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Project ECHO tele-mentoring primary care for individuals with IDD

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ABSTRACT

Background: As the prevalence of intellectual and developmental disabilities (IDD) has increased over time, more youth with IDD will be transitioning into adult care. Individuals with IDD have a spectrum of behavioral, medical, adaptive, and home/community support needs depending on their cognitive ability, behavior concerns, mobility impairment, and/or medical complexity. Unfortunately, data suggests that adult primary care providers often lack knowledge about the condition-specific medical and adaptive needs of the IDD population leading to decreased access to adequate primary care.
Methods: To ultimately improve access to high quality healthcare for individuals with IDD, we created a 6-session virtual Project ECHO(R) (Extension for Community Healthcare Outcomes) telementoring course offered to an interprofessional audience.
Results: We successfully launched this course, demonstrated statistically significant increased knowledge and confidence among attendees regarding six topics pertinent to this population, and had high levels of satisfaction from a diverse group of attendees.
Conclusion: Including nurses, social workers, advanced practice providers, physicians, and case managers in this course made for robust discussion in the delivery of high-quality care for this population. This model is a viable option to increase knowledge and confidence surrounding primary care for youth and adults with IDD.

1. Introduction

Intellectual and developmental disabilities (IDD) are a group of conditions associated with impairment in cognitive, physical, learning, language, or behavior areas that begin during the developmental period (before age 22) and impact daily function usually throughout a person's lifetime.[1] Examples include autism spectrum disorder (ASD), genetic conditions such as Down syndrome (DS) or Fragile X, and perinatal/congenital conditions such as cerebral palsy (CP) and spina bifida (SB). Individuals with IDD have a spectrum of behavioral, medical, adaptive, and home/community support needs depending on their cognitive ability, behavior concerns, mobility impairment, and/or medical complexity. Data from the 2009–2017 National Health Interview Survey demonstrated that the prevalence of developmental disabilities in children ages 3–17 has increased over time (16.2 %-17.8 %, $P < .001$) suggesting that an increasing number of individuals with IDD will be transitioning into adult care.[2] However, adult primary care providers often lack knowledge and training to care for the condition-specific medical and adaptive needs of the IDD population leading to decreased access to adequate primary care.[3–9] Lack of primary care providers equipped to care for this population leads to unsuccessful healthcare transition, return to pediatric care, and increased risk for medical and behavioral exacerbations and acute care use for potentially preventable conditions.[10–14] Additionally, without appropriate primary care clinic accommodations for behavior or physical adaptive needs, individuals with IDD may not have adequate exams and accrue traumatic medical experiences that may limit their future ability to tolerate needed medical evaluations.[15,16]

From 2022 to 2023, the National Alliance to Advance Adolescent Health Got Transition® convened an advisory group to develop recommendations to increase the workforce of adult primary care providers prepared to care for those with IDD and medical complexity and emphasized the need to expand education and training.[17] The Project ECHO$^{(R)}$ (Extension for Community Healthcare Outcomes) telementoring model developed by the University of New Mexico as an "all teach all learn" model where multidisciplinary healthcare teams can learn from experts and from each other through didactics and case discussion.[18] Project ECHO$^{(R)}$ has been used to address clinical education

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gaps on a variety of topics including care for children and youth with ASD and dementia care in older adults with IDD but had not yet been used for general primary care topics for adults with IDD.[19–21] The purpose of this demonstration project was to (1) assess the feasibility using the Project ECHO$^{(R)}$ model to deliver education and training for clinicians (physicians and nurse practitioners), nurses, and social workers on primary care topics for youth and adults with IDD and (2) assess the impact of the curriculum on participant knowledge and self-efficacy.

