

AWARD NUMBER: W81XWH-19-1-0581

TITLE: A Novel Provider-Focused Training Program to Serve Transition-Age Youth and Adults with Autism Spectrum Disorder

PRINCIPAL INVESTIGATOR: Micah Mazurek, PhD

CONTRACTING ORGANIZATION: University of Virginia

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<b>13. SUPPLEMENTARY NOTES</b>					
<b>14. ABSTRACT</b> The purpose of this project is to develop and pilot test a novel primary care provider training program with the goal of increasing high-quality community-based health care for adults with autism spectrum disorder. In the last year, we developed the ECHO Autism Adult Healthcare Training curriculum and protocol. To inform curriculum and program development, we conducted interviews and focus groups with adults with ASD, family members and primary care providers. Autistic adults reported issues related to access to care, the clinic environment, provider knowledge, communication, and rapport, and the patient-provider partnership. Families/caregivers highlighted areas to emphasize related to providers, accommodations, unmet needs, and parent involvement in healthcare. Providers listed challenges, helpful strategies, and training program and topic suggestions. We also have successfully completed regulatory documents for our upcoming ECHO program to begin in Year 2 and have made substantial progress recruiting participants for the sessions.					
<b>15. SUBJECT TERMS</b> Autism, autism spectrum disorder, health services, primary care provider, provider training, adults, provider training, healthcare barriers, healthcare access, co-occurring medical conditions, mental health, behavioral health, self-determination, sexuality, self-advocacy, post-secondary education, employment					
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## 1) INTRODUCTION

Dramatic increases in prevalence of autism spectrum disorder (ASD) have been accompanied by a rising tide of adolescents with ASD who are entering adulthood. Adults with ASD have complex healthcare needs due to frequent co-occurring medical and psychiatric conditions, yet they experience poor healthcare access, experiences and outcomes. This is due in part to shortages of healthcare providers with knowledge and expertise in ASD. Training of community healthcare providers to serve the unique needs of transition-age youth and adults with autism spectrum disorder (ASD) requires novel approaches to develop and support provider expertise and competence. The Project Extension for Community Healthcare Outcomes (Project ECHO) framework is one such novel approach. Project ECHO uses secure multi-point videoconferencing technology to create a learning community by connecting primary care providers (PCPs) in local communities (“spokes”) to an interdisciplinary team of experts (“hub”) during regular sessions. During these sessions, learning is facilitated through brief evidence-based didactics, case-based learning (during which PCPs present their own cases for discussion and co-management), collaborative mentorship, and guided practice. The objective of this project is to develop and pilot test a novel PCP training program using the Project ECHO framework with the goal of increasing high-quality community-based healthcare for adults with ASD. Our specific aims are to: 1) develop the ECHO Autism Transition/Adult Healthcare Training curriculum and protocol, and 2) implement and test the ECHO Autism Transition/Adult Healthcare Training curriculum in PCPs caring for transition-age youth and adults with ASD. The study design includes both qualitative and quantitative (mixed method) approaches to develop and test the new program. To ensure that the model is clinically relevant and responsive to their needs, qualitative input from adults with ASD, their caregivers, and their providers will inform initial program development and refinement (Aim 1, Year 1). The program will then be implemented and tested in an initial cohort of 25 PCPs focused on feasibility, acceptability, and fidelity, followed by evaluation and revision prior to testing in a second cohort of 25 PCPs. (Aim 2, Years 2 and 3).

## 2) KEYWORDS

Autism, autism spectrum disorder, health services, primary care provider, provider training, adolescents, adults, continuing medical education, provider training, healthcare barriers, healthcare access, identifying autism, co-occurring medical conditions, co-occurring psychiatric conditions, mental health, behavioral health, community supports, self-determination, relationships, sexuality, self-advocacy, post-secondary education, employment.

