This is provided as an example proposal. It is important that you follow the current guidelines.

The mentor letter has been removed.
TITLE OF PROJECT: Caregivers' Perspectives of their Experiences with their Child with Autism Spectrum Disorder in Healthcare Settings

NAME OF APPLICANT: Bridget Coolaghan
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DEPARTMENT: Communication Sciences and Disorders

BUDGET: $879.52

CLASS RANK: Senior
GPA: 3.948

EXPECTED DATE OF GRADUATION: April 2017
* Note: Students must be enrolled and maintain undergraduate student status during the proposed project period.

FACULTY MENTOR INFORMATION:

NAME: Dr. Joann Benigno
E-MAIL ADDRESS: benigno@ohio.edu
CAMPUS ADDRESS: Grover Center W222
DEPARTMENT: Communication Sciences and Disorders
DEPARTMENT ADMIN/EMAIL: tyson-dr@ohio.edu

We the undersigned have read the PURF Guidelines and understand the responsibilities we undertake should funding be granted. We certify that the application has been conceived, written and completed by the student.

Student signature: Bridget Coolaghan Date: 9/20/16
Faculty signature: Dr. Joann Benigno Date: 9/20/16
Faculty Advisor's Dept. Chair signature: Date: 9/20/16

IRB AND IACUC APPROVAL:
To ensure that the University is in compliance with all federal regulations, complete the checklist below. Note: your proposal can be approved prior to IRB or IACUC approval (put “pending” or “to be submitted” instead of approval number), but funding will be withheld until notification of approval or exemption.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Office of Research Compliance</th>
<th>Policy #</th>
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<tr>
<td>X</td>
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<td>Human Subjects in Research (including surveys, interviews, educational interventions): Institutional Review Board (IRB) Approval #: Pending Expiration Date:</td>
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<tr>
<td>X</td>
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<td>Animal Species: Institutional Animal Care &amp; Use Committee (IACUC) Approval #: Expiration Date:</td>
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☑ Optional: If selected for funding, I give permission to the Research Division to use my proposal as an example during training and workshop exercises. (Sign below)
Signature: Bridget Coolaghan Date: 9/20/16
ABSTRACT

Little is known about the experiences of children with Autism Spectrum Disorder (ASD) and their families in healthcare settings. The purpose of this study is to examine caregivers’ perceptions of their children’s behaviors and the strategies they use to prepare and support their children with ASD in two healthcare settings: the doctor’s office and the speech-language therapy clinic. Results will discuss whether there are differences between settings and what visual supports are beneficial in preparation and facilitation of these appointments. This information will benefit caregivers to potentially provide them with a better overall experience at their child’s healthcare appointment.
PROJECT NARRATIVE

Project Description

According to the U.S. Centers for Disease Control and Prevention (CDC), 1 in 68 American children is diagnosed with autism spectrum disorder (ASD). Over 3 million individuals in the United States are affected by ASD and tens of millions are affected worldwide (Autism Speaks Inc., 2016) whether they are the person being diagnosed or the family members. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) characterizes ASD by varying degrees of difficulty in the areas of social interaction, verbal and nonverbal communication, and repetitive behaviors (American Psychiatric Association, 2013). To date, there is no known cause of ASD (Autism Speaks Inc., 2016).

Living with and taking care of these children with ASD affects not only the child, but the whole family - especially the child’s caregivers. These parents often have high levels of stress and social anxiety caused by the behavioral problems and consequences of their child’s disorder (Kuhlthau, Payakachat, Delahaye, Hurson, Pyne, Kovacs, & Tilford, 2014). Caregiver stress may be enhanced in public settings because of the behaviors exhibited by their child with ASD. Children who are diagnosed with ASD often have behavioral problems stemming from the social, intellectual, and sensory difficulties they encounter everyday (Ryan, 2010). Healthcare settings pose particular challenges for both a child with ASD and his or her caregivers. There are several anxiety-provoking factors in healthcare settings, including: the unpredictable waiting time, sensory overload, and loud, crowded waiting rooms (Vaz, 2010).

