. Parents will be contacted via electronic, face-to-face, or written communication either through the facility or directly from the researcher. This will be at the discretion of the facility.

B. Identify all applicable recruitment methods. (Please provide copies of materials).

- ☐ Flyers
- ☐ Purchased Sample List
- ☐ Email
- ☐ Telephone
- ☐ Newspaper
- ☐ Poster
- ☐ Class Announcement
- ☐ Departmental Communication
- ☐ Third Party (Professional or Charitable Organization)
- ☐ Internet
- ☐ Letter
- ☑ Personal or Professional Contacts
- ☐ Amazon MTurk
- ☐ Social Media
- ☐ SONA
- ☑ Snowball method (if used, must describe process in detail)
- ☐ Other (describe)

C. Are you recruiting students from a class you teach or for which you have responsibility? ◯ Yes ◉ No

D. Are you recruiting employees who directly or indirectly report to you?

◯ Yes ◉ No

E. If yes to either VI C or D, please explain why this population is necessary and describe what precautions have been taken to minimize potential undue influence or coercion.

N/A

VII. Compensation

- ☑ Participants will not receive compensation
- ☐ Students will receive extra credit or course credit
- ☐ Participants will receive monetary compensation
- ☐ Participants' names will be entered into a drawing for a prize

Describe the compensation or credit, including amount, scheduling and method. Explain what will happen if participants withdraw from the study.

Participants will not be directly compensated for their participation. Participation is voluntary, and participants may choose to withdraw at any time without penalty.

VIII. Risks and Benefits

A. Describe the anticipated benefits of the research for individual subjects.

The survey will allow participants to reflect on both their stress as well as any positive aspects associated with their experiences as a result of participating in the study. Often these children do not disclose their feelings to their parents. Following the completion of the survey, their participation creates the opportunity for children to discuss with their parents the stressors that most influence them.

B. Describe the anticipated benefits of the research for society or the discipline. Explain how the benefits outweigh the risks.

The information gathered from the study will provide benefit both to parents and counselors by indicating the most common causes of stress in sibling of children with disabilities. With this information, they can target specific parts of these children's lives and work to reduce stress. The study will bring attention to the stress experienced by children with siblings of disabilities and the need for support services. The results of the study may renew interest in the research community and lead to large scale studies.

C. Does this study involve any of the following? (Check all that apply.)

- ☐ Deception
- ☐ Omission
- ☐ Misleading Information/false feedback
- ☐ Physical or mental stress
- ☐ Collection of fluids or tissue
- ☐ Substances taken internally or applied externally
- ☐ Information pertaining to illegal activity
- ☐ Information relating to sexual attitudes, orientation or practice
- ☐ Private identifiable information
- ☐ Personal or sensitive information
- ☐ Private records (academic or medical)
- ☐ Social or economic burden to participants
- ☐ Mechanical or electrical device applied to subjects
- ☐ Information pertaining to substance use
- ☐ DXA Scan, X-RAY, MRI
- ☐ Information that, if released, could damage an individual's financial standing, reputation, employability, or cause social stigmatization, discrimination, or embarrassment
- ☐ Other
- ☑ **None of these**

D. Describe the nature and degree of the risk or harm checked above. If using deception, include a justification for the deception.

Minimal risk is anticipated. However, in order to further minimize any potential risks, we will get parental permission for children to participate as well as stress that participation is voluntary and their responses will be kept anonymous.

E. What steps will be taken to minimize risks or harm and to protect the subject's welfare (when risk is greater than minimal)?

A risk of this study is breach in confidentiality. To reduce the risk, the PI will be the sole administer and collector of the data. The PI will also store informed consents separately from the surveys. The surveys will be labeled with ID numbers and no names will be identified with the children's responses.

The study also presents a risk of psychological distress. To prevent any distress, The PI will disclose to the parents and participants the types of information that will be collected prior to obtaining their informed consent and assent. The PI will make it clear to children that they are able to stop at any time for any reason. The PI will debrief both the participant and the parents and provide information on who to contact if the child feels distressed. Finally, The PI will ask the children to tell me of a story of a fun time that they had their siblings with disabilities at the end of the study in order to alleviate any negative mood caused as a result of the study.

The PI will provide thorough debriefing for children without disabilities and their parents. The PI will also explain services available in the case of emotional distress and present children with the contact information for their school counselor. The PI will be available to answer any questions and address concerns. The PI will also report any information children give about past or present abuse or intent to harm themselves or others.