## 3) ACCOMPLISHMENTS

### What were the major goals of the project?

**Major Goal 1:** To develop the ECHO Autism Transition/Adult Healthcare Training curriculum and protocol

**Major Task 1:** Protocol Development and Regulatory Review

**Subtask 1.1:** Finalize Aim 1 study protocol

Status: Complete

**Subtask 2:** University of Virginia IRB submission

Status: Complete

**Subtask 3:** HRPO submission

Status: Complete

**Milestone:** Local IRB Approval

Status: Achieved

**Milestone:** HRPO Approval

Status: Achieved

**Major Task 2:** Qualitative Data Collection

**Subtask 2.1:** Develop focus group and interview discussion guides

Status: Complete

**Subtask 2.2:** Participant recruitment, screening, and enrollment

Status: Complete

**Subtask 2.3:** Conduct focus groups with caregivers

Status: Complete

**Subtask 2.4:** Conduct individual interviews with primary care providers

Status: Complete

**Subtask 2.5:** Conduct individual interviews with adults with ASD

Status: Complete

**Milestone:** *Qualitative data collection complete*

Status: Achieved

**Major Task 3:** Qualitative Data Analysis

**Subtask 3.1:** Review transcripts & code data

Status: Complete

**Subtask 3.2:** Prepare final coding report outlining list of topics/content areas

Status: Complete

**Milestone:** *Qualitative data analysis complete*

Status: Achieved

**Major Task 4:** Curriculum & Measure Design

**Subtask 4.1:** Design ECHO Autism Transition/Adult Healthcare curriculum

Status: Design Complete

**Subtask 4.2:** Design and finalize measures to evaluate Aim 2

Status: Complete

**Milestone:** *Curriculum and measures complete*

Status: Achieved

**Major Goal 2:** To implement and test the ECHO Autism Transition/Adult Healthcare Training curriculum in primary care providers caring for transition-age youth and adults with ASD

**Major Task 1:** Protocol Development and Regulatory Review

**Subtask 1.1:** Vanderbilt University IRB submission

Status: Complete

**Subtask 1.2:** HRPO submission

Status: Complete

**Milestone:** *Local IRB Approval*

Status: Achieved

**Milestone:** *HRPO Approval*

Status: Achieved

**Major Task 2:** Conduct Cohort 1

**Subtask 2.1:** Develop lists of eligible primary care providers (PCPs) for recruitment

Status: Complete

**Subtask 2.2:** Recruit /Enroll PCPs for participation  
Status: In progress; target completion date: October 2020

**Subtask 2.3:** Train all Hub Team members on ECHO Autism implementation procedures and processes  
Status: Complete

**Subtask 2.4:** Carry out Cohort 1 with ECHO Autism sessions and baseline and post-training surveys  
Status: Target dates: November 2020-April 2021

**Subtask 2.5:** Monitor Fidelity to ECHO model  
Status: Target dates: November 2020-April 2021

**Milestone:** *PCPs completed Cohort 1 sessions and surveys*  
Status: In progress; target achievement date: April 2021

**Major Task 3:** Analyze data from first cohort/Revise curriculum and procedures

**Subtask 3.1:** Analyze data  
Status: Target dates: May 2021-June 2021

**Subtask 3.2:** Reconvene stakeholders, revise curriculum and procedures, amend IRB as needed  
Status: Target dates: July 2021-August 2021

**Milestone:** *Revised Curriculum for Second Cohort*  
Status: Target achievement date: August 2021

**Major Task 4:** Conduct Cohort 2

**Subtask 4.1:** Recruit /Enroll PCPs for participation  
Status: Target dates: September 2021-October 2021

**Subtask 4.2:** Carry out Cohort 2 with ECHO Autism sessions and baseline and post-training surveys  
Status: Target dates: November 2021-April 2022

**Subtask 4.3:** Monitor Fidelity to ECHO model  
Status: Target dates: November 2021-April 2022

**Milestone:** *PCPs completed Cohort 2 sessions and surveys*  
Status: Target achievement date: April 2022

**Major Task 5:** Analyze Data/Prepare Manuscripts

**Subtask 5.1:** Analyze Data  
Status: Target dates: May 2022-June 2022

**Subtask 5.2:** Prepare Manuscripts  
Status: Target dates: July 2022-August 2022

**Milestone:** *At least two manuscripts completed (one on process and one on outcomes)*  
Status: Target achievement date: August 2022

### **What was accomplished under these goals?**

The current report describes activities and accomplishments conducted during Year 1 of the project (since the project start date of September 1, 2019). Our major activities during this reporting period have

focused on project start-up; recruitment, enrollment and data collection primarily related to Major Goal 1; and initial tasks for Major Goal 2. Most activities related to Major Goal 2 are not planned until Years 2 and 3, as outlined above and in our Statement of Work. Activities, objectives, and results for each goal are described in more detail below.

## **Major Activities**

### Project Start-Up Activities:

During the initial project start-up period, activities included personnel training, finalization of study team protocols and procedures, and establishment of regular site-specific team meetings and multi-site videoconferencing calls to discuss issues related to project planning, coordination, and implementation across major goals. Additional start-up activities included finalizing the protocol for Goal 1 data collection, and successful local IRB and HRPO submission and approval prior to study launch.

