

1. Specific Aims

Detection of autism spectrum disorder (ASD) and receipt of evidence-based interventions can alter a child's developmental trajectory, decrease long-term economic burden, and improve quality of life (Estes et al., 2015; Cidav et al., 2017), but these benefits are not equitably distributed, with racial/ethnic disparities in ASD diagnosis and service use well documented (Baio et al., 2018; CDC, 2014; Durkin et al., 2017; Magana et al., 2012). The proposed study, 'Experiences of African American Caregivers of Children with Autism: Rurality and Resources during the COVID-19 Pandemic' aims to investigate the impacts of social distancing, home schooling, stress, and resultant social isolation. Specifically, the aims relate to the RFP's suggestion of, "... activities related to monitoring and addressing the public health and economic impacts of COVID-19".

COVID-19 is more easily transmitted and has a higher mortality rate than other viruses. Further, since its detection in the United States at the beginning of 2020, health disparities in mortality have emerged, disproportionately affecting African Americans (AA). So as not to overload healthcare facilities and to reduce transmission, social distancing and quarantines have made in-person gatherings like therapy, school, recreation, church, funerals, non-essential work, or elective healthcare services impossible. While this has greatly impacted all citizens, it uniquely affects the routines of children with ASD, many of whom thrive on structure. The ability to predict routines allows children with ASD to feel safe and helps families organize and plan actions so the child can prepare emotionally for upcoming events; thereby decreasing anxiety and avoiding emotional disorganization, irritability, or discomfort.

The cause(s) and physiological processes of ASD are unclear, leaving educational and behavioral assessment and treatments as primary service methods (Boat & Wu, 2015). Though studies of culturally and linguistically diverse (CLD) children with ASD are increasing, multilingual, racial/ethnic minorities from low socioeconomic (SES) homes are still underreported in research (Crosland et al., 2013; Kasambira Fannin, 2017; Pierce et al., 2014). This impedes generalizability of existing intervention and assessment methods, leaving the research-to-practice gap wide. One must consider language background, environmental context, and culture when designing interventions because such factors influence caregiver knowledge, acceptance, and utilization of ASD services; and including these considerations increases the ecological and external validity of ASD interventions and policies (Stahmer et al., 2018). Geographic region is also important to analyze in ASD studies because, given limited access to evidence-based professional development and, consequently, the shortage of rural personnel trained to work with students with disabilities, service equity for rural children is of concern (Hott et al., 2019; Nichols, 2017; U.S. Department of Education, 2020). Social distancing further compounds existing educational inequities where schools have shifted to online educational delivery; which is problematic when considering disparities in resources (e.g., reliable internet connection, computer devices for students to complete schoolwork, loss of meals normally received at school). **Hence, this proposal is designed to examine the experiences of AA families dealing with educational and health disparities within this unique context of COVID-19.**

Though factors such as community stigma or cultural distrust of providers have impeded service uptake (Murry et al., 2011), one must also account for the shortage of effectively trained providers in rural and low income areas (Morrier & Hess, 2012) and how some rural school districts receive 50% less federal Title 1 funding per student than urban, Title 1 schools (Gutierrez, 2016; Hott et al., 2019; Lee & Nichols, 2014; Murphy & Ruble, 2012). Geographic isolation also requires rural patients to bear increased travel time and transportation costs (Collins & Ludlow, 2018). Barriers to timely assessment and intervention are also thought to relate to: limited English proficiency, variations in cultural interpretation of symptoms; stigma; cultural validity of 'gold standard' measures to identify symptoms and track ASD treatment response (Murry et al., 2011); reduced caregiver alliance with the health system and providers, and limited health literacy (Yingling et al., 2015). The racial/ethnic, SES, and geographical disparity is a critical public health and clinical care challenge that will grow over time because the increased prevalence of ASD disproportionately impacts minority populations (Durkin et al., 2017).

The proposed inquiry is in line with the National Institute of Mental Health and Federal Interagency Autism Coordinating Committee Strategic Plans, "...to develop an innovative early ASD intervention platform that advances treatment personalization in community settings; and reduce disparity in access and outcomes for underserved populations". I thereby propose to explore and document contextual factors that affect children with ASD, guided by Stahmer et al.'s (2019) Exploration, Preparation, Implementation, and Sustainment (EPIS) model of community-based ASD research. A novel method of qualitative inquiry (Bosch et al., 2019) might also illuminate the experiences of CLD families of children with ASD during the pandemic using the following aims:

Aim 1. Using the EPIS Framework, describe whether AA caregivers of children with ASD differ by geography and SES on reported family needs, sources of support, stress, and contextual factors they consider important to ASD services in their community during the time of social distancing as a result of COVID-19.

Aim 2. Using the EPIS Framework, describe the personal and varying daily experiences of rural and urban, low and middle SES, AA caregivers of children with ASD during social distancing as a result of COVID-19.

2. Research Strategy

As we are in the midst of the pandemic, **the impacts of social distancing have been largely anecdotal, thereby requiring methodical, scientific documentation of caregivers' experiences to make informed decisions on how to serve families of children with ASD.** Some caregivers of children with ASD have reported significantly higher amounts of emotional and economic stress than caregivers of children with other developmental disabilities (Abbeduto et al., 2004; Estes et al., 2009). **It is no longer enough to gather only quantitative data if one is to conduct thorough, robust analyses of caregiver perspectives,** and this has been borne out in a documented increase in qualitative studies of racial/ethnic minority caregivers of people with ASD (Guler et al., 2018). Studies have shown caregivers to cite personal challenges and their own emotional distress as barriers to effective caregiving (Fewster & Gurayah, 2015) and some AA caregivers experience the added cultural stressor of racial discrimination.

