Proposals for review by the IRB may be submitted at any time. With the exception of expedited reviews, complete proposals submitted no later than ten (10) business days prior to a scheduled meeting will be reviewed at that meeting. Late proposals will be reviewed at the next scheduled meeting. The IRB meeting schedule is posted on the website. Incomplete proposals will not be reviewed until the researcher supplies the missing information. Be sure to respond to all sections.

**Type of Request:**

- **Full Review**
  - Complete Application and Relevant Forms
- **Expedited Review**
  - Complete Application and Expedited Review Attachment
- **Exempt from Review**
  - Complete Application and Exempt Review Attachment

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 include:

- Completed application (including relevant parts of section IX if a vulnerable population is involved)
- A completed form requesting Exemption, Expedited or Full Review.
- 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.
I. 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 his/her 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 in 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 consent form
   ○ Protecting identifiable health information in accordance with HIPAA Privacy rule
   ○ Promptly reporting significant or untoward adverse effects to the IRB
Application Information:

II. Activity or Project Title: Factors Affecting Daily Stress in Siblings of Children with Special Needs

Time period for activity: From May 2011 To May 2012 *If longer than 1 year, annual review will be needed

III. List all people involved in research project:

<table>
<thead>
<tr>
<th>Name &amp; Title</th>
<th>Institution &amp; Department</th>
<th>Phone</th>
<th>Email</th>
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<tbody>
<tr>
<td>* Sheldon Cooper</td>
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<td>** Dr. Howard Wolowitz</td>
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*Principal Investigator
**Faculty Research Advisor (if student is Principal Investigator)
If there are additional investigators, please attach their information to the application.

IV. Type of investigator and nature of the activity: (Check all the 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
   - Special
   - Thesis
   - Specialist Field Study
   - Graduate Research Paper
   - Independent Study
   - Class Project (Course Number and Course Title):
   - Other (Please Explain):

C. Other than faculty, staff, or student at FHSU (Unaffiliated with FHSU).
V. Human Subjects Research Ethics Training: The Principal Investigator must have completed the appropriate CITI training modules OR provide a summary below regarding training completed in Human Subjects Research (such as coursework, workshops, etc.) Enrollment in or completion of a research methods-type course is appropriate for a student PI as they are under supervision of a Faculty Research Advisor. Faculty Research Advisors, when listed above, must also indicate either CITI training or provide a brief summary of relevant training such as coursework, workshops, etc. If the PI is not affiliated with FHSU, documentation of CITI or other training must be provided.

Completed FHSU CITI Training:  ☑ Yes  ☐ No
(If no, describe relevant human subjects ethics training below):

VI. Description of Project

Completely describe the research project below. Provide sufficient information for effective review, and define abbreviations and technical terms. Do NOT simply attach a thesis, prospectus, grant proposal, etc. If an item is not applicable, please provide justification.

A. Project purpose(s):  
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 faculties in our area provide no specialized support for this specific population. This project is intended to bring attention to the stress and uplifts these children experience and the need for family and schools to seek out various forms of support services.

B. Describe the proposed participants (number, age, gender, ethnicity, etc)  
Approximately 50 participants ranging from ages 7-18 that have a sibling with a disability will participate. Both genders and any ethnicities will be allowed to participate.

C. What are the criteria for including or excluding subjects? Are any criteria based on age, gender, race, ethnicity, sexual orientation, or origin? If so, justify.  
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). They also require parents willing to participate, and be 7 to 18 years old, so they can fully understand the survey. 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.
D. Population from which the participants will be obtained:

**General Populations:**
- Adult students (18-65 years) on-campus
- Adults (18-65 years) off-campus

**Protected or Vulnerable Populations*:**
- Elderly (65+ Years)
- Prisoners
- Wards of the State
- Pregnant Women
- Fetuses
- Mentally disabled
- Children (under the age of 18)

*See Section IX for additional information

E. Recruitment Procedures: Describe in detail the process to be used to recruit participants. 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 for the study.

**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.

F. Describe the benefits to the participants, discipline/field, and/or society for completing the research project. This description is necessary for determining if the risks are reasonable in relationship to anticipated benefits. Research that provides no benefit or potential for benefit will not be approved.

The survey will allow participants to reflect on both the stress and uplifts they experience 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.

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 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.

