

Name: _____, RN, FNP-BC, PhD

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Professional title: Associate Professor (also certified Family Nurse Practitioner)

Tenure status: Tenured

Number of years at TCNJ: 7.5

Department: Nursing

Title of project: Matching Family Needs with Systems of Care for Older Adult
Individuals with Autism

Names of student collaborator: _____

Email address of student: _____@tcnj.edu

Requested dollar amount: \$ 6,482.24

IRB (human subjects) approval: Required

Date of most recent MUSE: 2018

Intellectual Merit. As an increasing proportion of the US population is over age 65 (20% by 2030), healthcare providers must understand and plan for the senior's needs. While much is known about best practices in healthcare for older adults, far less is known about needs of emerging subpopulations, such as those with Autism Spectrum Disorders (ASD).

Autism and its heterogenic spectrum of disorders affects 1 in 41 children in NJ. Per the Diagnostic and Statistical Manual (DSM) V, ASD includes three components: deficits in social communication, restricted behaviors (e.g. inflexibility) and impairment in functioning (e.g. self-care such as bathing). First identified in 1943, the initial wave of individuals with an ASD is now entering older adulthood and primed to face challenges related to both ASD and aging. Those with ASD have a life expectancy nearly 30 years shorter than non-affected individuals (Guan & Li, 2017). Medical concerns include gastrointestinal issues, seizure disorders, and sleep disruption. Common problems related to aging occur at high rates in individuals with an ASD. These include high blood pressure and hip fracture (11 times risk in women with ASD; Neumeyer et al., 2015). There is 2-3 times the risk for psychiatric conditions (e.g. bipolar disorders, anxiety, and depression) in middle-aged adults with ASD compared to the non-affected population. All of these places older adults with ASD in a particularly vulnerable category, likely to experience disparity in health outcomes.

Normal aging challenges are likely to affect this population as well. Mobility limitations related to osteoarthritis, make self-care more difficult, increase pain and risk for falls. Memory disorders, such as Alzheimer's, increase unsafe behaviors such as wandering and increased accidents. The extent of, and how these 'normal' problems related to aging will affect individuals with ASD over 65 years old are unknown, but it is likely that healthcare needs will be complex.

The knowledge base for gerontology healthcare providers and policy makers related to ASD is significantly limited. Of particular concern are the needs of families with an aging ASD member. Research indicates that over 50% of adults with ASD live with their family, and have parents that are aging themselves. Little is known about how these families are planning for the later life of their aging ASD family member, as they are among the first wave to experience this developmental stage. Thus, healthcare providers have little knowledge about how to help these families work toward a safe and healthy future and how to begin to address the substantial disparity in lifespan.

Eden Autism (Princeton, NJ), a local provider of services to families and individuals with an ASD, has recognized these gaps in knowledge and agreed to work with this researcher to study ~~research~~ family needs and goals and to explore optimal evidence-based directions for future services. This agreement includes researcher access to families for interviews.

Goals. The purpose of this study is threefold. First, to conduct an integrative literature review regarding best healthcare practices in caring for older adult individuals with ASD; second, to complete and analyze data from focus groups and interviews with family members of aging individuals with an ASD; and third, to align expressed family desires with best practices identified in the literature and community survey.

Methods. Using qualitative research processes, I will begin family interviews in April. The student and I will complete remaining interviews and begin analysis of the transcripts. We will utilize software (NVivo) and thematic identification by reading the transcripts independently and coding them for common phrases and words. We will meet with each other to confirm coding and to developing themes. We will develop a guide for best practice in meeting family needs by integrating interview data with findings from the literature review and a community provider survey.

Importance. The findings from this project will inform Eden Autism and will contribute to the literature by identifying family goals/dreams and demonstrate how using best practices in the literature can be connected with family needs. This area is substantially under-researched.

Feasibility. The researcher will begin this project in Spring 2021. By June 2021, the literature review, interviews and transcription of interviews should be complete. The analysis, refinement of the literature review, validation of findings, community survey and submission of an article for publication are thus feasible.

Role of Student and Mentor. _____ will learn components of qualitative research methods, including critiquing the literature in her nursing research course this Spring. During my Health Assessment course, _____ asked clear questions and followed suggestions for improvement well. She enjoyed my ‘discuss, demonstrate and do’ mentoring style and seeks a collaborative faculty relationship. We will meet at minimum twice per week, and using email/phone otherwise. Each week I will provide written and verbal instruction related to the research tasks, leaving time for question and discussion.

Week 1: How to read and code interview transcripts. Code 50% of transcripts

Week 2: How to enter raw data in NVivo and run the analysis. Finish independent coding and meet to begin to come to consensus about findings/themes. Begin to correlate with NVivo.

Week 3: Finalize themes and then compare to the NVivo findings. Conduct a ‘member check’ with 1 or 2 families, as an additional step in validating the findings. Revise literature search to explore previous knowledge about these themes/experiences.

Week 4: Create a visual graphic that demonstrates how the themes interconnect. Locate a target journal for our publication. Create a sample outline and begin writing methods/findings.

Week 5: Overlay/integrate literature with family needs. Community survey (internet, phone calls) of existing ASD programs. Draft discussion section/ Eden presentation.

Week 6: Compile demographic data and create tables for publication/poster presentations. Collate findings from our survey of existing programs. Finalize reference page.

Week 7: Finalize the paper in tandem, co-editing. Present the findings to Eden Autism.

Week 8: Revise the paper/submit. Poster for MUSE. Abstract conference submission.

Broader Impacts: For _____, a first-generation college student of Hispanic descent, this is an opportunity to explore a nursing research career. Hispanic nurses are quite underrepresented at all levels of a nursing career. For me, the opportunity to re-engage with MUSE after a 3-year hiatus will assist in this important new sub population focus to my gerontology work.

BUDGET

Student stipend	\$3000
Student housing	\$1,732.24
Faculty stipend	\$1,250
Project-related expenses	
<i>NVivo software</i>	\$500

(note: this software costs ~\$1500; I will use the funds to support the purchase and seek funding elsewhere or personally sponsor)

Total **\$6,482.24**