Although it is acknowledged that caregiving of people with ASD has its challenges, this data comes from primarily homogeneous (European American, middle SES, urban) study samples, so the full experience of caregiving across cultures is still in question. So as not to presume that AA caregivers are necessarily having negative experiences, the Co-Care KIT is an Experience Sampling Method (ESM; Hektner et al., 2006) tool from the field of positive psychology, designed to capture the range of experiences. By processing the personal and varying daily experience of caregivers, they are empowered to reflect on their experiences in an emic way, before researchers impose intervention methods developed with primarily urban, middle SES, European American families in mind (Stahmer et al., 2011). By analyzing variables within racial/ethnic and across geographical and SES groups, service providers can be more responsive to what CLD families may or may not need in their communities, and better develop targeted implementation strategies to promote health equity during the current and future pandemics that require social distancing.

Study procedures will be guided by the first phase of the Exploration, Preparation, Implementation and Sustainment (EPIS) Framework (Exploration) (Aarons et al., 2011) to gather a comprehensive corpus of knowledge from caregivers to promote culturally appropriate services for their CLD schoolchildren. EPIS emphasizes the importance of Outer and Inner Contextual Factors and examines potential barriers or facilitators to the ASD service implementation process. The proposed study will focus on **Family Cultural Characteristics, a component of Outer Contextual Factors:** To date, ASD intervention research has overlooked diverse sociocultural contexts in which children live. This study is therefore designed to improve understanding of sociocultural contexts and perceived barriers and facilitators of daily living. **The study will also examine Individual Characteristics, a component of Inner Contextual Factors:** Understanding caregiver characteristics that impact views on caring for a child with ASD is vital. Participants will complete web-based surveys with questions on: (a) Demographics; (b) Autism Knowledge (Kuhn & Carter, 2006); (c) Caregiver Strain Questionnaire (Brannan et al., 1997); (d) Social Support (Sherbourne & Stewart, 1991); (e) Family Empowerment (Koren et al., 1992); (f) Everyday Discrimination Scale (Williams et al., 1997); (g) Coping with Discrimination (Kreiger, 1990; McNeilly et al., 1996) and; (h) Family Outcomes (Bailey et al., 2011). Related to the stress and discrimination surveys, participants will also wear a heart rate and sleep pattern monitoring wristband for the 2 weeks of data collection for an additional index of stress, and to assist in the interpretation of photo and journal data.

a. Design and Methodology

Participants. Participants will be purposefully sampled including AA caregivers of schoolchildren (ages 4-12 years old) diagnosed with ASD who live in Halifax County ($n=12$) and Durham County ($n=12$) and are from both low and middle SES homes (as indicated by a pre-screening questionnaire). Participants will need video and internet access for the initial and final interviews, as they will be conducted via an internet video platform. They will also need computer access to complete the eight surveys via Qualtrics (Qualtrics, Provo, UT). As the entire state of North Carolina has gone to online homeschooling for children, the PI is confident that participants with internet access can be recruited. An N of 24 is considered large for the amount of qualitative data that will be generated. In fact, the developers of the Co-Care KIT (Bosch et al., 2019) had only seven participants in their validation study. Low income will be designated as a household income less than or equal to 150% of the federal poverty guideline, which is \$30,680 for a family of five (USDHHS, 2020) in 2020. Various approaches will be used to recruit such as collaboration with community organizations that have been facilitated by the NCCU CEOC, the NCCU Communication Disorders Program clinic, community events, or the Duke Autism Center research registry. Participants will sign an online consent form explaining the study and participation methods will adhere to the NCCU Institutional Review Board (IRB) guidelines. The IRB application is to be submitted by June 3, 2020.

Mixed methods will be used to gather data about the contexts wherein CLD families of children with ASD exist, and how those factors impact access to and quality of services. Quantitative and qualitative data will be collected in a simultaneous, balanced arrangement, with equal importance being given to both. Individual interviews will be video and audio-recorded through the web platform (e.g., Zoom or WebEx), transcribed verbatim, and cross-checked for accuracy. Data will be inductively analyzed via content analysis using NVivo software (Elo & Kyngas, 2008). **Quantitative and**

qualitative results will be triangulated for interpretation (O’Cathain et al., 2010). This involves a) collecting qualitative and quantitative data; b) distinguishing salient results; c) examining confidence in the results and; d) developing criteria for inclusion of results for interpretation. To wit, the Co-Care KIT has not yet been applied to caregivers of children with ASD. The Co-Care-KIT includes:

- a journal for writing and reflecting about daily experiences with predesigned pages for supporting experience disclosure, and writing tools like pens, markers, and Post-it notes
- a small, digital camera with an instant photo printer to visually capture experiences with photos.
- a waterproof activity wristband to continuously measure heart rate variability (HRV) as a stress indicator and the wearers’ sleep stages overnight. Many children with ASD have sleep disturbances and insomnia, so sleep patterns of the caregivers might be of interest. Heart-rate graphs will be printed and displayed along with participants’ photos and journal quotes for a visual interpretation of how participants felt at the time the photo was taken.

Data Collection and Analysis. The PI has experience conducting and teaching qualitative research and working with children with ASD, as well as implementing caregiver mediated models of intervention.

1. Potential participants are screened via an online questionnaire and, if they qualify, will complete an online consent form. The initial interview will also be scheduled via phone.
2. The entire Co-Care KIT will be left on the participants’ doorsteps to avoid physical contact.
3. Each caregiver will undergo a semi-structured interview to gain an understanding of their general experience of caregiving and daily routines. In the initial interview, each caregiver will be questioned about (1) the context of their care situations and (2) their emotional experiences of caring for their child with ASD. Caregivers will also discuss their experience of combining school, work, and caregiving now that schools and workplaces have been closed due to COVID-19. This will last 60 to 90 minutes where use of the camera, heart rate monitor, and web-based surveys will be described via a Zoom or WebEx meeting.
4. Participants will then proceed with completion of the surveys of which they will be notified via a SonaSystems website platform. The website emails participants when surveys are ready for them to complete, and presents the Qualtrics surveys that have been interfaced with the SonaSystems platform. The participant simply clicks on a link in the email, logs onto the website, and proceeds with the surveys.
5. Once surveys are completed, the 2-week Co-Care KIT collection will begin on a day agreed upon with the PI.
6. The Co-Care KITs will be collected from the participants’ doorsteps at the end of the 2 week journaling for the PI to download the heartrate readings onto the lab computer. Each caregiver will be debriefed with a closing interview (lasting approximately 90 minutes) where data will be discussed and evaluated by the participant and PI. Biofeedback in the form of heartrate measurements can be used as a physiological indicator of mental effort and emotions like worry or stress, and be a measure of psychological health and stress (McDarby, 2005). These measurements will not be used for medical purposes. Rather, it is a visual representation of psychological states to complement the pictures and journal entries. Heart rate measurements of each caregiver will be plotted by the PI on daily timelines with the printed photos, providing an overview and context for the recorded moments such as time, location, and people. These data will be discussed with each caregiver, using the data conversation prompts. For example, photos and heart rate measurements will be shared and discussed and interpreted by the caregivers while the PI questions them about it. A modified version of the 13-question Caregiver Strain Questionnaire will be used to guide the interview. It is modified for caregivers of children with ASD from its original caregivers of older adults.