G. Describe the potential risks to participants for completing the research project. A risk is a potential harm that a reasonable person would consider important in deciding whether to participate in research. Risk categories include physical, psychological, social, economic and legal, and include pain, stress, and invasion of privacy, embarrassment, or exposure of sensitive or confidential information. All potential risks and discomforts must be minimized to the greatest extent possible by using appropriate monitoring, safety devices and withdrawal of a subject if there is evidence of a specific adverse event.

A risk of this study is breach in confidentiality. To reduce the risk, I will administer and collect all the research myself. I 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, I will disclose to the parents and participants the types of information that will be collected prior to obtaining their informed consent and assent. I will make it clear to children that they are able to stop at anytime for any reason. I will debrief both the participant children and the parents of who to contact if they feel distressed. Finally, I will ask the children to tell me of a story of a fun time that they had their siblings with disabilities.

X Minimal Risk: the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.
H. Describe the follow up efforts that will be made to detect any harm to subjects, and how the IRB will be kept informed. Serious adverse or unexpected reactions or injuries must be reported to the IRB within 48 hours. Other adverse events should be reported within 10 days.

I will provide thorough debriefing for children without disabilities and their parents. Explaining services available in the case of emotional distress, and present children with the contact information for their school counselor. I will make myself available to answer any questions and address concerns. I will also report any information children give about past or present abuse or intent to harm themselves or others. I will contact my thesis chair who is XXX department IRB representative in the case of any harm to participants is evident, as well as XXX and the University IRB within 24 hours.

I. Describe in detail the procedures to be used in the research project. What will all participants experience during the research project?

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 conducted 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.

J. List all measures/instruments to be used in the project, include citations and permission to use (if measure/instrument is copyrighted) if needed or if it will be changed for this study. Attach copies of all measures, such as surveys, interview questions, instruments, etc. to the package.

Giallo, R. & Gavidia-Payne S. (2006) the Daily Events Scale for Siblings of with Disabilities or Chronic Illness
Parent Demographic Form-Self constructed

K. Describe in detail how confidentiality will be protected or how anonymity will be ensured before, during, and after information has been collected? Please note the difference between confidentiality (researcher knows identity of subjects and keeps information secret) and anonymity (researcher does not know identity of participants).

The informed consent and assent will be stored separately from 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 fill out. No information will be identified by the child’s name only by ID number.
L. Data Management: How will the data be stored? When will the data be destroyed? Who will have access to the data? If audio or video recordings are used, how will they be kept confidential?

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 lock file cabinet in my apartment. After the completion of my thesis the consent forms will also be shredded.

M. Informed Consent: Describe in detail the process for obtaining consent. If non-English speaking subjects are involved, describe how consent will be obtained.

I will talk to the parents about potential risks and benefits of my study. I will highlight important information from the consent statement. I 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, I 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.

N. If informed consent is to be waived or altered, complete Supplemental: Consent Waiver Form N/A

O. If written documentation of consent is to be waived, complete Supplemental: Documentation Waiver Form N/A

P. Explain Debriefing procedures/end of study information that will be given to all participants.

I will give both the parents and children an opportunity to ask questions, explain the services available if the participant feels distressed by the survey, highlight important information from the debriefing statement, and give them a copy of the statement.

Q. Emergencies. How will emergencies or unanticipated adverse 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 event happen as a result to my 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.

R. Will information about the research purpose and design be held from subjects? If yes, justify the deception. No deception.
VII. If the research involves protected health information, it must comply with the HIPAA Privacy Rule.

Select one:

___X___ The research does not involve protected health information

___ Do you plan to use or disclose identifiable health information outside FHSU?

   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 chair 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.

VIII. Conflict of Interest: Each individual with a personal financial interest or relationship that in the individual’s judgment could reasonably appear to affect or be affected by the proposed study involving human subjects is required to disclose the existence of financial interests. It is unnecessary to report any financial interests or relationships that do not reasonably appear to affect or be affected by the proposed study.

Definitions:

“Conflict of interest” occurs when an independent observer may reasonably question whether an individual’s professional actions or decisions are influenced by considerations of the individual’s private interests, financial or otherwise.

Conflicting financial interests do not include:

- Salary and benefits from Fort Hays State University;
- Income from seminars, lectures, teaching engagements, or publishing sponsored by federal, state, or local entities, or from non-profit academic institutions, when the funds do not originate from corporate sources;
- Income from service on advisory committees or review panels for governmental or non-profit entities;
- Investments in publicly-traded mutual funds;
- Gifts and promotional items of nominal value; and
- Meals and lodging for participation in professional meetings.