### Activities Related to Major Goal 1

Recruitment, enrollment and data collection related to Major Goal 1 were successfully completed during this period. This included recruitment, enrollment, and completion of surveys and qualitative interviews and focus groups with adults with ASD (n=20), caregivers of adults with ASD (n=24), and primary care providers (n=14). Quantitative (survey) and qualitative (interview) data were collected by the UVA study team. Qualitative interviews were recorded and transcribed, and the UVA study team checked raw data for errors, resolved any discrepancies, and completed fine-grained data cleaning in preparation for analysis. Survey data and transcriptions of interviews and focus groups were entered into a qualitative data analysis software platform (Dedoose, Version 8.3.35) for coding and analysis. The study team utilized an iterative and collaborative qualitative data analysis process, involving multiple phases of discussion, coding (including establishment of inter-rater reliability), categorizing, theme development and review. Data visualizations, including code co-occurrence and frequency, were used to inform understanding of connections between themes and codes and to identify opportunities for consolidation and synthesis. Following data analysis, a summary of results and themes was prepared and shared to inform decisions regarding the ECHO Autism Curriculum and program logistics. The curriculum and measures for ECHO Autism implementation and evaluation were also finalized in preparation for Major Goal 2 activities.

### Activities Related to Major Goal 2

As noted above, the measures and materials for implementation and measurement of the ECHO Autism curriculum were finalized during this project period. Major Goal 2 activities included development and finalization of the protocol, local IRB and HRPO submission and approval for recruitment, enrollment, and data collection related to Major Goal 2. Additional Major Goal 2 activities during this period focused on preparation for launch of the first ECHO Autism cohort (scheduled for November 2020). The study team developed a robust and multipronged recruitment strategy and began recruitment efforts after multi-site IRB and HRPO approvals were obtained (with 11 participants enrolled to date 9/24/20). In addition, new Hub Team members received an immersive 2-3-day training in ECHO Autism implementation and procedures in preparation for program launch. Work to provide AMA PRA Category 1 Credit for each session as well as Maintenance of Certification Parts 2 and 4 is being finalized.

## **Specific Objectives**

### Specific Objectives for Major Goal 1

The specific objectives associated with Major Goal 1 were to inform the development of an ECHO Autism Transition/Adult Healthcare program for training healthcare providers in caring for transition-age youth and young adults with ASD. A direct understanding of the specific needs and priorities adults with ASD, their caregivers, and their providers was deemed to be an essential first step in order to ensure that the content and format of the new training program directly addressed the needs of this unique population. As such, qualitative methods were used in the first phase of the project to gather input from key stakeholders, including adults with ASD, parents/caregivers, and primary care providers (PCPs). The goal of this work was to inform the development of the ECHO Autism training model to optimize its relevance and impact, with a particular focus on enhancing healthcare quality, reducing barriers to delivery and access, and addressing the unique needs of

adults with ASD. The results directly informed key decisions regarding learning objectives, curriculum content, ideal composition of the expert hub team (professional disciplines represented), and other logistical details.

### Specific Objectives for Major Goal 2

The specific objectives associated with Major Goal 2 are to implement and pilot test the newly developed 6-month ECHO Autism Transition/Adult Healthcare Training program in two cohorts of PCPs caring for transition-age youth and young adults with ASD. This iterative implementation and testing process will allow us to examine the extent to which participation in the program is feasible and acceptable for PCPs, and to assess the degree to which the program can be implemented as planned and with fidelity to the ECHO model, and to identify potential barriers or facilitators to participation and retention over the six-month program. These data will be critical for informing future large-scale examinations of efficacy and effectiveness.

### **Significant Results or Key Outcomes**

Results associated with Major Goal 1 are provided separately by participant group. The first group included adults with ASD who provided information about their healthcare experiences and perspectives by completing a series of brief questionnaires (including a Demographic Survey, Patient-Provider Communication Self-Report survey, and Barriers to Healthcare Checklist) and participating in an individual qualitative interview focused on healthcare experiences and perceptions. Participants (n=20) ranged in age from 18 to 35 years (M=25.6, SD=5.1), and the majority were male (65%). Most respondents (85%) received regular primary care services. Based on survey responses, the three most commonly reported healthcare barriers included: “trouble following up on care (for example, going to pharmacy, taking prescribed drugs at the right time, or making a follow-up appointment),” (reported by 35% of participants), “fear, anxiety, embarrassment, or frustration” (reported by 30%), and “problems filling out paperwork” (reported by 25%). Results of qualitative analysis of interview responses revealed four primary themes and subthemes pertaining to both positive and negative healthcare experiences, and suggestions for improvement. Four primary themes and subthemes included: **1) Access to Care** (*Subthemes*: Getting an Appointment, Healthcare Costs and Insurance Coverage, Location and Transportation, Continuity of Care), **2) Clinic Environment** (*Subthemes*: Accommodating Sensory Needs, Managing Anxiety and Pain, Wait Time and Visit Length), **3) Provider Factors** (*Subthemes*: Provider Knowledge of ASD, Provider Communication, Provider Rapport), and **4) Patient-Provider Partnership** (*Subthemes*: Healthcare Independence and Caregiver Involvement, and Promoting Treatment Plan Adherence).