All interviews will be transcribed and coded by two research assistants (RA). Transcriptions will be analyzed using applied thematic analysis, a broad inductive method in which key themes are identified in text and transformed into codes. Applied thematic analysis assumes a researcher’s effect on the data because journal entries, photos, heartrate readings will be reviewed to formulate additional questions for the final debriefing interview (Elo & Kyngäs, 2008). The PI will then train another set of blinded undergraduate RAs to verify the transcripts and code them. Because the sample is small and outcome distributions cannot be assumed to be normal, nonparametric design (Dallal, 2000) will be used to measure relationships between the quantitative measures. An independent samples Kruskal-Wallis H test will be used with a null hypothesis that there is no statistically significant differences in survey results based on SES or geography.

b. Future Funding and Publication Plan. Neurohumanities Research Group scholars at Duke (and one of the developers of the Co-Care KIT) have agreed to assist me in taking a humanities approach to learning about underrepresented populations’ experiences with disability. The advent of COVID-19 has heightened the necessity to study cultural and environmental factors affecting people with disabilities in the context of healthcare and educational systems that are extraordinarily taxed, and the field of humanities lends itself well to the study of cultural effects on people with ASD. Those of us focused on CLD populations try to avoid pathologizing cultural differences, while recognizing potential inter-and intra-cultural aspects of disability for which our services could be of use. I aim, however, to move beyond reiterating that there are health disparities and inequities in the services we provide. Rather, I want to refine the cultural

focus in our field through more appropriate and effective ways to a) approach community-engaged research; b) discover various views of disability and communicative behaviors and; c) interpret and disseminate results.

Data from this proposed study is integral to development an NIH R21 or Diversity Supplement application that will target implementation strategies to promote access to appropriate ASD services and reduce disparity in rural and low resource counties; with the ultimate goal of extrapolating this knowledge to a more broad, rural American setting of CLD residents. The PI has budgeted to attend the Training in Grantsmanship for Rehabilitation Research (TIGRR) Workshop for 2021 to assist with securing future external funding, if selected. The current, focused proposal is a crucial, formative step in the process of conducting culturally appropriate caregiver-mediated, treatment research and culturally appropriate identification/assessment research for CLD children with ASD. The study should yield feasibility information for whether the adjustments to the Co-Care KIT for a) social distancing; b) limited resources (for the investigator and the participants) and; c) participant types (ASD caregivers versus Dementia caregivers) are useful. This study should also elucidate whether a larger study using the adjusted Co-Care KIT with a wider variety of participants (by race/ethnicity, bilingual background, geography, and severity of ASD) and other biometric indicators like sleep patterns yielded from the wristbands should be included as an Aim of future applications. As drastic changes in caregiver occupation, economic stability, child education, healthcare service access, and socialization may become the 'new normal,' it is crucial that both challenges and successes in the lives of people during the pandemic be identified in order for providers to make well-informed adjustments to systems that serve families with ASD, and I plan to disseminate these insights through presentations at academic meetings and peer reviewed publication.

Budget: Total requested \$34,263. \$23,600 is requested for personnel to complete data collection, data entry, transcript coding, analysis. The PI is requesting two course releases for the fall semester. Equipment is for the Co-Care KITs and Supplies are for the lab. The original Co-Care KITs called for dedicated cellular phones (~\$600), but some of the rural areas have unreliable Wifi connections and the PI did not want participants to worry about using their own data plans. Therefore, instead of cellphones to take pictures, cameras that print photos instantly will be more cost effective. Travel rates are based on NC state mileage guidelines and I reduced travel by eliminating claims for local travel to Durham.

Personnel: \$23,600

- 2 course releases PI – fall 2020 \$6000 + .30 fringe = \$15,600
- 2 Research Assistant stipends for 6 months at \$500 per month. - \$6000
- Stipend for quantitative statistical consultant – **(\$2000 will be from internal funds)**

Equipment: \$5104.78

- 15 Canon IVY CLIQ Instant camera and printer (blue)- \$115.89 = \$1738.35
- 30 Canon Zink Photo Paper 50-Pack - \$23.74 = \$712.20
- 35 Custom Designed Journals via Bookwright.com - \$15 = \$525.00
- 15 Dual Port USB wall chargers for activity bands and cameras- \$17.09 = \$256.35
- 15 Fitbit Charge 3 graphite activity trackers for heart rate and sleep patterns- \$93.09 = \$1396.35
- 15 Case Logic Compact Camera Cases - \$8.54 = \$128.10
- Co-Care KIT boxing and packing material, pens, Post-it notes, poster board for data presentation-\$348.43

Office Supplies: \$637.12

- Training and transcription binders, dividers, printer paper- \$120
- 2 Trip Lite Surge Protectors for charging Fitbits and cameras- \$43.68
- 1 Lexmark C3224dw printer - color – laser - \$ 116.84
- 1 Lexmark – cyan, yellow, magenta, black toner cartridges - \$356.60

Travel to participants: \$2861.10

Travel to participants 30x total to deliver 15 Co-Care KITs - 175 miles round trip from Cary to Halifax County @ 54.5 cents per mi = \$95.37 x 30 = \$2861.10

Software: \$2060.00 (\$1000 will be from internal funds)

Cloud-Based Participant Management via Sona Systems. - \$400 per year for 500 participant entries (Low Use). NVivo qualitative software – 1 perpetual Mac license, \$600, 1 perpetual NVivo PLUS license, \$800 = \$1400 IBM SPSS year subscription for PI's off-campus use Hearne Software - \$260.00

Incentive Money will be funded from internal funds: \$50 for pre- Interview and questionnaires + \$50 for post-interview/debriefing - \$3000

Total requested from CARES: \$31,263.