“Principal investigator or other key personnel” means the principal investigator and any other person, including students, who are responsible for the design, conduct, analysis, or reporting of research involving human subjects.
Request for Full Review

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

Name of Principal Investigator:

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<tr>
<th>Departments with Human Subjects/Ethics Review Committees</th>
<th>Departments without Human Subjects/Ethics Review Committees</th>
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<tr>
<td>Departmental Representative (Department Chair/Ethics Chair)</td>
<td>xxx</td>
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<tr>
<td>Date of Departmental Review</td>
<td>xxx</td>
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<tr>
<td>Committee Members:</td>
<td></td>
</tr>
<tr>
<td>Votes for: 4</td>
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<tr>
<td>Votes Against: 0</td>
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<td>Abstained: 1</td>
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II: Full Review Requested

G. Process:
This form should be attached to the Application Package for Human Subjects Research. All components must be included:
• Application
• Informed Consent Process and Documentation (if needed)
• Recruitment materials
• Any research instruments that will be used for the study (interviews, questionnaires, advertisements) If the study is designed to develop instruments and test the instruments for validity, state this in the Research Summary. Provide a copy of the materials to the OHRPP once developed using an Amendment Form.

Departments with Human Subjects/Ethics Review Committees:
The Chair of the Committee provides the completed form to the Principal Investigator to upload.

Departments without Human Subjects/Ethics Review Committee:
The Department Chair provides the completed form to the Principal Investigator to upload, and recommends the study be considered for full review.
<table>
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<th><strong>ELECTRONIC SIGNATURES</strong></th>
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<tr>
<td><strong>PRINCIPAL INVESTIGATOR</strong></td>
</tr>
<tr>
<td>Your electronic signature means that the research described in the application and supporting materials will be conducted in full compliance with FHSU policies, as well as federal, state, and local laws on the protection of human subjects in research. You have the ultimate responsibility for the conduct of the study, the ethical performance of the project, and the protection of the rights and welfare of human subjects. In the case of student protocols, the faculty supervisor and the student share responsibility for adherence to policies.</td>
</tr>
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<td><strong>FACULTY RESEARCH ADVISOR - REQUIRED FOR STUDENT RESEARCH</strong></td>
</tr>
<tr>
<td>Your electronic signature certifies that you have read the research protocol submitted for IRB review, and agree to supervise these activities in accordance with the guidelines for human subjects in research. Although the Principal Investigator has 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, faculty who are serving as the Principal Investigator’s Faculty Advisor are responsible for providing appropriate supervision.</td>
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<td><strong>DEPARTMENT HUMAN SUBJECTS/ETHICS REVIEW COMMITTEE CHAIR REQUIRED FOR FACULTY OR STUDENT RESEARCH FOR DEPARTMENTS WITH HUMAN SUBJECTS/ETHICS REVIEW COMMITTEES</strong></td>
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<tr>
<td>Your electronic signature certifies that the Committee has reviewed the application and all supporting documents pertaining to this research protocol. The Committee has determined that the proposed activity meets the criteria for exemption from IRB review.</td>
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<tr>
<td><strong>SIGNATURE OF DEPARTMENT CHAIR REQUIRED FOR FACULTY RESEARCH FOR DEPARTMENTS WITHOUT HUMAN SUBJECTS /ETHICS REVIEW COMMITTEES</strong></td>
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<tr>
<td>Your electronic signature affirms you have been informed of the research, and recommend that this study be considered for exemption.</td>
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Supplemental Form:
Vulnerable Populations – Children

Vulnerable Populations ONLY:
When using a special population, additional consents and debriefings need to be conducted. The researcher must recruit a site or location; consent from the head of these locations must give permission to use the facilities. In addition, the guardians, parents, etc. of young, elderly, or cognitively impaired participants must also give permission. Finally, the actual participant must give assent to participate.

Additional considerations include:
How will the research location/site, parent/guardian/etc., participant be contacted? Attach copies of the 1) recruitment letter and consent for each location/site that will be used during this research project; 2) recruitment letters and consent forms for parent/guardians/etc.; and 3) participant assent forms and/or process used to obtain and document assent.
Upon completion of the research project, how will the site/location, parents/guardians/etc., and participants be debriefed and notified of the termination of the project.
Complete and include with the application package.