2. Methods

Health care service delivery for the IDD population often involves a multidisciplinary team of physicians, advanced practitioners, nurses, and social workers to address the medical, behavioral, care coordination, and social support needs of this population. The Baylor College of Medicine Transition Medicine Clinic (TMC) is a medical home primary care clinic for adults with IDD aged 19 and above who are transitioning from the affiliated children's hospital or who are referred from community providers due to needing more IDD-specific health care and care coordination. The clinic has a multidisciplinary team of clinicians, nurses, and social workers who specialize in IDD primary care and who teach medical, nursing, and social work learners in the clinical setting. The clinic is in an academic faculty group practice and thus partners with subspecialists within the academic institution to address specific needs such as epilepsy and chronic pulmonary conditions. To address the knowledge and confidence gaps in providing care for individuals with IDD, Baylor College of Medicine partnered with United Healthcare of Texas Medicaid to develop a multidisciplinary Project ECHO telementoring series entitled "Caring for Adolescents and Adults with IDD". Continuing education credits for physicians, physician assistants, nurse practitioners, nurses, and social workers were awarded by the Baylor College Medicine Division of Continuing Professional Development according to the number of sessions attended with no cost to the participants.

2.1. *Curriculum development and recruitment*

Following the Project ECHO design and criteria for continuing education credits, a multidisciplinary advisory committee was convened including two physicians, a nurse, a physician assistant, a nurse practitioner, and two social workers. The group determined six priority care topics for the sessions based on common co-occurring conditions leading to increased morbidity and mortality in the IDD population and their clinic accommodation needs. Virtual Project ECHO sessions included 25 minutes of didactics, 5 minutes for a case presentation, and 30 minutes of participant discussion of the lecture and case. Topics included were (1) adapting clinic visits for individuals with IDD, (2) evaluating behavior change, (3) constipation evaluation and management, (4) aspiration evaluation and management, (5) epilepsy in the IDD population, and (6) aging in the IDD population. Subspecialists from applied behavior therapy, psychiatry, pulmonology, and neurology were recruited as content experts to develop the relevant didactic topics. Case discussions included clinician, nursing, and social work questions to be relevant to the multidisciplinary participant group. Didactics, case presentations, and maintenance of certification questions for each session were reviewed and approved by two advisory committee members.

Participants were recruited locally from Baylor College of Medicine via the Continuing Professional Development office and Texas Children's Hospital via the Nursing Continuing Education office, state-wide via the United Healthcare of Texas provider network, and colleague contacts.

2.2. *Implementation*

The six virtual sessions were held over the lunch hour monthly across six months. The sessions were also recorded to be posted on the Baylor College of Medicine Continuing Professional Development website for later viewing and obtaining continuing education credit. Participants were encouraged to attend as many sessions as possible to facilitate the "all teach all learn" discussion.

2.3. *Program evaluation measures*

The American Academy of CME Outcomes Model guided the program evaluation. Evaluation measures used were program participation tracked by the Continuing Professional Development Office and a retrospective self-assessment survey determining changes in knowledge and confidence pre-and post-session for each topic which was sent to participants after each session. Knowledge and confidence were assessed using a 10-point Likert scale (1 = not at all knowledgeable or confident, 10 = very knowledgeable or confident). Unique knowledge and confidence questions for each session are listed in Table 1, and these questions are directly tied to learning objectives. Participant satisfaction and experience was also assessed via a post-survey delivered after each session that was the same for each session. Sample survey is included in the addendum.

2.4. *Data analysis*

Along with count/percentage calculations, each paired knowledge and confidence item was analyzed independent of one another through paired samples t-test and Hedge's g effect size calculations.

3. Results

3.1. *Participant characteristics*

In total, 120 unique participants registered for the course with 39 physicians, 11 advanced practitioners, 27 nurses, 28 social workers, 2 psychologists, and 13 other IDD care providers. The attendance at each of the 6 sessions varied from 14 to 26 with some participants attending all 6 sessions and others attending only some. Evaluation surveys were conducted after each session with a differing number of participants completing each survey. Participants were from across the United States and included those working in a variety of primary care settings as well as multiple subspecialties including neurology, physical medicine and rehabilitation, orthopedics, and pulmonology. Medical students and residents rotating with the Transition Medicine clinic also attended and participated in each session, however they did not register to seek CME credit.