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.
Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Danai Fannin

eRA COMMONS USER NAME (credential, e.g., agency login):

POSITION TITLE: Associate Professor

EDUCATION/TRAINING (*Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.*)

INSTITUTION AND LOCATION	DEGREE (if applicable)	Completion Date MM/YYYY	FIELD OF STUDY
Bradley University, Peoria, IL (BU)	B.S.	05/1997	Communication
Southern Illinois University, Edwardsville, IL (SIUE)	B.S.	05/2001	Communication Sciences & Disorders
Saint Louis University, St. Louis, MO (SLU)	M.A.R.	05/2003	Speech Language Pathology
University of North Carolina, Chapel, Hill, NC (UNCCH)	PhD.	05/2008	Speech & Hearing Sciences
University of California, Los Angeles (UCLA)	Postdoctoral Training	07/2011	Educational Psychology

A. Personal Statement

I am well suited to be a PI on a research project involving services for culturally and linguistically diverse (CLD), young children with Autism Spectrum Disorders (ASD) because of my research training and clinical experience. During my doctoral studies, I received training on the administration of unstandardized/standardized evaluations, surveys, questionnaires, and collection of language samples for a longitudinal study on academic outcomes, cognitive-linguistic processes, peer interactions, auditory processing, dialectical code switching, and executive functioning in African American youth. Other highlights of doctoral work included assisting on quantitative and qualitative projects to mobilize and support partnerships among Head Start centers, public schools, families, and community agencies with the goal of improving academic and social development of 3- to 8-year-old boys of color. This experience fostered my ability to appreciate the intersection of family systems, educational systems, and interventions for diverse children. I postponed my PhD studies to complete a clinical fellowship in three, urban public schools with the majority being from bilingual and low SES households. While providing intervention for toddlers to 5th-graders, I realized I was not as prepared to work with minimally verbal children with autism, prompting my postdoctoral research interest. As a postdoctoral scholar, I worked in Connie Kasari's lab in the NIH-funded UCLA Intellectual and Developmental Disabilities Research Center, assisting on randomized controlled clinical trials. While in this position, I a) provided assessment and parent education intervention for infants and preschoolers at-risk for autism from CLD families; b) helped write a grant for a multi-site clinical trial on toddlers and preschoolers with autism; c) coordinated the revision of an active control treatment condition manual (parent education);d) trained and supervised transcribers and; d) administered all of the UCLA site active control treatment condition.

As a tenure track faculty member, I have contributed to the development of student research interests and writing skills as a committee member on two master's thesis committees and have chaired another. I have also served as a clinical supervisor where I have expanded my postdoctoral experience by adapting the caregiver-mediated, clinical trial intervention (JASP+EMT) to an SLP implemented clinical model. Using this model, I provided skilled services and collected data on preschoolers with autism. Undergraduate students used the data for their Honors Capstone and Research Rookie projects. These clients served as pilot data for two grant proposals, and I wrote them with the assistance of Ann

Kaiser (Vanderbilt), a mentor provided by the NIU Principal Investigator's Academy who also provided training materials for JASP+EMT.

While I was a postdoctoral fellow I had two children (both subsequently diagnosed with autism), limiting some of the progress I had planned to make. I have been able to accelerate my scholarly work, however, as evidenced by recent publications, data collection, grant writing, and securing promotion and tenure at Northern Illinois University (NIU). I started a new tenure track position at North Carolina Central University (NCCU) in close proximity to mentors who conduct autism intervention research at both my alma mater (UNCCH) and Duke University. Thus, I am confident that my productivity will continue to increase and that I can be a good steward of funds. Since arriving at NCCU, I was awarded a grant from the Provost's office, demonstrating successful internal grant writing my first semester at NCCU. Efforts to secure external funding are exemplified by my participation in a grant writing seminar by the Innovative Nonprofit Solutions Group through Duke University on May 19, 2020; and summer 2020 matriculation in the Duke University course, CLP 217: Community Engaged Approaches to Health Improvement.

Having been a clinician in the schools and clinical supervisor at a university clinic, inquiry into implementation of culturally sensitive, evidence-based autism assessment and treatment is of great interest to me. My ultimate research goals are to a) continue to develop a line of interdisciplinary research focusing on functional language and play skills in children with autism and other developmental disabilities; b) gain external support for my research and; c) mentor students in developing their research skills and interprofessional collaborations across academic programs and community agencies.

B. Positions and Honors

OCCUPATION	BEGINNING	ENDING	FIELD	INSTITUTION	SUPERVISOR
Associate Professor	08/2018	present	Speech Language Pathology	NCCU	Jianping Hao
Assistant-Associate Professor	08/2011	08/2018	Speech Language Pathology	NIU	Sherrill Morris
Postdoctoral Scholar	05/2008	06/2011	Educational Psychology	UCLA	Connie Kasari
Speech Language Pathologist	09/2005	05/2006	Speech Language Pathology	EBS Healthcare	Marva Mount
Teaching Assistant, Graduate Assistant	08/2003	05/2008	Speech & Hearing Sciences	UNCCH	Oscar Barbarin, Elizabeth Crais, Linda Watson, Melody Harrison
Graduate Assistant	08/2001	05/2003	Speech Language Pathology	SLU	Deborah Hwa-Froelich
Sr. Claims Adjuster	09/1997	09/2000	Fire Insurance	State Farm	Colleen Siegrist