A. Children as Subjects
1. What is the age range of the children in this research?
   - 7-18
2. Where will the children participate?
   - Home
   - School
   - College or lab/office
   - Other Specify:
3. Will any of the research take place in school settings?
   - Yes
   - No
   If yes, have you obtained the necessary permission from the school district?
   - Yes
   - No
   If yes, attach documentation of permission
   If no, explain or attach a draft of the letter you plan to use: [Form is attached]
4. Are any of the children wards of the State or any other agency, institution, or entity?
   - Yes
   - No
   If yes, provide details:
5. Designation Risk / Benefit: Check the risk designation you believe appropriate:
   - Research not involving greater than minimal risk. [45 CFR 46.404]
   - DHHS will conduct or fund research in which the IRB finds that no greater than minimal risk to children is presented, only if the IRB finds that adequate provisions are made for soliciting the assent of the children and the permission of their parent or guardians, as set forth in 46.408.
   - Minimal risk means that the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests. [45 CFR 46.102(i)]
   - Permission of only one parent is necessary for research designated 46.404 or 46.405.
   - Research involving greater than minimal risk but presenting the prospect of direct benefit. [45 CFR 46.405]
DHHS will conduct or fund research in which the IRB finds that more than minimal risk to children is presented by an intervention or procedure that holds out the prospect of direct benefit for the individual subject, or by a monitoring procedure that is likely to contribute to the subject’s well being, only if the IRB finds that:

a) the risk is justified by the anticipated benefit to the subjects;  
b) the relation of the anticipated benefits to the risk is at least as favorable to the subjects as that presented by available alternative approaches.

Permission of only one parent is necessary for research designated 46.404 or 46.405.

☐ Research involving greater than minimal risk and no prospect of direct benefit to individual participants, but likely to yield generalizable knowledge about the subjects’ disorder or condition.  [45 CFR 46.406]

DHHS will conduct or fund research in which the IRB finds that more than minimal risk to children is presented by intervention or procedure that does not hold out the prospect of direct benefit for the individual subject, or by a monitoring procedure that is not likely to contribute to the well-being of the subject, only if the IRB finds:

a) the risk represents a minor increase over minimal risk;

b) the intervention or procedure presents experiences to participants that are reasonably commensurate with those inherent in their actual or expected medical, dental, psychological, social or educational situations;

c) the intervention or procedure is likely to yield generalizable knowledge about the subjects’ disorder or condition, which is of vital importance for the understanding of the participants condition.

Permission of both parents is necessary.  If the research is designated 46.406 or 46.407, both parents should give their permission, unless one parent is deceased, unknown, incompetent, or not reasonably available, or when only one parent has legal responsibility for the care and custody of the child.

Permission of one parent only for research designated 46.406 or 46.407, when one parent is deceased, unknown, incompetent, or not reasonably available, or when only one parent has legal responsibility for the care and custody of the child.

☐ Research not otherwise approvable which presents an opportunity to understand, prevent, or alleviate a serious problem affecting the health or welfare of children.  [45 CFR 46.407]

DHHS will conduct or fund research that the IRB does not believe meets the requirements of sections 46.404, 46.405, or 46.406 only if:

a) the IRB finds that the research presents a reasonable opportunity to further the understanding, prevention, or alleviation of a significant problem affecting the health and welfare of children; and

b) the panel of experts must also find that the research will be conducted in accordance with sound ethical principles.

Permission of both parents is necessary.  If the research is designated 46.406 or 46.407, both parents should give their permission, unless one parent is deceased, unknown, incompetent, or not reasonably available, or when only one parent has legal responsibility for the care and custody of the child.
Permission of one parent only for research designated 46.406 or 46.407, when one parent is deceased, unknown, incompetent, or not reasonably available, or when only one parent has legal responsibility for the care and custody of the child.

Alteration or waiver of parental permission: Complete appropriate supplemental form to request for alteration or waiver of the consent process.

6. If the research is being conducted in a group setting (e.g., a classroom), explain what provisions have been made for children whose parents have not given permission for them to participate:

Conducted on an individual basis

7. Assent by children - In determining whether children are capable of providing assent, you should take into account the ages, maturity, and psychological state of each child who will be involved. If the IRB determines that the research holds out a prospect of direct benefit to individuals, assent of the children may not be a necessary requirement.

