

Human Subjects Research Proposal, Modified for FACS100 S23

A. Student Investigator Information	
Student Investigator:	Emma Hansen
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B. Project Information	
Project Title:	Alternative or augmented communication (AAC) and the effects on relationships of people with autism spectrum disorder (ASD).
Are other institutions/organizations involved?	<input type="checkbox"/> No <input type="checkbox"/> Yes: List name of institution/organization: Do you have support from the organization? <input type="checkbox"/> No <input type="checkbox"/> Yes

C. Project Overview
a) Objective Statement
Explore perspectives and experiences of people with autism spectrum disorder and their families and their “reasons for their convergence/divergence with professional attitudes to AAC” (Doak, 2021).
b) Main Research Questions (Qualitative) or Hypothesis (Quantitative)
<ol style="list-style-type: none">1. What factors influence parents of children with autism spectrum disorder to choose augmented or alternative communication (AAC) devices, and how it affects relationships moving forward?2. What are the perceived benefits of AAC in fostering communication as well as how it affects the family dynamics, as reported by parents of children with ASD? (Blackstone & Hung-Berg, 2012; Thiemann-Bourque et al., 2018; Faldt et al., 2020)3. What challenges associated with AAC, such as technical difficulties and learning curves, impact family solidarity and interactions? (Ronski and Sevcik, 2005; Lorah, 2012; Boster and McCarthy, 2018)
c) Methodology
<p>This study will use mixed methods research designs. It will use both quantitative and qualitative approaches to gain an understanding of this complex topic (Johnson and Onwuegbuzie, 2004). The combination of both quantitative survey data and qualitative interviews will allow for a full understanding of the parental decision-making process as well as capture the depth of the families’ experiences (Creswell and Plano Clark, 2011). The use of quantitative surveys will show the demographic information and quantification of factors that influences AAC interventions, while the qualitative interviews will provide more insight to the individual experiences of parents and their perception of AAC’s impact of the family dynamic.</p> <p>In the study by Corin, Ganz, Gregori, Foster, Gerow, Genc-Tucson and Hong (2018), which highlighted the need for evidence-based practices in AAC intervention, this study will utilize surveys to achieve accurate qualitative data. The qualitative component of the study will use the information from Butler, Gregg, Calam, and Wittkowski, who emphasize the importance of parent relationships and their perspectives on AAC devices in their homes and family dynamics. Semi-structured interviews will allow for flexibility in many diverse family experiences and viewpoints, to fully capture the experiences on all levels (Creswell, 2013). Ethical considerations, such as obtaining informed consent and ensuring confidentiality, will be addressed in the following guidelines by the Sacramento State review boards (Boster and McCarthy, 2018) Overall, the mixed-methods approach in this study will provide a strong methodology for</p>

investigating parental decision making regarding AAC use and its impact on family relationships, informed by research.

d) Development of/Contribution to Generalizable Knowledge

The research will contribute to generalizable knowledge by providing insights into parental decision-making regarding the implementation of alternative or augmented communication (AAC) devices for children on the Autism spectrum, as well as its impact on family relationships. This study will aim to deepen the understanding of the parental decision-making and all of the complex factors when prescribing the child with ASD this technology (Lewis, Patton Freebairn, Tag, Iyengar, Stein, and Taylor, 2016; Morin, Ganz, Gregori, Foster, Gerow, Genc-Tocun, and Hong, 2018). Investigating the dynamic shift within the family will offer valuable insight into the relationships, communication patterns, and social interactions, ultimately informing the development of family-first interventions and support services aimed to enhance family dynamics, as well as quality of life. (Butler, Gregg, Calam, and Wittkowski, 2020; Faladt, Fabian, Thunberg, and Lucas, 2020). This will help to understand how we can help other families with the new technology in creating programs to train families for app guidance, language comprehension with these devices, and social interactions. (Light, and McNaughton, 2013).

D. Participant Population

I. Who are the research participants?

Parents or primary caregivers of children diagnosed with autism spectrum disorder (ASD) who have chosen to implement alternative or augmented communication (AAC) devices as a form of communication for their children.

e) Will any special population be included?