2020	NCCU-Duke University Partnership Community Engagement Core Scholar
2019	ASHA Faculty Development Institute
2018	ASHA Award for Continuing Education
2017	NIU College of Health and Human Sciences Fisher Award for Excellence in Service
2017-'18	NIU Presidential Commission on the Status of Women Outstanding Mentor Award
2016	NIU Gender & Sexuality Resource Center LGBTQIA+ Ally Award
2015	ASHA Convention Young Professional Leading the Way for Cultural Competence
2013-'14	NIU Great Journeys Award
2009-'11	National Institutes of Health (NIH) Loan Repayment Program Award
2008-'10	NIH/NICHD T32 Post-Doctoral Fellowship, UCLA
2007	ASHA Minority Student Leadership Program

2002-'04	ASHA Travel Fellow Awards
2003-'08	UNCCH Graduate School Thomas S. and Caroline H. Royster, Jr. Doctoral Fellowship
2003	SLU Communication Sciences & Disorders' Outstanding Graduate Student of the Year
2003	Missouri Speech Language Hearing Association Outstanding Graduate Student of the Year Nominee
2003	Sigma Xi <i>Outstanding Research Award</i> , SLU Graduate Student Association Research Symposium
1993	Commended Minority National Merit Scholar
1993	Stephen Register Memorial Service & Leadership Award

C. Contributions to Science

Peer Review/Continuing Education Programming

1. Editor of *Perspectives of the ASHA Special Interest Groups* (14), 2021-2024
2. NIU Graduate Faculty Scholar - PhD in Health Sciences dissertation chair for Marisol Perez, 2017-present
3. Coordinator for *Perspectives* Special Forum honoring 50th anniversary of the ASHA Office of Multicultural Affairs, 2019-2020
4. Editorial Advisory Board for *Cases on Communication Disorders in Culturally Diverse Populations* (Ed. D. Scott). IGI Global, 2020
5. Peer Reviewer for: *Communication Disorders Quarterly*, *Teaching and Learning in Communication Sciences & Disorders*, *Journal of the National Black Association for Speech-Language and Hearing*, *International Journal of Speech Language Pathology*, *Clinical Archives of Communication Disorders*, *Perspectives on the ASHA Special Interest Groups*, and *Journal of Poverty*- 2010-present
6. Invited Book Reviewer: Wallach G., & Ocampo, A. (Eds.), *Language and literacy: Interventions for school-age children and adolescents*. San Diego, CA: Plural Publishing., 2020.
7. NCCU McNair Scholar Mentor, 2019
8. ASHA Convention Topic Chair for Cultural and Linguistic Issues, Los Angeles, CA, 2017
9. Invited Peer Reviewer: *Teaching and Learning in Communication Sciences & Disorders*; *Journal of the National Black Association for Speech-Language and Hearing*; *International Journal of Speech Language Pathology*, 2017-present
10. Invited Peer Reviewer: *Perspectives on the ASHA Special Interest Groups, SIG 14*, 2010-present
11. ASHA Special Interest Group 14 Steering Committee Professional Development Manager - 2015-2021
12. ASHA Special Interest Group 14 *Perspectives* Continuing Education Administrator - 2010-2020
13. Invited Peer Reviewer for ASHA Self-Study course: Assessment and Intervention of Communication in Children Birth to 5: A Developmental Approach - 2013

Edited Book Chapters

1. Fannin, D.C., & Watson, L.R. (2014). Social communication assessment and intervention for children on the autism spectrum. In D.A. Hwa-Froelich (Ed.), *Social communication development and disorders*. New York: Psychology Press.
2. Kasari, C., Kasambira Fannin, D.C., & Stickles, K. (2012). Joint attention intervention for children with autism. In P. Prelock, & R. McCauley (Eds.), *Treatment of Autism Spectrum Disorders: Evidence-based intervention strategies for communication & social interaction*, Baltimore: Paul H. Brookes.
 - My research interests aggregate around a common thread of establishing functional language in young children with disabilities. During my first year at Northern Illinois University (NIU), I co-authored two book chapters: One on joint attention intervention for children with autism with my postdoctoral mentor and another on evidence-based autism assessment and intervention. Both texts are used in classrooms across the country.

Refereed Publications

1. Kasambira Fannin, D. (2020). Special Forum: Celebrating the 50th Anniversary of the Office of Multicultural Affairs. *Perspectives on the ASHA Special Interest Groups*, 1-2. doi.org/10.1044/2019_PERSP-19-00042
2. Kasambira Fannin, D., Crais, E.R., & Barbarin, O.A. (2018). Correlation between communicative functions of mothers and preschoolers of different racial and income groups. *Journal of the National Black Association for Speech-Language and Hearing*, 13(1), 9-30.
3. Kasambira Fannin, D., Barbarin, O.A., & Crais, E.R. (2018). Communicative function use of preschoolers and mothers from differing racial and socioeconomic groups. *Language Speech and Hearing Services in Schools*, 49, 306-319.