It is important to include each child in the discussion of the research as appropriate for his or her maturity level. A signature line for assent may be included on the consent form when children may be enrolled. The nature of the study, however, determines if a child’s signature should be obtained in connection with an assent to study participation. Please indicate below your judgments about including a signature in the assent process:

- a. Assent signature obtained: This study does not involve interventions likely to directly benefit the health or welfare of individual children. They are likely, however, to comprehend and appreciate what it means to be a volunteer for the benefit of others.

- b. Assent signature not obtained: Children will be included in the discussions about research participation. The children who will participate in the study, however, either have the prospect of an important and direct benefit to the health or well-being of each child or are unlikely to understand research participation sufficiently to provide meaningful assent.
Mr./ Mrs. X
Head of School
Address

Permission to Conduct Research Study

Dear Mr./Mrs. X:

I am writing to request permission to conduct a research study at your institution. I am currently enrolled in the Educational Specialist Degree at Fort Hays State University, Hays, KS and am in the process of writing my Master’s Thesis in the field of School Psychology. The study is entitled *Factors Affecting Daily Stress in Siblings of Children with Special Needs*.

Due to the nature of the study, I hope that the school administration will allow me to recruit students with a sibling who is receiving special education services from the school to complete a 60 question survey (copy enclosed). The survey will indicate some of the stress they experience as a sibling of a child with a disability. Due to the nature of the study, I hope to recruit (the mother, father, or guardian) of these students to a brief one page document indicating demographic information (copy enclosed). Willing parents, who volunteer to participate, will be given a consent form to be signed (copy enclosed) and return to the primary researcher at the beginning of the survey process. The students will also be given a document they will need to sign that indicates their willingness to participate in my study.

The survey process will be conducted at a time and place as decided by the parent and will not take time away from the school day. The process should take approximately 15 to 30 minutes. The survey results will be pooled for the thesis project and individual results of this study will remain absolutely confidential and anonymous. Should this study be published, only pooled results will be documented. No costs will be incurred by either your school/center or the individual participants.

Your approval to recruit participants for this will be greatly appreciated. I will follow up with a telephone call next week and would be happy to answer any questions or concerns that you may have at that time. You may contact me at my email address.

If you agree, kindly sign below and return the signed form in the enclosed self-addressed envelope. Alternatively, kindly submit a signed letter of permission on your institution’s letterhead acknowledging your consent and permission for me to conduct this survey/study at your institution.

Sincerely,

Enclosures

Approved by: _____________________

____________________

_________

Print your name and title here   Signature          Date
CONSENT TO PARTICIPATE IN RESEARCH
Department of Psychology, Fort Hays State University

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

Researcher: 
Contact Information: 
Faculty Supervisor: 

You are being asked to allow your child to participate in a research study. Before you give your permission, it is important that you read the following information and ask as many questions as necessary to be sure you understand what your child will be asked to do. It is your choice whether or not your child will participate.

Your decision of whether or not to allow your child to participate will have no effect on benefits or services to which you are otherwise entitled, including education services given to both your children by their school. Please ask questions if there is anything you do not understand.

What is the purpose of this study?
The study is intended to evaluate the most stressful and most uplifting experiences children have as a result of having a sibling with a disability. The study will increase our and your child’s knowledge of his/her feelings and the support he/she needs to cope with daily stressors. Research has found that siblings of children with disabilities are more mature, independent, and selfless than their peers, based on parents’ perceptions (Glendinning, 1983).

What does this study involve?
If you chose to allow your child to participate, you will be asked to fill out a brief questionnaire that will include your children’s ages, genders, race, last year’s estimated household income, and the amount of daily care the child with a disability requires. The child with a disability will not participate or be asked to provide any information for this study. Your participating child will be asked to fill out two surveys. One will ask about daily stress in your child’s life as a result of having a sibling with a disability and the other asks them to rate how uplifting certain life experiences make them feel.

If you decide to permit your child to participate in this research study, you will be asked to sign this consent form, after you have all your questions answered and understand what will be asked of you and your child. The length of time of your child’s participation in this study is 15 to 30 minutes. Approximately 50 participants will be in this study. The study will be administered to your child at a place and time at your convenience. To preserve confidentiality, the survey will be administered in a place far enough away to not be heard by others, but within sight of other individuals.