IX. Emergencies

How will emergencies or unanticipated events related to the research be handled if they arise? (Please note that this refers to an emergency situation associated with the research activity not an emergency such as a fire alarm.)

In the case that adverse events occur as a result of the study, I will follow protocols for breaking confidentiality if intent to harm themselves or others is indicated by the participant. I will alert the appropriate person depending on the situation. I will also alert my thesis chair and the IRB within 24 hours of the event.

X. Data Collection and Security

A. Procedures: Describe the setting and tasks subjects will be asked to perform. Describe the frequency and duration of procedures, tests, and experiments. Include a timeline or a step-by-step description.

Each parent will be asked to give their consent for their child to participate. Then, they will be asked to fill out a brief information form. The children will then be asked to give their assent. They will then be asked to fill out the Daily Events Scale in a location that is far enough away so that it cannot be heard but within sight of others. The children will have the option to read the question themselves, or have the questions read to them. Finally, the children and the parents will both receive debriefings. The process will be conduct separately for each child. After the debriefing statement is read, the child will be asked to provide a story of a fun time they had with their disabled sibling. This will leave them with a positive feeling about their brother or sister.

B. Describe the steps that will be taken to secure the data during storage, use, and transmission. How and where will the data be stored, for how long will it be kept, when will it be destroyed, what safeguards are in place for data with identifying information? Include a description of physical and electronic security.

The data will be shredded after answers are coded into a database. The computerized data will be stored on a flash drive locked in a file cabinet when not in use. Consent forms will be stored in a separate locked file cabinet in the thesis advisor's office. After the completion of this thesis, the consent forms will be shredded.

C. Identify any direct identifiers like name, unique identifier, address, email, etc. that will be kept with the records. Explain why it is necessary to record the identifiers and describe the coding system to be used.

No direct identifiers will be kept with the records. The informed consent and assent will be stored separately from the surveys. The demographic information filled out by the parents will have an ID number which will correspond to the ID number on the survey the children complete. No information will be identified by the child’s name only by ID number.

D. If retaining a link between study code numbers and direct identifiers after data collection is complete, please explain why this is necessary, how long the link will be kept, how it will be stored, and when it will be destroyed.

N/A

E. Data collection methods (check all that apply)

- ☐ Observation
- ☐ Interviews
- ☐ Focus groups
- ☑ Surveys/Questionnaires
- ☐ Psychological tests
- ☐ Educational tests
- ☐ Blood draw, saliva swab, or other biological sampling
- ☐ Audio recording (see section X. F)
- ☐ Video Recording (see section X. F)
- ☐ Previously collected data (no individual identifiers)
- ☐ Previously collected data (with individual identifiers)
- ☐ Internet-based methods
- ☐ Other (describe)

F. If using audio or video recording, describe how the recordings will be used, how confidentiality will be maintained, who will have access, and how and when the recordings will be destroyed or completely deidentified.

N/A

G. Protected data to be collected (check all that apply)
☐ Protected health Information (see Section X, Part H)
☐ Unique ID number (e.g. employee ID, driver's license number, student ID number, etc.)
☐ Academic records
☐ Social security number
☐ Other personally identifiable information

H. If the research involves protected health information, it must comply with the HIPAA Privacy Rule.
Select one:
☑ The research does not involve protected health information
Do you plan to use or disclose identifiable health information outside FHSU?
○ Yes ◉ No
If yes, the consent form must include a release of protected health information.

The IRB may make a waiver of authorization for disclosure if criteria are met under the HIPAA Privacy Rule. *If a waiver of authorization is being requested, the researcher must contact the IRB administrator prior to submitting this application.*

Will the protected health information to be used or disclosed be deidentified, or will a limited data set be used or disclosed? *Please describe*:

N/A

I. Sharing results with subjects (Indicate if results, like tests or incidental findings, will be shared with the subject or others, and if so, indicate how it will be shared.)

If the study is presented at a conference or possibly published, results will be aggregated and no identifiable information will be included.

J. Withdrawal of subjects (Describe the procedures to be followed when subjects withdraw from research or under what circumstances subjects may be withdrawn without their consent.)

Participation in the study is voluntary; participants may choose to withdraw at any point during the study and their materials will not be used in the study.