4. Kasambira Fannin, D., Barbarin, O.A., & Crais, E.R. (2017). Effects of mothers' and preschoolers' communicative function use and demographics on concurrent language and social skills. *Journal of the National Black Association for Speech-Language and Hearing*, 12(2), 79-99.
 - These three articles resulted from my dissertation which was derived from the analysis of 95 typically developing preschoolers and their mothers from the National Center for Early Development & Learning database. I adapted a communicative function coding system and considered the variables of socioeconomic status and race/ethnicity in relation to outcomes.
5. Kasambira Fannin, D. (2017). Reporting of underrepresented populations in autism treatment studies across 25 years. *Clinical Archives of Communication Disorders*, 2(3), 250-263.
 - I received an NIU Great Journeys Award to analyze eight journals for the presence of underrepresented populations in autism treatment studies over 25 years (N~12,000/n~291). This study served as impetus for me to explore whether augmenting the peer review process might improve reporting of underrepresented populations in ASHA publications. I involved undergraduates at all stages of the project and developed training procedures for the research assistants who worked on large database, gaining the opportunity to refine my abilities to (a) manage the data and (b) promote the ability to access the data again for replication purposes or for additional statistical analyses.
6. Kasambira Fannin, D. (2016). The intersection of culture and the ICF-CY Personal and Environmental Factors for Alternative and Augmentative Communication. *Perspectives on the ASHA Special Interest Groups*, 1(SIG 12), 63-82.
 - My research and teaching emphasizes the importance of cultural considerations in clinical practice. On the national level, I support cultural competence of ASHA members as the Continuing Education Manager and Professional Development Manager for Special Interest Group 14. Given the changing demographics of our country, I work to stay abreast of developments in the area of cultural competence in order to ensure that students are clinically competent to treat all clients.
7. Hooper, S.R., Roberts, J.E., Nelson, L., Zeisel, S., & Kasambira Fannin, D.C. (2010). Preschool predictors of narrative writing skills in elementary school children. *School Psychology Quarterly*, 25(1), 1-12.
 - During my doctoral studies, I worked on manuscript/grant preparation and editing which resulted in the above-referenced publication (Hooper et al., 2010). Along with writing, I re-transcribed all of the narratives for that study, recognizing that previous research assistants (RA) had transcribed some dialectical writing into Standard American English. This made me keenly aware of the importance of analyzing data correctly the first time. This study has been cited at least 52 times.
8. Hwa-Froelich, D., Kasambira, D.C., & Moleski, A.M. (2007). Communicative Functions of African American Head Start Children. *Communication Disorders Quarterly*, 28(2), 77-91.
 - This study, using my Master's thesis data, is one of the few on communicative functions of African American children. It, along with my dissertation, was recently cited in a meta-analysis of pragmatic analysis of African American children and adolescents (Hyter, River, & DeJarnette, 2015) and contributes to this understudied area of research.
9. Kasambira Fannin, D.C., Ghosh-Roy, P., Odeh, C. (in preparation) A qualitative study of graduate students' perspectives on interdisciplinary developmental playgroup.
10. Odeh, C., Ghosh-Roy, P., & Kasambira Fannin, D. Feasibility of an interprofessional clinical education program for a parent-toddler developmental playgroup: A pilot study. (in review).
 - My last two years at NIU, I joined a team of Physical Therapy and Nutrition researchers. The resultant parent-toddler developmental playgroup opened my research scope to include a focus on Interprofessional Education (IPE). We have presented at three national conventions and submitted the above-referenced article. The abstract of a peer-reviewed poster was published and we have another, qualitative manuscript in preparation.
11. Kim, E.T.¹, Franz, L.¹, Kasambira Fannin, D.², Howard, J.³, & Maslow, G.⁴ Classifying rates of preschoolers with autism and intellectual disability in North Carolina: of the intersection of race, rurality, and resource availability. (in review at *Autism Research*).
 - This epidemiological study is the impetus for the currently proposed study, finding that CLD racial minorities, especially those in rural counties with low resource availability at the school- and at the county-levels, had higher probabilities of being classified as having Intellectual Disability (ID) than ASD, yet, there is no definitive evidence to suggest ASD prevalence differences can be attributed to physiological factors.

12. Kasambira Fannin, D., Margolis, E., Franz, L., & Hudson, K. (in preparation). A scoping review of Autism Spectrum Disorder research for indigenous populations in rural North America.
13. Ramseur, K., Franz, L., Kasambira Fannin, D., & Hudson, K., (in preparation). A scoping review of parent-child interaction research for children with autism in rural Sub-Saharan Africa.

D. Additional Information: Research Support and/or Scholastic Performance

Ongoing Research Support

2019-2020 Increase Research Capacity and External Funding: NCCU Innovation Grant – \$25,000

Language Role Modeling and Dialect Variation between Caregivers and Children with Autism Using the Diagnostic Evaluation of Language Variation™ (PI: Danai Kasambira Fannin; Consultants: Robert Meyer, Ventris Publishing; Barbara Z. Pearson, University of Massachusetts, Amherst; Nan Bernstein Ratner, University of Maryland, College Park)

Submitted Research Support

- 2020 American Speech Language Hearing Association Foundation – in review (\$25,000), *Contextual Factors Affecting Identification of Rural African American Children with Autism*
- 2020 NCCU JLC BBRI COVID-19 Response Pilot (CORP) grant for Community Health Research – in review (\$10,000), *Experiences of Rural and Urban African American Caregivers of Young Children with Autism During the 2020 COVID-19 Pandemic*

Completed Research Support

- 2016 Tri-County Endowment - \$10,000, *Autism Caregiver Support Group* (Co-Developers: C. Odeh & Gladfelter)
- 2015 Tri-County Endowment - \$10,000, *Interdisciplinary Developmental Playgroup Renewal* (Co-Developers: C. Odeh, J. Robackouski, & A. Gladfelter)
- 2014-'15 NIU Statistical Consulting - \$800, *Underrepresented Populations in ASD Treatment Studies*
- 2013-'14 NIU Great Journeys Award- \$14,000, *Underrepresented Populations in ASD Treatment Studies*
- 2003-'08 UNCCH Graduate School Thomas S. and Caroline H. Royster, Jr. 5-Year Doctoral Fellowship

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Response

Recruitment of Participants. Participants will be purposefully sampled including AA caregivers of schoolchildren (ages 4-12 years old) diagnosed with ASD who live in Halifax County ($n=15$) and Durham County ($n=15$) and are from both low and middle SES homes (as indicated by a pre-screening questionnaire). Various approaches will be used to recruit such as collaboration with community organizations that have been facilitated by the NCCU CEOC, the NCCU Communication Disorders Program clinic, community events, or the Duke Autism Center research registry. For example, recruitment/informational fliers will be distributed through paper postings around town, email, and social media postings for participants to contact the PI for screening. The PI will also inquire with local service providers as to whether they have potential participants.