One way caregivers can improve their child’s challenging behavior in public healthcare settings and, in turn, overall experience is through the use of visual supports. These supports are helpful for those who have trouble understanding or using language. One aim of visual supports
is to help improve social interactions; this is relevant to my study because they can be used in the child’s healthcare appointment (Armstrong, DeLoatche, Preece, & Agazzi, 2015). Children with ASD respond well to visually presented information and modeling as opposed to verbal instruction (Vaz, 2010). They have strengths in their ability to easily process visual information rather than other modes of communication (Meadan, Ostrosky, Triplett, Michna, & Fettig, 2011). Temple Grandin (1995), a popular adult advocate with ASD, describes her mind as one that “thinks in pictures.” This relative strength in visual thinking is enhanced by the use of visual supports for children with ASD.

My project focuses on the ways in which caregivers of children with ASD can use visual supports to prepare their child before the healthcare appointment and support their child during the healthcare appointment. There is a gap in the literature as to what strategies and supports caregivers use in these settings. It is imperative to conduct this research because caregivers and their children with ASD deserve better public experiences, especially unavoidable healthcare appointments. This study will enhance the current state of the field as well as provide areas for further research in the future. Presentation of the findings of my study at conventions will allow others to learn more about the ways in which caregivers can have less-stressful experiences.

Methods

This study has specific research questions. They are as follows: (1) What are the caregivers’ perspectives of their children’s behaviors in healthcare settings? (2) What do caregivers use to prepare their children before the visit? (3) What strategies and visual supports do caregivers use to support their children during the visit? (4) What are the similarities and differences between visits to the physician versus the speech-language pathologist?

In order to answer these questions, a 46-item survey was created using Qualtrics survey
software. The survey will consist of three parts encompassing a variety of closed- and open-ended questions. Part I, Demographics, asks participants about their age, sex, health status, education, geographic location, and primary language. This section also asks questions regarding their child with ASD’s sex, age, education level, age of diagnosis, and primary mode of communication. Open-ended questions pertain to the child’s communication strengths and weaknesses because this could be a potential factor influencing their behavior in public.

Parts II and III, “Doctor’s Office” and “Speech-Language Therapy Clinic,” respectively, will consist of questions designed to gain insight into participants’ experiences preparing for and facilitating these settings. These two settings were chosen because the relative frequency of appointments throughout a year is expected to be different, thus potentially distinguishing the results. Questions will include topics such as frequency of appointment, time duration of appointment, behaviors exhibited by the child, supports used in preparation, and supports used at the appointment. Rating scales based off of Schwartz and Drager’s (2008) study will be utilized. Open-ended questions will inquire about what could make the participants’ experiences better as well as any additional comments they may have.

To recruit participants, an email describing the intention of the study will be sent to autism societies and parent and caregiver groups in the state of Ohio. Once approval from these societies is granted for recruitment, an email including a brief description of the study and the link to participate in our investigation will be sent to the organizational contact. Depending on their preference, the contact will share the research opportunity with families via email or via their social media site (e.g., organization group on Facebook). If a caregiver wishes to participate in this study, they will then be directed to the online Qualtrics survey after completing the online consent form. Participants will be caregivers including but not limited to mothers, fathers,
grandparents, aunts, uncles, or foster parents of a child diagnosed with ASD, aged 2-22 years old. Caregivers will be of any race, age, health status or education. All participants will be residents of the state of Ohio.

Quantitative and qualitative data will be collected through the Qualtrics software. Data will be analyzed to determine means, standard deviations, and ranges on each item as appropriate through SPSS software. Qualitative data obtained from the open-ended questions of the survey will be organized by a thematic analysis identifying themes and subthemes of participants’ responses. An independent coder will independently code 20% of the qualitative data for reliability. Disagreements will be resolved through discussion amongst the researchers.