XI. Informed Consent

A. Specify the type of informed consent you will use with this research project.

☑**Signed Consent**

Consent forms included with this submission:

☑Adult ☑Assent Script/Procedures ☐Parent/Guardian

☐Foreign Language Version ☐Agency Consent

☐**Oral Consent** (Waiver of documentation of consent, include script with application)

☐Signed consent form would be the only record linking the subject to the research, and the principal risk of signing a consent form would be the potential harm resulting from a breach of confidentiality.

☐The research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside the research context.

☑**Information Statement** (include with application)

☑**Debriefing Statement** (include with application)

B. Describe any potential concerns with obtaining informed consent (Foreign language, minimizing possibility of coercion, etc.)

There are no anticipated concerns for obtaining informed consent. In order to minimize the possibility of perceived coercion, the researcher will reiterate that the study is voluntary and participants may withdraw at any time without penalty.

C. Describe the process you will follow to obtain consent and/or assent. Include names of individuals on the research team who will obtain consent, where and when the process will take place, and how you will ensure the subject's understanding.

The PI will talk to the parents about potential risks and benefits of the study. The PI will highlight important information from the consent statement and will give the informed consent to them to read, giving them the opportunity to ask any questions they may have prior to signing the consent. Following the parents' authorization to participate in the survey, the PI will talk to the child about what they can expect if they choose to participate, and give them the opportunity to also ask questions, read the assent document, and sign.

All materials related to this study must be uploaded into your IRBNet study workspace. Instructions for using IRBNet are located at the FHSU IRB website. Required materials may include, but are not limited to:

- Completed application
- Copies of all recruiting materials, including scripts, emails, letters, posters, advertising, etc.
- Copies of all measurements, instruments, surveys, interview questions being used, etc.
- All consent forms and assent forms or scripts (for children).
- Debriefing materials, if used.

Please note that all materials and scripts to be used for this study need to be reviewed and approved by the IRB.

XII Certifications:

I am familiar with the policies and procedures of Fort Hays State University regarding human subjects in research. I subscribe to the university standards and applicable state and federal standards and will adhere to the policies and procedures of the Institutional Review Board for the Protection of Human Subjects. I will comply with all instructions from the IRB at the beginning and during the project or will stop the project.

AND

I am familiar with the published guidelines for the ethical treatment of human subjects associated with my particular field of study.

Statement of Agreement:

By electronically signing and submitting this application package, I certify that I am willing to conduct and /or supervise these activities in accordance with the guidelines for human subjects in research. Further, I certify that any changes in procedures from those outlined above or in the attached proposal will be cleared through the IRB.

If the Principal Investigator is a student, the electronic signature of the Faculty Advisor certifies:
1) Agreement to supervise the student research; and, 2) This application is ready for IRB review. The Student is the "Principal Investigator". The Faculty Research Advisor is the "Advisor". Designees may not sign the package. It is the student's responsibility to contact their Faculty Research Advisor when the study is ready for the Advisor's signature.

I certify the information provided in this application is complete and correct.
I understand that I have ultimate responsibility for the conduct of the study, the ethical performance of the project, the protection of the rights and welfare of human subjects and strict adherence to any stipulations imposed by the IRB.
I agree to comply with all FHSU policies, as well as all federal, state and local laws on the protection of human subjects in research, including:

- Ensuring all study personnel satisfactorily complete human subjects research training.
- Performing the study according to the approved protocol.
- Implementing no changes in the approved study without IRB approval.
- Obtaining informed consent from subjects using only the currently approved process and form.
- Protecting identifiable health information in accordance with HIPAA Privacy rule.
- Promptly reporting significant or untoward adverse effects or unanticipated problems to the IRB.

Example of Parent-Guardian Informed Consent Statement

Name of the Study: Factors Affecting Daily Stress in Siblings of Children with Special Needs

INTRODUCTION

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

PURPOSE OF THE STUDY

Children who have siblings with disabilities have a unique experience when growing up, often taking on responsibilities beyond what their peers might experience. With these extra responsibilities comes more daily stress. Currently, the public schools and mental health facilities in our area do not provide specialized support for the students in this specific population. This project is intended to bring attention to this form of stress and experiences as well as promote awareness of the need for family and schools to seek out various forms of support services.