Selection Bias: The purpose of this inquiry is to include participants who are not normally included in ASD research studies, and to focus on a group disproportionately affected by both COVID-19 and health and educational disparities for children with ASD. Therefore, some amount of selection bias is unavoidable as we are purposefully screening people who will know what the study entails as far as time commitment and technology needed (internet for ZOOM meeting). The study does have an internal comparison group (SES and geography) among the AA participants, which is a strategy used to minimize selection bias. To minimize information bias, standard surveys, standard activity trackers, and standard cameras will be given to all participants and data will be collected similarly across all participants. Multiple sources of information (surveys, journal, heart rate and sleep pattern monitoring) will be used. We will minimize interviewer/bias by having only the PI, and 2 graduate RAs conduct the interviews.

Co-Care KIT Details:

The Co-Care-KIT includes:

- a journal for writing and reflecting about daily experiences with predesigned pages for supporting experience disclosure, and writing tools like pens, markers, and Post-it notes
- a small, digital camera with an instant photo printer to visually capture experiences with photos. On the back of each photo, the participant will write the date, time, a caption (e.g., weekly Zoom meeting with SLP), and fill in a likert-type scale of smiley faces asking, “How did it make you feel?” from “not good” to “very good”

Figure 4. The experience sampling: taking a picture, writing a caption, and indicating mood (Bosch, 2019).



- a waterproof activity wristband to continuously measure heart rate variability (HRV) as a stress indicator and the wearers' sleep stages overnight. Many children with ASD have sleep disturbances and insomnia, so sleep patterns of the caregivers might be of interest. Heart-rate graphs will be printed and displayed along with participants' photos and journal quotes for a visual interpretation of how participants felt at the time the photo was taken.

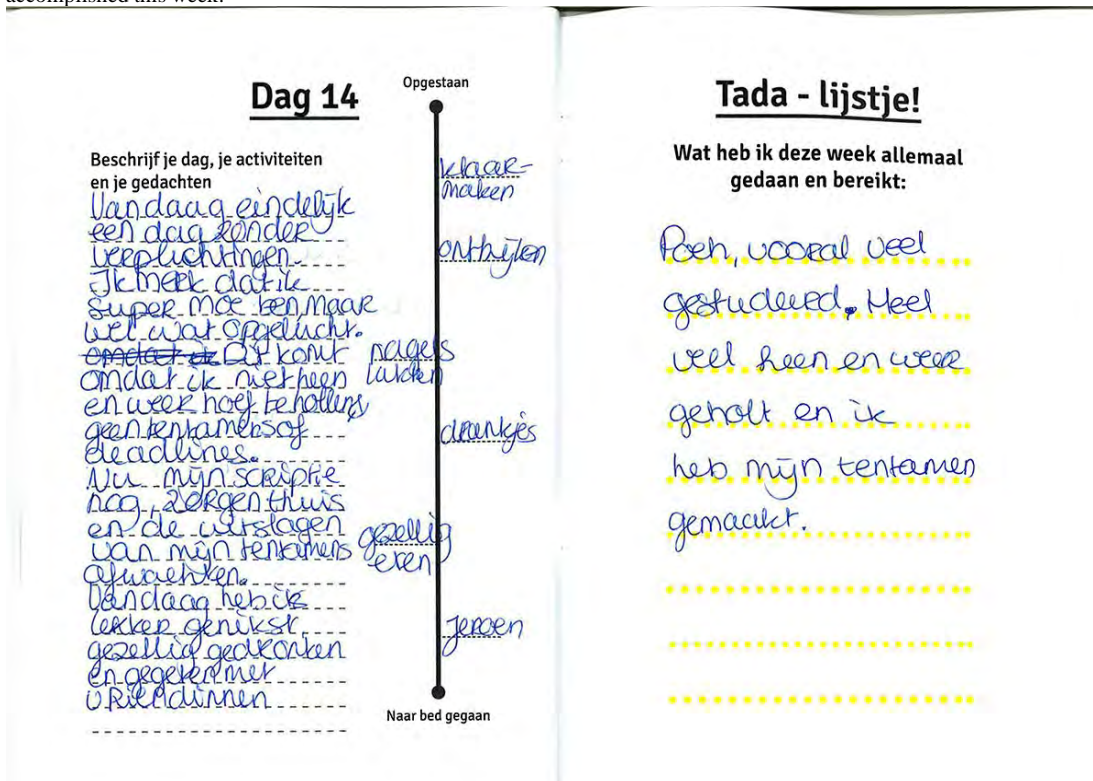
You requested more information about the Co-Care KIT so perhaps this image will help:

Figure 1. The Co-Care-KIT, including a custom-designed journal, photography-based experience sampling app, and heart rate tracker. (Bosch et al., 2019)



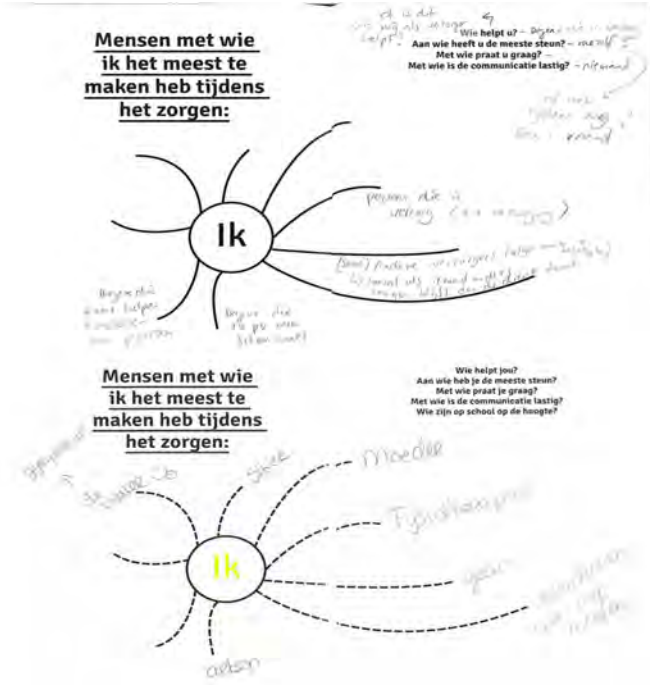
Here is a journal detail that illustrates why I am going to have the journals custom made, rather than just giving blank journals. This will ease participants' fear of not knowing what to write about.