3.2. *Participant impact*

3.2.1. *Knowledge and confidence*

Across the six sessions, the twelve knowledge and confidence items resulted in improved ratings after participation in the learning sessions (Table 1). The largest effect sizes, representing meaningful improvement, came from learning objectives related to the Aging with IDD session (Confidence in identifying important changes in support needs as individuals age in adulthood, Hedge's g=-1.95; Knowledge of the unique challenges in caregiving for older individuals with IDD, Hedge's g=-1.60).

3.2.2. *Experience*

We distributed a survey after each of the 6 sessions. In total across the 6 sessions, we received 104 responses to questions regarding satisfaction. 102 responses said they would recommend this program to others and two did not respond to this individual question. 81 responses ranked the programs as "excellent", 20 as "good", and three did not respond. 89 responses indicated the program "definitely" included sufficient interactive opportunities to answer questions, 94 "definitely" felt evidence base for best practice recommendations were provided, and 94 felt the

Table 1
Changes in Knowledge and Comfort After Participation in Learning Sessions.

Learning Objective	Before Mean (SD)	After	Test Statistic & Effect Size
Session 1: Adapting primary care visits to individuals with IDD			
Confidence in discovering common causes of intellectual and developmental disability.	5.57 (2.18)	6.48 (1.91)	t(20)= −4.39, p<.01, Hedge's g=−0.92
Knowledge in the health disparities that exist for youth and adults with IDD and assess your own practice for barriers to quality health care for adults with IDD.	5.83 (2.27)	7.00 (1.81)	t(22)= −5.47, p<.01, Hedge's g=−1.10
Session 2: Behavior change and management			
Confidence in building a differential of common causes of behavior change in youth and adults with IDD including a variety of physical and psychosocial causes.	5.38 (2.34)	6.67 (1.69)	t(23)= −5.13, p<.01, Hedge's g=−1.01
Knowledge of common medications used to treat depression, anxiety, and aggressive behavior.	5.04 (2.22)	6.42 (1.89)	t(23)= −6.15, p<.01, Hedge's g=−1.21
Session 3: Constipation management in the IDD population			
Knowledge of various causes of constipation in youth and adults with IDD	7.33 (1.84)	8.6 (1.68)	t(14)= −6.14, p<.01, Hedge's g=−1.50
Knowledge in summarizing common bowel management strategies including diet, medications, and surgeries	6.82 (2.13)	8.35 (1.87)	t(16)= −5.91, p<.01, Hedge's g=−1.36
Session 4: Aspiration prevention and management			
Confidence in constructing patient questions and interpret physical exam findings that may indicate aspiration in people with IDD.	6.18 (2.89)	7.45 (2.54)	t(10)= −4.67, p<.01, Hedge's g=−1.30
Knowledge of the common management strategies to treat aspiration pneumonia and prevent aspiration in patients with dysphagia and poor airway clearance.	6.27 (2.49)	7.91 (2.07)	t(10)= −4.85, p<.01, Hedge's g=−1.35
Session 5: Seizures in the IDD population			
Confidence in evaluating causes of increased seizure frequency and common seizure medication side effects.	5.69 (2.43)	7.31 (2.39)	t(12)= −4.88, p<.01, Hedge's g=−1.27
Knowledge of the prevalence of co-occurrence of seizure disorders and IDD and identify patients at risk for SUDEP.	5.08 (2.66)	7.15 (2.15)	t(12)= −5.96, p<.01, Hedge's g=−1.55
Session 6: Aging with IDD			
Confidence in identifying important changes in support needs as individuals age into adulthood.	5.93 (1.64)	7.64 (1.45)	t(13)= −7.77, p<.01, Hedge's g=−1.95
Knowledge of the unique challenges in caregiving for older individuals with IDD	5.71 (1.77)	7.71 (1.38)	t(13)= −6.36, p<.01, Hedge's g=−1.60

learning objectives were met. Overall, there was a high level of satisfaction with the program amongst most participants.

4. Discussion

Currently, there are few clinics that provide comprehensive primary care and care coordination for adults with IDD, and most are in academic medical centers.[13,14,22] The Project ECHO telementoring platform can facilitate connecting experienced, multidisciplinary clinic providers to community-based providers and facilitate professional networking and share knowledge.