PROCEDURES

If you decide to allow your child to participate in our study, you will be asked to fill out a brief information form. Your child will also be asked to give their assent to participate. If your child also agrees to participate, they will be asked to fill out the *Daily Events Scale* in a private location that is far enough away from other students so that it cannot be heard but within sight of the teacher and researcher. Your child will have the option to read the questions individually, or have the questions read out loud by the researcher. This process will be conducted separately for each child. After the survey has been completed and the debriefing statement has been read, your child will be asked to provide a story of a fun time he/she had with his/her disabled sibling. This will leave your child with a positive feeling about his/her brother or sister after completing the study.

RISKS

We anticipate minimal risk with our study. However, to further minimize potential risks, we will be sure to reiterate that participation is voluntary and that the responses will be anonymous. There is also the potential risk of psychological distress. To prevent and minimize distress, we will answer any questions you may have about the information we will be collecting prior to you signing the consent. If your child does begin to feel distressed, we will stop the study and explain services available through the school counselor.

BENEFITS

The survey will allow your child to reflect on both his/her stress as well as the positive aspects associated with his/her experiences with their sibling. Often these children do not disclose their feelings to their parents. Following the completion of the survey, there will be an opportunity for you and your child to discuss the stressors that most influence them. The information gathered

from the study will provide benefits to both you as a parent and to the counselors by indicating the most common causes of stress in a sibling of child with a disability. With this information, the counselors can target specific parts of these children's lives and work to reduce stress. The study will bring attention to the stress children with siblings who have disabilities might experience and the need for support services. The results of the study may renew interest in the research community and lead to large scale studies.

PAYMENT TO PARTICIPANTS
You and your child will not be directly compensated for your participation. Participation in this study is voluntary, and you may choose to withdraw at any time without penalty.

PARTICIPANT CONFIDENTIALITY
Your child's name will not be associated in any publication or presentation with the information collected about your child or with the research findings from this study. Instead, the researcher(s) will use a study number or a pseudonym rather than your child's name. Your child's 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 child's information, excluding your child's name, 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 might be receiving or may receive from the University or to participate in any programs or events of the University. However, if you refuse to sign, your child cannot participate in this study.

CANCELLING THIS CONSENT AND AUTHORIZATION
You may withdraw your consent to allow participation of your child in this study at any time. You also have the right to cancel your permission to use and disclose further information collected about your child, in writing, at any time, by sending your written request to: Sheldon Cooper, Department of Psychology, 600 Park St., Fort Hays State University, Hays, KS 67601.

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

QUESTIONS ABOUT PARTICIPATION
Questions about procedures should be directed to the researcher(s) 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 child's rights as a research participant, I may call (785) 864-7429,

write to I may call (785) 628-4349, write the Office of Scholarship and Sponsored Projects (OSSP), Fort Hays State University, 600 Park St., Hays, Kansas 67601, or email irb@fhsu.edu.

I agree to allow my child 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

_____

Parent/Guardian Signature

[If signed by a personal representative, a description of such representative's authority to act for the individual must also be provided, e.g. parent/guardian.]

Researcher Contact Information

Sheldon Cooper
Principal Investigator
Department Psychology
600 Park St.
Fort Hays State University
Hays, KS 67601
(785) 628-5555

Howard Wolowitz, PhD
Faculty Supervisor
Department of Psychology
600 Park St.
Fort Hays State University
Hays, KS 67601
(785) 628-5555

Assent Procedures

Assent is an active affirmation of a desire to participate and differs from consent which is recognized as being granted from an individual with the legal authority to do so. When children/minors under eighteen are involved in research, informed consent must be obtained from the parent/guardian ***and*** assent must be obtained from the child/minor. Similarly, participants for whom the ability to give informed consent may be otherwise compromised, such as individuals with developmental disabilities, must be afforded the same process.

Assent should be obtained in a manner that is easily understood by the potential participant (either written or verbal) and should be limited to a one-page format. The individual should be given an explanation of the proposed research procedures, the purpose of the research, and any discomforts, in language that is appropriate to the individual's age, experience, maturity, and condition. Illustrations might be helpful and larger type makes it easier for some individuals to read.

If an assent procedure is to be used, a prototype of the 'script' of this procedure should be included with the application. Whereas an assent 'script' may not be appropriate considering the age range or cognitive capacity of some subjects, researchers should nonetheless provide a description of the measures they will take to assess whether the individual assents or is comfortable participating, such as explaining how they will interpret non-verbal cues like crying or fatigue.