Figure 2. Journal pages from P5. On the left page: a diary of day 14 of the field study and on the right page: a list of things she was proud to have accomplished this week.



Here is an example of another type of custom page we will design for the journal:

Figure 3. Journal pages from P7 (top) and P4 (bottom). The statement at the top of the page prompts participants: People most involved in the care process. The participant is in the center of the page and writes down who is involved (care recipient, family, friends, and the professional help) (Bosch et al., 2019).



Thus, we are not requiring participants to write 30 pages of narrative journaling. Although they will be free to write whatever they would like on blank pages, the customized pages will often be answering simple questions like, “Who helped you in this situation today?”.

Data Analysis:

1. Heart rate measurements of each caregiver will be plotted by the PI on daily timelines with the printed photos, providing an overview and context for the recorded moments such as time, location, and people. These data will be discussed with each caregiver, using the data conversation prompts. For example, photos and heart rate measurements will be shared and discussed and interpreted by the caregivers while the PI questions them about it. Here is an example of the heart rate monitor juxtaposed with the photos and affective state (i.e., “How did you feel?”) and caption information on the back of the photo).



Quantitative Analysis: Quantitative surveys will include a) Demographics; b) Maternal Agency, Guilt, and Autism Knowledge (Kuhn & Carter, 2006); (c) Caregiver Strain Questionnaire (Brannan et al., 1997); (d) Social Support (Sherbourne & Stewart, 1991); (e) Family Empowerment (Koren et al., 1992); (f) Everyday Discrimination Scale (Williams et al., 1997); (g) Coping with Discrimination (Kreiger, 1990; McNeilly et al., 1996) and; (h) Family Outcomes

(Bailey et al., 2011) and; (i) Family Functioning. Because the sample is small and outcome distributions cannot be assumed to be normal, nonparametric design (Dallal, 2000) will be used to measure relationships between the quantitative measures. An independent samples Kruskal-Wallis H test will be used with a null hypothesis that there is no statistically significant differences in survey results based on SES or geography. Summary Statistics will be part of the analysis plan as well as correlations. We will look at whether there are significant differences by group (SES and geography) in the responses to these surveys. Correlations among surveys will also be run to explore a relationship between measures like caregiver strain and family functioning. For instance, it is expected that families with higher scores (i.e., better functioning) on the Family Functioning would report lower caregiver strain on the Caregiver Strain questionnaire. The surveys have a variety of quantitative items like True False or Likert Scale. Related to the stress and discrimination surveys, participants will also wear a heart rate and sleep pattern monitoring wristband for the 2 weeks of data collection for an additional index of stress, and to assist in the interpretation of photo and journal data.

c. Budget Total: \$34,263. \$23,600 is requested for personnel to complete data collection, data entry, transcript coding, analysis. The PI is requesting two course releases for the fall semester. This is actually 1 course but 2 sections. Equipment is for the Co-Care KITS and Supplies are for the lab. The original Co-Care KITS called for dedicated cellular phones (~\$600), but some of the rural areas have unreliable Wifi connections and the PI did not want participants to worry about using their own data plans. Therefore, instead of cellphones to take pictures, cameras that print the pictures instantly will be more cost effective. Travel rates are based on NC state mileage guidelines and I reduced travel by eliminating claims for local travel to Durham. The PI and RAs can deliver Co-Care KITS to Durham while in the vicinity of work and school, so the travel is only for the 2-hour trips rural Halifax County. Because you want me to increase the N, I will just need to send the KITS out in phases so I will not need 24 cameras at once. I have therefore reduced the cameras to 15 and increased the Fitbits by 3 for a total of 15 Fitbits. So I will have Phase 1 of 15 participants doing the 2 week data collection and Phase 2 will be the other 15 for an N of 30. I deleted the TIGRR workshop funds as I might not be selected.

Personnel: \$23,600

- 2 course releases PI – fall 2020 \$6000 + .30 fringe = \$15,600
- 2 Research Assistant stipends for 6 months at \$500 per month. - \$6000
- Stipend for quantitative statistical consultant - \$2000

Equipment: \$5104.78

- 15 Canon IVY CLIQ Instant camera and printer (blue)- \$115.89 = \$1738.35
- 30 Canon Zink Photo Paper 50-Pack - \$23.74 = \$712.20
- 35 Custom Designed Journals via Bookwright.com - \$15 = \$525.00
- 15 Dual Port USB wall chargers for activity bands and cameras- \$17.09 = \$256.35
- 15 Fitbit Charge 3 graphite activity trackers for heart rate and sleep patterns- \$93.09 = \$1396.35
- 15 Case Logic Compact Camera Cases - \$8.54 = \$128.10
- Co-Care KIT boxing and packing material, pens, Post-it notes, poster board for data presentation-\$348.43

Office Supplies: \$638.01

- Training and transcription binders, dividers, printer paper- \$120.89
- 2 Trip Lite Surge Protectors for charging Fitbits and cameras- \$43.68
- 1 Lexmark C3224dw printer - color – laser - \$116.84
- 1 Lexmark – cyan, yellow, magenta, black toner cartridges - \$356.60

Travel to participants: \$2861.10

Travel to participants 30x total to deliver 15 Co-Care KITS - 175 miles round trip from Cary to Halifax County @ 54.5 cents per mi = \$95.37 x 30 = \$2861.10

Software: \$2060.00

Cloud-Based Participant Management via Sona Systems. - \$400 per year for 500 participant entries (Low Use).

NVivo qualitative software – 1 perpetual Mac license, \$600, 1 perpetual NVivo PLUS license, \$800 = \$1400

IBM SPSS year subscription for PI's off-campus use Hearne Software - \$260.00

Incentive Money will be funded elsewhere: \$50 for pre- Interview and questionnaires + \$50 for post-interview/debriefing - \$3000