Are there any benefits from participating in this study?
Your child’s participation will help us learn more about stress experienced by siblings of children with disabilities. It will also give your child the opportunity to reflect on his/her experiences, and provide him/her with the opportunity to discuss his/her feelings with you or a school counselor if he/she so chooses.
Will you be paid or receive anything to participate in this study?
You will not receive any compensation, but your participating child will get their choice of a small toy from a treasure box.

What about the costs of this study?
There are no costs for participating in this study other than the time you will spend filling out the surveys.

What are the risks involved with being enrolled in this study?
It is unlikely that participation in this project will result in harm to you or your child. Your child may feel uncomfortable talking about his/her feelings or behaviors, or may become frustrated when trying to complete the survey. To minimize this discomfort, I will tell your child that he/she needs only tell me he/she wishes to stop, either temporarily or permanently. Your child may stop participating at any time. If your child does indicate or show signs of emotional distress or want to speak with someone about his/her feelings, counseling services are available at:

- Name of School Counselor
- Phone number
- Email Address

How will your child’s privacy be protected?
Potentially identifiable information about your child will consist of the demographic information you disclose and the surveys your child fills out. Data is collected only for research purposes. Your child’s data will be identified by ID number, not name, and will be stored separately in a locked file cabinet. All personal identifying information will be kept in locked files and these files will be deleted within a month of completion. Other records of your signed consents will be kept in a locked file for 1 year until the study ends and will be destroyed at that time. Access to all data will be limited to the researcher and FHSU supervising personnel.

The information collected will be used only for the purposes of conducting this study. What we find from this study may be presented at meetings or published in papers but your child’s name will never be used in these presentations or papers.

We will not tell anyone the answers your child gives us. However, if your child tells us that someone is hurting her or him, or that s/he might hurt him/herself or someone else, the law says we have to let people in authority know so they can protect your child.

Other important items you should know:
• Withdrawal from the study: If you decide to allow your child to participate, you are free to withdraw your consent and to discontinue his/her participation at any time and without any penalty. Your decision to stop your child’s participation will have no effect on the educational services provided to your child.

• Funding: There is no outside funding for this research project.

Whom should you call with questions about this study?
Questions about this study may be directed to the researcher in charge of this study at xxx-xxx-xxxx.
If you have questions, concerns, or suggestions about human research at FHSU, you may call the Office of Scholarship and Sponsored Projects at FHSU (785) 628-4349 during normal business hours.

**CONSENT**

I have read the above information about “Factors Affecting Daily Stress in Siblings of Children with Special Needs” and have been given an opportunity to ask questions. By signing this, I agree to allow my child to participate in this study and I have been offered a copy of this signed consent document for my own records. I understand that I can change my mind and withdraw my consent at any time. By signing this consent form, I understand that I am not giving up any legal rights.

Parent or Legal Guardian Signature  Date

Name of Your Child with Consent to Participate
My name is xxx; I am a graduate student obtaining my Education Specialist Degree from Fort Hays State University. I would like to invite you and your child to participate in my research study to evaluate stress in the lives of siblings of children with special needs. Participating children are required to be between the ages of 7-18 and have a sibling with a diagnosed or school recognized disability.

As a participant, you will be asked to read and sign a consent form and fill out a brief form indicating the demographic information of your children. I will be asking your child to fill out a 60-question survey regarding hassles and uplifts they experience as a sibling of a child with a disability. The study will take approximately 15 to 30 minutes.

The confidentiality of you and your child will be protected. Your information will be referred to only by ID number and after data is compiled into a computer file, your information will be shredded. Participating in my study will provide no direct compensation to you, but your child will receive a small toy for their participation. Your child may benefit from the opportunity to reflect on his/her experiences, and provide him/her with the chance to discuss his/her feelings with you or a school counselor if he/she so chooses. Participating in the study comes with minimal risk. You or your child might feel briefly uncomfortable; however, you and your child can stop and withdraw from the study at anytime. In the event you chose to withdraw, all information given will be excluded from my data and the information will be immediately shredded.

If you would like to participate in this research study, I will have you read and sign the attached consent form.

If you have any questions or wish to have you and your child participate please contact me at xxx or you may contact my faculty advisor, xxx.
Fort Hays State University  
Department of Psychology  

Assent to participate in Research  

Factors Affecting the Level Stress Experienced by Siblings of Children with Special Needs  

Investigators: I am a college student working to obtain my degree in school psychology. I am conducting this study to learn more about feelings you may be having about having a sibling with a disability.  