Timeline
-Finalize survey; IRB submission; Autism Societies contact: September 2016
-Introduction & method writing of senior thesis; Launch survey: October 2016
-Data collection/analysis: December 2016
-Results & discussion writing of senior thesis: March 2016
-Ohio Speech Language Hearing Association Convention; College of Health Sciences and Professions Showcase; Student Research and Creative Activity Expo Presentations: April 2017
-Senior thesis submission to Honors Tutorial College: April 2017
*at least 10 hours per week devoted to project including weekly tutorial meetings (1.5 hours)

Student’s Role
This project will be completed to fulfill my senior thesis requirement for the Honors Tutorial College. I have created the survey, and obtained feedback from experts in the area of focus. I will play a primary role in recruiting participants, organizing and analyzing the data, and writing up the results. I will be working alongside of a doctoral student, also conducting research
in Dr. Benigno’s lab. She is working on another aspect of this study; the goal of her project is to evaluate the perceptions of the healthcare professionals and how prepared they feel when working with children with ASD. This project fits within the scope of Dr. Benigno’s research agenda. She is also involved in another outreach study creating these various visual support materials for families in the community. This project will help to determine the supports that are most effective and beneficial for the families. I will present my project at three professional locations: the Ohio Speech Language Hearing Association Convention, the College of Health Science and Professions Showcase, as well as the Student Research and Creativity Expo at Ohio University. In March, I will prepare a submission for the American Speech-language Hearing Association Convention to be held in Las Angeles in Fall of 2017.

**Significance**

Given the increasing rates of ASD and the impact on behavior, managing these behaviors in healthcare settings is important. Caregiver experiences of children with ASD in healthcare settings is an important area of focus. This study is novel because it is the first of its kind to explore what supports caregivers use to prepare their child as well as support their child during healthcare appointments. Current literature explores these topics independently, not together. Society will also gain an understanding of techniques, supports, and strategies needed to help caregivers navigate through these healthcare experiences with their child with ASD. This study is important to help manage children with ASD’s behavior in public, healthcare settings. In doing so, we will alleviate some of the stress that their caregivers possess. This project is imperative in helping caregivers care for their child. The visual supports that my study is observing will help to manage these challenging behaviors, and in turn, provide better overall experiences for the caregiver.
BIBLIOGRAPHY


BIOGRAPHICAL INFORMATION

My experiences at Ohio University in the Honors Tutorial College have prepared me to execute my project under the guidance of Dr. Benigno. The theme of my tutorials was on areas of ASD including specific characteristics of the disorder and families of children with ASD. I have read approximately 40 articles and book chapters that motivated the design of this study.

Additionally, I participated in a two semester training program on ASD with Dr. Benigno, and I am currently enrolled in a graduate level seminar on ASD. Topics include characteristics of ASD, empirical articles in the field, and workshops designing evidence based materials. All three courses involve outreach to families of children with ASD as well as speech-language pathologists who work with this population in school settings. This outreach involves creating all of the visual supports inquired about in my study.

Consequently, I was a research assistant on a study examining the language of children with and without ASD completing a high level cognitive drawing task. I presented this study at three professional conventions, preparing me for my current project. These experiences have helped me gain an understanding of the current field as well as the need for visual supports.
## BUDGET

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<td>Data Storage- Dedicated external hard drive (WD 1TB Black My Passport Ultra Portable External Hard Drive - USB 3.0 - WDBGPU0010BBK-NESN)</td>
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<td>External hard drive needed so store data, results, and analysis specifically dedicated to this project.</td>
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<td>SPSS Student License (IBM® SPSS® Statistics Standard GradPack 24 for Windows (06-Mo Rental: $54.99+$4.99 plus Parallels Desktop® 12 for Mac: $39.99)</td>
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<td>Student Licensure needed to work on data analysis of de-identified data.</td>
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<td>Travel expenses to present- Ohio Speech Language Hearing Association Convention (March 30-April 1) Registration- $115 Transportation (mileage(74.4) x rate(.54) x 2)-$80.35 Hotel (two nights at Hyatt Regency, Columbus, OH $304 + tax $53.20)-$357.20 Meals 3 days at $56 OU per diem-$168</td>
<td>$720.55</td>
<td>PURF</td>
<td>Presentation of research results is needed to educate society about the supports that can be used to better facilitate experiences in healthcare settings for children with ASD and their caregivers.</td>
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**Total** $879.52
MENTOR’S ENDORSEMENT

Included separately from application from Dr. Joann Benigno.