The second stakeholder participant group included parents and caregivers of adults with ASD. They also provided their perspectives on the healthcare experiences of their adult child/dependent with ASD by completing questionnaires (Demographic Survey, Patient-Provider Communication Supporter-Report survey, and Barriers to Healthcare Checklist) and participating in a focus group to share perspectives on healthcare experiences and suggestions for improvement. The sample included 24 caregivers of adults with ASD (21 mothers, 1 father, and 2 non-parent caregivers), ranging in age from 38 to 63 (M=54.3, SD=6.7). Their children/dependents with ASD ranged in age from 18 to 32 (M=23.7, SD=4.5), and the majority were male (89%), lived with their parent(s) (63%), and had a moderate-to-high need for support in daily activities (70%). The majority of caregivers (89%) accompanied the adult with ASD to healthcare appointments, and most (96%) were very familiar with the adult’s healthcare needs. Results of survey responses indicated that the three most commonly reported healthcare barriers were: “when the patient experiences pain and/or other physical symptoms, they have difficulties identifying them and reporting them to the provider” (reported by 44%), “cannot find a provider who will accommodate the patient’s needs”(reported by 18%), and “the patient’s behaviors are misinterpreted by the provider or the staff” (reported by 18%). Results of qualitative analysis of focus group data revealed the following primary themes and subthemes: **1) Provider Problems** (*Subthemes*: Access, Lack of Provider Knowledge, Lack of Appropriate Care), **2) Helpful Provider Behavior** (*Subthemes*: Open/Collaborative Approach, Rapport, Understanding of ASD), **3) Accommodations** (*Subthemes*: Communication Strategies, Clinic Environment), **4) Unmet Needs** (*Subthemes*: Knowledgeable Providers, Resources and Services), **5) Parent Involvement in Healthcare** (*Subthemes*: Coordinating Services, Advocacy, Tracking/Recordkeeping).

The third participant group included primary care providers (PCPs) caring for transition-age youth and adults. Participants completed questionnaires (Demographic Survey, Provider Self-Efficacy Scale-Adult Autism) and participated in qualitative interviews to share their experiences, barriers, and needs regarding providing healthcare for adults with ASD. The sample included 14 PCPs (8 Family Medicine Physicians, 4 Combined Internal Medicine & Pediatrics Physicians, 1 Physician Assistant, and 1 Nurse Practitioner) with a

range of 2-30 years of practice (M=11.0, SD=9.3). Most (57%) had not previously received specific training on autism, and (64%) had a current caseload of more than 10 patients with ASD. Results from survey responses indicated that PCPs perceived caring for adults with ASD to be moderately challenging (M=6.7 on a scale of 0, *not at all*, to 10, *extremely challenging*); however, they also described caring for adults with ASD as being generally rewarding (M=7.5 on a scale of 0, *not at all*, to 10, *extremely rewarding*). Regarding confidence in providing care for adults with ASD, PCPs reported an average total Self-Efficacy score of 22.8 (SD=3.3) (out of a total possible score of 30). Results of qualitative analysis of interview data revealed the following primary themes and subthemes: **1) Challenges** (*Subthemes*: Challenging Behavior, Communication, Coordination with Caregivers, Symptom Assessment, Physical Exam/Procedures, Finding Resources, Reimbursement), **2) Helpful Strategies/Accommodations** (*Subthemes*: Pre-visit Assessment, Clinic Environment, Scheduling, Care Coordination, Sensory Accommodations), **3) Training Program Suggestions** (*Subthemes*: Specialist Disciplines, Logistics), **4) Training Topic Suggestions**: (*Subthemes*: Evidence-Based Guidelines, Psychiatry/Behavioral Health, Communication Strategies, Comorbidities, Resources, Guardianship).