Purpose and Description of the Study: I will be asking you to fill answer some questions about your feeling towards time you spend with brother/sister who has a disability or illness.  

Risks or Discomforts: I believe my study will not make you upset. However, if you feel that answering the questions is making you sad or upset you may quit the study at any time.  

Confidentiality: Your name will not be placed on any pages where you are writing your answers. Your answers will not be shared with anyone including your parents and teachers. So please answer honestly.  

Voluntary Nature of Participation: Your mother or father has said it is O.K., if you are part of the project, but you do not have to participate unless you want to. It is up to you. No one will be upset with you or give you a bad grade if you do not want to participate. You may stop at any time without any penalty.  

Questions about the Study: Please ask any questions you may have or have me explain anything that you do not understand.  

Please mark one of the choices below to tell us what you want to do:  

____ No, I do not want to be in this project  
____ Yes, I do want to be in this project  

________________________________________  
Write your name here  

Date  

________________________________________  
Researcher’s Signature  

Date
Parent Demographic Form

As part of this study, we would like to obtain some general information. The answers you provide will help us interpret the responses your child provides. However, if at any point you would rather not reply to the question, please feel free to leave them blank.

**Question about your family**

Does your child with a disability have regular contact with the child participating in the study?

Yes    No

How many children are in your family? ______

Last year’s estimated household income (circle one)

- $0-$14,999
- $15,000-$24,999
- $25,000-$34,999
- $35,000-$49,999
- $50,000-$74,999
- $75,000+

My children primarily live with:

- A single parent
- Dual biological parents
- Step parent/biological parent
- Other (specify) _______________

Highest academic degree completed (if applicable):

**Yourself:**
- Some High School
- Associates
- High School/GED
- Bachelors
- Post Graduate

**Your partner:**
- Some High School
- Associates
- High School/GED
- Bachelors
- Post Graduate

**Questions regarding your child with a disability**

Child’s Age: _______

Child’s Gender:  Male    Female

Amount assistance your child needs to perform activities of daily living, such as using the bathroom, getting dressed, and using a fork.

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<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td>No</td>
<td>Very Little</td>
<td>Some</td>
<td>A Lot of</td>
<td>Assistance</td>
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</tr>
<tr>
<td>Assistance</td>
<td>Assistance</td>
<td>Assistance</td>
<td>Assistance</td>
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</table>

Circle the response that indicates your child with a disability’s abilities when compared to other children of the same age.
Verbal Ability:

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<th>4</th>
<th>5</th>
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<tbody>
<tr>
<td>Below Peers</td>
<td>Same as Peers</td>
<td>Above Peers</td>
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</table>

Academic Ability:

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<tr>
<td>Below Peers</td>
<td>Same as Peers</td>
<td>Above Peers</td>
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Ability to form Relationships with Peers:

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<tr>
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<td>Same as Peers</td>
<td>Above Peers</td>
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Ability to form Relationships with Adults:

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<tbody>
<tr>
<td>Below Peers</td>
<td>Same as Peers</td>
<td>Above Peers</td>
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</table>

**Questions regarding the sibling**

Child’s Age_________

Child’s Gender: Male Female

How much does your child help you care for their child with a disability?

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<tbody>
<tr>
<td>no</td>
<td>Helps</td>
<td>some</td>
<td>Helps</td>
<td>a lot</td>
<td></td>
</tr>
</tbody>
</table>
Study: Factors Affecting the Level Stress Experienced by Siblings of Children with Special Needs

Thank you for allowing your child to be a part of my study. I will be using the data to analyze which factors of having a sibling with a disability has effected the stress level your child experiences in his/her everyday life. Research has found that these siblings of children with disabilities are more mature, independent, and selfless than their peers, based on parents’ perceptions (Glendinning, 1983).

If you have questions or concerns about ethics or participants rights, you may call the Office of Scholarship and Sponsored Projects at FHSU or contact my faculty advisor.

In the event that you or your child feels emotionally distressed by the survey, you may seek counseling from your community mental health facility or your child’s school counselor:

High Plains Mental Health
208 East 7th Street
Hays, KS 67601
(785) 628-2871

Name of School Counselor
Phone number
Email Address

If you would like a copy of my results from this study or have any additional questions you may contact my faculty advisor or me.

Primary Researcher: Name
Number
Email

Faculty Advisor: Name
Number
Email