- ☐ Children (Please consider if this is appropriate. Conducting research with minors requires parental consent and potentially expertise)
- ☐ DACA (Please consider if this is appropriate for a classroom project)
- ☐ Prisoners (not allowed)

f) How will they be recruited?

(Be specific with your steps. Include specifics on outside people who would be pivotal to the success of your project.)

Participants will be recruited through many different places including autism support groups, clinics specializing in ASD, and educational institutions. Announcements will be distributed throughout these channels, providing information about the study and its purpose. Snowball sampling may be utilized as well, to recruit more members within these networks. This will help to gain a diverse group of participants and ensure a varied population of different backgrounds and experiences.

E. Participant Experience

g) Data collection procedures

Discuss when you plan to collect the data, where you will collect it, how long it will take. Include information on incentives.

Data collection will be held over a period of nine months. The data collection process will be held at various locations in order to convenience the participants. These locations will include autism support groups, clinics specializing in ASD, and educational institutions. Participants will have the ability to choose their preferred location to take an online survey or participate in an interview to ensure convenience, accessibility, and confidentiality. Online surveys will also have the option to be completed in the comfort of their homes. The survey has been tested to take approximately 10-15 minutes to complete depending on the depth of the answers that they provided. Interviews should be expected to take about 45-60 minutes allowing for in-depth exploration of participants' emotions, experiences, and perspectives. Incentives such as gift cards or vouchers will be offered to participants for participating in the study. Flexibility is also a priority for interviews in order to accommodate all participants.

F. Data Maintenance

I. What is your data maintenance plan? How will confidentiality be maintained during collection and analysis?

Confidentiality of participants will be maintained throughout all stages of data collection, storage, and analysis. During data collection, participants will be assigned an identification number to remain anonymous during their interviews, with no personal or identifiable information collection. Surveys and interview responses will be securely stored on a password protected electronic device only accessible to the research team. Also, hard copies of identifiable information collected in the consent process will be in a locked file in a secure location. Any identifying information will be removed from the transcript and replaced with the assigned identification number to preserve confidentiality only further. These steps will ensure confidentiality and the integrity of participants throughout the research process.

h) Collection of Direct and Indirect Identifiers

Check all of the identifiers you plan to collect.

(Direct) Identifiable data:

- ☐ Name
- ☐ Email
- ☐ Phone number
- ☐ Username
- ☐ Student ID or other unique ID
- ☐ Other: _____

(Indirect) Demographic data:

- ☐ Gender
- ☐ Age
- ☐ Race
- ☐ Sexuality
- ☐ Income
- ☐ other demographic data: _____

i) ***How*** and ***when*** will data be maintained or destroyed after publication/presentation (password protected, locked drawer; erase files, shred documents; 3 years after completion)? For research practice, it is not necessary to retain data for long periods of time.

Data will be securely stored in password-protected electronic devices and locked file cabinets during the research process. After publication, files will be erased and hard copies will be shredded. This will occur three years after the completion of the study.

G. Benefits and Risks

I. Describe the benefits to the individual (if any) and to society:

The benefits for the individuals participating in the research are the opportunity to contribute to the advancement of knowledge in the field of autism spectrum disorder (ASD) and augmented or alternative communications (AAC). By participating in the study, participants may feel empowered and may potentially shape the future of AAC interventions as well as support services for ASD individuals and their families (Butler, Gregg, Calam and Wittkowski, 2020). This may also give people the opportunity to express their perspective and provide a platform to express concerns, coping strategies, and connect with other parents or caregivers facing similar challenges which in turn fosters a sense of community and support (Faldt, Fabian, Thunberg, and Lucas, 2020).

For society, the research has potential to generate evidence-based practices and intervention that may improve quality of life for individuals with ASD and their families. By gaining knowledge on the decision-making process when selecting AAC for their family and its impact on family relationships, the findings can help support services, educational programs, and policies aimed at enhancing communication, language comprehension, and social interaction (Morin, Ganz, Gregory, Foster, Gerow, Genc-Tosun and Hong, 2018). Also, raising awareness about AAC interventions and experiences in the home can potentially reduce the stigma and promote inclusivity within our society as well as more support for families and individuals with ASD (Lewis, Patton, Freebairn, Tag, Iyengar Stein, and Taylor, 2016). Overall, the research has potential to make a positive impact for both individual and society by advancing knowledge, fostering empowerment, and enhancing support for individuals with ASD and their families.

j) Physical Risk (i.e., exercise, sensors placed on skin, cheek swabs, saliva samples, etc.)