The results of Major Goal 1 activities informed the development and refinement of the ECHO Autism Transition/Adult Healthcare program curriculum, which is scheduled to launch in November 2020. Results from Major Goal 2 activities and analyses will be available after completion of this first ECHO Autism cohort (to be completed in April 2021, as outlined in the Statement of Work and target dates outlined previously), and those results will, in turn, inform the need for further adjustments and refinements to the curriculum prior to the launch of the second cohort of PCPs (in November 2021).

**What opportunities for training and professional development has the project provided?**

Nothing to report.

**How were the results disseminated to communities of interest?**

Nothing to report.

**What do you plan to do during the next reporting period to accomplish the goals?**

As noted above, activities in the next reporting period (Year 2) will include implementation and testing of the first ECHO Autism Transition/Adult Healthcare training program (November 2020-April 2021). This will include recruitment and enrollment of the first cohort of PCP participants, implementation of ECHO Autism, fidelity monitoring of program implementation, and collection of pre- and post-training quantitative and qualitative data from participating PCPs (including knowledge tests; self-efficacy, practice patterns, and satisfaction surveys; and qualitative interviews). After completion of this first cohort, data will be analyzed and additional refinements will be made to further improve the training program prior to the launch of the second ECHO Autism cohort in Year 3.

**4) IMPACT**

**What was the impact on the development of the principal discipline(s) of the project?**

Nothing to Report. Implementation and testing of the newly developed ECHO Autism Transition/Adult Healthcare training program are still ongoing.

**What was the impact on other disciplines?**

Nothing to Report. Implementation and testing of the newly developed ECHO Autism Transition/Adult Healthcare training program are still ongoing.

**What was the impact on technology transfer?**

Nothing to report.

**5) CHANGES/PROBLEMS**

**Changes in approach and reasons for change**

Nothing to report.

**Actual or anticipated problems or delays and actions or plans to resolve them**

Nothing to report.

**Changes that had a significant impact on expenditures**

Nothing to report.

**Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents**

Nothing to report.

**Significant changes in use or care of human subjects**

Nothing to report.

**Significant changes in use or care of vertebrate animals**

Nothing to report.

**Significant changes in use of biohazards and/or select agents**

Nothing to report.

**6) PRODUCTS****Publications, conference papers, and presentations**

Nothing to report.

**Journal publications**

Nothing to report.

**Books or other non-periodical, one-time publications**

Nothing to report.

**Other publications, conference papers, and presentations**

Nothing to report.

**Website(s) or other Internet site(s)****Technologies or techniques**

Nothing to report.

**Inventions, patent applications, and/or licenses**

Nothing to report.

**Other Products**

Nothing to report.

**7) PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS**

Name	Micah Mazurek, PhD
Project Role	Principal Investigator
Research Identifier (e.g. ORCID ID)	<a href="https://orcid.org/0000-0001-7715-6538">https://orcid.org/0000-0001-7715-6538</a>
Nearest person month worked (160 hours per person month)	1.8
Contribution to the project	Dr. Mazurek has collaborated with Dr. Malow (Partnering PI) to oversee the entire project, provided oversight of qualitative data collection and analysis, and assisted with development and

	refinement of the new ECHO Autism Transition/Adult Healthcare curriculum and measures.
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Name	Emily Meltzer
Project Role	Research Specialist
Research Identifier (e.g. ORCID ID)	
Nearest person month worked (160 hours per person month)	2.4
Contribution to the project	Project coordination and assistance with recruitment and enrollment.

Name	Amber Hardin
Project Role	Research Specialist
Research Identifier (e.g. ORCID ID)	
Nearest person month worked (160 hours per person month)	1.2
Contribution to the project	Assistance with recruitment, qualitative data collection, data entry, data processing, and coding.

Name	Kristin Thomas Sohl, MD
Project Role	Co-Investigator
Research Identifier (e.g. ORCID ID)	
Nearest person month worked (160 hours per person month)	0.6
Contribution to the project	Assistance with curriculum development for the ECHO Autism Transition/Adult Healthcare program, and assistance with training the hub team members for ECHO Autism implementation.

Name	Nancy Cheak-Zamora, PhD
Project Role	Co-Investigator
Research Identifier (e.g. ORCID ID)	<a href="https://orcid.org/0000-0003-3645-3469">https://orcid.org/0000-0003-3645-3469</a>
Nearest person month worked (160 hours per person month)	0.6
Contribution to the project	Assistance with measure design, interpretation of qualitative findings, and curriculum development.

## 8) SPECIAL REPORTING REQUIREMENTS

Independent reports have been submitted by both the Initiating PI (Dr. Beth Malow, Vanderbilt University) and the Partnering PI (Dr. Micah Mazurek, University of Virginia).

## 9) APPENDICES

Not applicable.