4.1. Lessons learned

Implementation of this project was made feasible by having a robust continuing professional education support team who had infrastructure in place to provide continuing education credits for a variety of clinicians, distribute surveys, and report on evaluation data. The internal cost for continuing education credits was approximately $4000 thus having funding from United Health Care made these credits free to each learner. As we had a multidisciplinary audience, templating the case presentation to include questions directed towards the various team roles ensured that discussion questions highlighted the roles of physicians and advanced practice providers, social workers, nurses, and case managers and prompted their input. Some participants verbally contributed to the case discussion, but the majority preferred to engage with the chat feature of our teleconferencing platform. Having the facilitator monitor the chat box and reading them to the group helped promote participation and discussion. There is little available, free education for currently practicing clinicians and staff regarding primary care for IDD so it was encouraging to see statistically significant improvement in knowledge and competency across multiple sessions. The Aging with IDD session resulted in the largest increase in effect sizes. As individuals with IDD live longer secondary to advances in healthcare and community living, older adults with IDD have become a rapidly growing population with unmet healthcare needs, and thus there is a growing need for clinicians to be equipped to care for this population.[23] While there are similarities to general geriatric care, common conditions in aging adults including mental health concerns, dementia, and frailty may occur earlier and more commonly in the IDD population.[24–26] Additionally, primary care clinicians may have challenges in identifying and diagnosing these conditions in individuals with IDD who have underlying cognitive and functional impairments, communication impairments, and/or multiple caregivers.[27] Continued development of evidence-based guidelines and provider education strategies such as Project ECHO® are needed to equip clinicians to address these care needs.

4.2. Limitations

The limitations of this project were the lack of a control group, small sample size, and reliance on self-assessment for evaluation. Generalizability was also limited by the convenience sample of healthcare providers affiliated with our institution, United Healthcare provider network, and colleague contacts thus the participants may not be representative of adult care providers serving those with IDD. The additive impact of attending multiple sessions was also not assessed with the small sample size but requires further study. During the case discussions, it was evident most participants already had experience in providing care for individuals with IDD. Further initiatives are needed to recruit primary care providers with less IDD experience to focus on expanding the workforce via managed care Medicaid provider lists and non-IDD based professional organizations and conferences. Finally, the series was limited to six months, so the longitudinal impact of this training on the participants' ability to better care for individuals with IDD or implement practice changes was not assessed.

4.3. Future studies

Future studies to evaluate this curriculum include implementing the curriculum with other providers with varying levels of experience treating individuals with IDD and assessing the longitudinal practice changes of participants. Both ideas would be helpful to further evaluate the impact of this education model on improving provider knowledge and self-efficacy in caring for youth and adults with IDD.

4.4. Conclusions

Project ECHO offers a feasible platform to improve clinical knowledge and self-efficacy to provide primary care for adults with IDD and support provider networking important to addressing the knowledge gap in adult IDD primary care.

CRediT authorship contribution statement

Ellen Fremion: Writing – review & editing, Writing – original draft, Project administration, Methodology, Funding acquisition, Conceptualization. **Nital Appelbaum:** Writing – review & editing, Writing – original draft, Visualization, Formal analysis, Data curation. **Kathryn Jordan Kemere:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Funding acquisition, Data curation, Conceptualization.

Ethical statement

- the work described has not been published previously except in the form of a preprint, an abstract, a published lecture, academic thesis or registered report.
- The article is not under consideration for publication elsewhere.
- The article's publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out.
- If accepted, the article will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder.

We agree with this ethical statement as evidenced by uploading this document.

Financial support

We applied for a grant opportunity entitled "*Strengthening Quality in Texas Communities Program*" from the United Healthcare Community Plan. We were awarded the funding which allowed us to create this educational opportunity and provide continuing education credit. The funders were not a part in any way of the design, collection, analysis, interpretation, writing, or decision to submit for publication.

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Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests K Jordan Kemere reports financial support was provided by United Healthcare. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.hctj.2024.100084.

Data availability

Data will be made available on request.

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