☒ Not applicable ☐ Minimal ☐ Greater than Minimal

a) Describe minimal or greater than minimal risk:

b) Describe how this risk will be addressed/minimized:

k) Psychological Risk (i.e., stress, embarrassment)

☐ Not applicable ☒ Minimal ☐ Greater than Minimal

a) Describe minimal or greater than minimal risk:

Participation may include minimal psychological risks such as stress of mild discomfort because participants will be describing personal experiences and emotions relating to their child with ASD.

b) Describe how this risk will be addressed/minimized:

Participants will be informed of the mild discomfort during the informed consent process and will be assured of their right to withdraw from the study at any point without penalty. The research team will also use empathetic approaches when interacting with participants to minimize discomfort. Participants will also be allowed to skip questions that they are uncomfortable discussing.

l) Sociological and Economic Risk (i.e., employability, reputation, financial standing, criminal prosecution)

☒ Not applicable ☐ Minimal ☐ Greater than Minimal

a) Describe minimal or greater than minimal risk:

b) Describe how this risk will be addressed/minimized:

m) Confidentiality Risk (i.e., collection of identifiable information, data maintenance, potential access to data from outside parties) <input type="checkbox"/> Not applicable <input checked="" type="checkbox"/> Minimal <input type="checkbox"/> Greater than Minimal	
a) Describe minimal or greater than minimal risk:	The research may involve minimal confidentiality risk, identifiable information such as name and contact information may be collected during the informed consent process.
b) Describe how this risk will be addressed/minimized:	Identifiable information will be stored separately from the research data and will not be accessible to authorized members of the research team. Data collected during the study will be coded with the participants' identification number to protect the anonymity of the participants.

H. Survey or Interview Questions
Include 5 - 10 questions you intend to ask your participants or respondents.
<ol style="list-style-type: none"> 1. When did you first learn about alternative or augmented communication (AAC) devices for individuals with autism spectrum disorder (ASD)? <ul style="list-style-type: none"> - Understanding how participants became aware of AAC devices can provide insight into their knowledge and awareness of different kinds of available communications, influencing their decision-making process (Lewis, Patton, Freebairn, Tag, Iyengar, Stein, and Taylor, 2016). It will also help to understand what other options parents or caretakers were given in the process of selecting interventions for their children. 2. What factors influenced your decision to choose an AAC device for your child? <ul style="list-style-type: none"> - This will explore the factors in the decision-making process and can help identify key considerations and priorities guiding parents' choices regarding AAC, informing future intervention strategies (Morin, Ganz, Gregori, Foster, Gerow, Genc-Tosun and Hong, 2018). This will also gain insight into what other options were given to families for interventions for their child. 3. What benefits have you observed in your home since implementing AAC devices for your child? <ul style="list-style-type: none"> - Gathers information about perceived benefits and can provide insight into the effectiveness of AAC pertaining to language comprehension, social interactions, and overall quality of life for individuals with ASD and their families (Butler, Gregg, Calam, and Wittkowski, 2020). I would like to gain knowledge into different dynamics of relationships such as sibling interactions. 4. What challenges have you encountered while using AAC devices with your child? <ul style="list-style-type: none"> - This can help identify areas of improvement for app design, training programs, and support services to enhance the AAC interventions (Boster and McCarthy, 2018). I would like to understand if AAC benefits not just child to caretaker, but also sibling relationships. I would like to understand how often AAC is used within the home. 5. How has the use of AAC affected family dynamics and relationships in your household? <ul style="list-style-type: none"> - This will explore the impact of relationships in the family dynamic and can provide insight into the broader psychosocial implications of AAC interventions (Faladt, Fabian, Thunberg, and Lucus, 2020). This will give overall insight into the relationships. I ponder if AAC is used as often in the home. In the child with ASDs closer relationships, is AAC used more or less?

References

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