A particular subject's capacity to assent must be evaluated on an individual basis. Keep in mind that your tone, facial expressions and body language may influence a child's assent!

We have provided some Assent Script templates for your assistance. While you are not required to use these templates, you may find them helpful in constructing your assent procedures. The first template represents an assent script that might be used for adolescents and which provides room for more detail regarding the study purpose and procedures. The second template represents an assent script that might be used for younger children. The third template represents assent procedures that describe how a researcher might interpret non-verbal cues.

You may use the templates on the following page as guidance →

Sample Assent Script (for adolescents)

Hello! My name is Sheldon Cooper. I am interested learning about your experiences having a sibling with special needs, because we want to know about your experience and make sure to support you and your family. If you would like, you can be in my study. I would like you to take part in some discussions that will meet for about 20 minutes today. I would like to ask some questions about your experiences and feelings and how you think these things affect how you feel about your relationship with your sibling.

If you decide you want to be in my study, you will be asked to answer some questions and tell stories about times with your sibling.

If you choose to participate, you will get to talk about your stressors as well as your joys growing up. It may also help us better understand how to help be supportive of kids with siblings who have special needs.

Other people will not know if you are in my study. I will put things I learn about you together with things I learn about other children and teens, so no one can tell what things came from you. When I tell other people about my research, I will not use your name, so no one can tell who I am talking about.

Your parents or guardian have to say it's OK for you to be in the study. After they decide, you get to choose if you want to do it too. If you don't want to be in the study, no one will be mad at you. If you want to be in the study now and change your mind later, that's OK. You can stop the study at any time.

If you don't feel like answering any questions, you don't have to, and you can stop speaking with me any time and that will be all right. I will be happy to answer any questions you may have now or when we are talking together. Do you want to take part in this project?

Sample Assent Script (young children)

Hello! My name is Sheldon Cooper, and I am learning about the stress and joys of growing up with siblings. I would like you to answer some questions that will take about 20 minutes. I would like you to talk with us about your sibling and for you to tell me some stories about growing up with your brother or sister. If you don't feel like talking, you don't have to. You can stop talking to me at any time and that will be all right. Do you want to take part in answering some questions?

Recruitment Message: Siblings of Students with Special Needs Study

Hello,

My name is Sheldon Cooper, and I am a graduate student in the Psychology Department at Fort Hays State. I would like to invite your child to participate in a psychology experiment. The purpose of my experiment is to ask children who have siblings with special needs about their experiences. If you choose to let your child participate, they will be given a survey to fill out asking questions about their thoughts and opinions on growing up with a sibling who has special needs. Your child's name and responses would be confidential and anonymous.

Results may help us to better understand the experiences of children who have a sibling with special needs and also may help us find new ways to be support siblings and family members who have a child with special needs. We would appreciate your help with this research project. If you would like your child to participate, you will be asked to fill out a consent form and an opportunity to ask questions about the study. If you agree, your child will be asked to complete a survey by either reading the questions on his/her own or having the questions read out loud by the researcher.

If you have any questions about this study, please do not hesitate to contact me or my faculty supervisor, Dr. Wolowitz.

Thank you!

Sheldon Cooper
secooper@mail.fhsu.edu

Dr. Howard Wolowitz
hwolowitz@fhsu.edu
(Faculty Supervisor)

Debriefing Form" "Factors Affecting Daily Stress in Siblings of Children with Special Needs"

You have just completed a study titled "Factors Affecting Daily Stress in Siblings of Children with Special Needs." The purpose of this study was to examine how children of siblings with special needs experience stress in their daily life. Students were asked to fill out a survey asking questions about their thoughts and opinions growing up and about their daily routines. The information provided will help us develop new supports for children and families.

We are so thankful for your help with this project! If your child feels sad after participating in this project, they can tell their teacher and they will help schedule an appointment to talk with someone about how the project made your child feel. If you have questions about the project, you can contact the Fort Hays State Office of Scholarship and Sponsored Projects at 785-625-4349. For more information about the research project, you can contact the principal researcher, Sheldon Cooper. You may also contact the faculty sponsor, Dr. Wolowitz.

Thank you again!

Sincerely,

Sheldon Cooper
secooper@mail.fhsu.edu

Dr. Howard Wolowitz
hwolowitz@fhsu.edu
(Faculty Supervisor)