

Integrating ADEPT-CARE for Youth with Intellectual and Developmental Disabilities into a Medical School Curriculum

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Objectives

1. Define the ADEPT-CARE protocol and how it addresses gaps in IDD-focused medical education.
2. Describe how ADEPT-CARE is implemented in the medical school curriculum.
3. Discuss outcomes and feedback for the ADEPT-CARE curriculum.
4. Outline future directions and next steps for improving the program.

Defining the Problem

Gaps in IDD-focused medical education promote healthcare disparities



Medical education curriculums often do not prepare physicians for disability-informed care

Only 52% of accredited MD and DO schools include a focus on disability in their curriculum.¹

50% of physicians do not feel confident in caring for people with disabilities.²



IDD is inconsistently represented in disability-focused curriculums

IDD-specific education is highly variable and where present, it often lacks standardized metrics for evaluation.³



Reduced healthcare accessibility and quality for people with IDD

Many clinicians lack training in how to evaluate and identify symptoms that can present differently in people with IDD.⁴

People with IDD face more barriers to accessing care, lower rates of preventive screenings, and higher rates of preventable diseases.⁵

Goal and Strategy

Goal: Use the ADEPT-CARE curriculum to improve medical student knowledge and confidence in evaluating patients with IDD.

Didactics + Ethics

Classroom instruction on ADEPT-CARE protocol with examples.

Disability self-advocacy panel provides insight into how to apply protocol in practice.

Medical ethics session on considerations related to communication, evaluation, and informed consent.

OSCEs

Objective Standardized Clinical Exams (OSCEs) working with community volunteers (youth and young adults with IDD and their caregivers or support persons).

Program Evaluation

Collect feedback from students and SPs to assess program effectiveness and promote quality improvement.

Students: Survey evaluating knowledge and confidence before vs. after ADEPT-CARE curriculum.

SPs: Post-OSCE debrief session with option to submit anonymous feedback.

Overview: The ADEPT CARE Protocol

Letter	Recommendation	Description & Problem Representation	Sample Questions/Statements
A	Ask about Access needs and Accommodations in the healthcare environment	<ul style="list-style-type: none"> • Accessibility-related barriers to healthcare, especially transportation and communication barriers, are common and mitigatable. • There is a lack of accessible medical diagnostic equipment. When accessible equipment is available, it is not consistently utilized. • Consider access needs related to interpreter services, physical facility accessibility, medical equipment, medical forms, time, face masks, services animals, assistive technologies, transportation, and scheduling. • When appropriate, document accommodations in the medical record for future visits. 	<ul style="list-style-type: none"> • What can we do to make your visit to our clinic more accessible to you? • Did you have any difficulty accessing the clinic today? • Did you find our scheduling system accessible?
D	Defer to the Disabled person	<ul style="list-style-type: none"> • It is okay to ask a patient about their disability. • Inquiring about a patient's disability status and/or identity can build rapport and allow one to provide enhanced patient-centered care. • When meeting someone for the first time, default to person-first language (i.e., a person with a disability). • Some patients may prefer identity-first language (i.e., a disabled person) • Use the patient's language preference after inquiring. 	<ul style="list-style-type: none"> • How do you explain your [disability/diagnosis] to others? • How does your [disability/diagnosis] affect you?
E	Engage with the patient	<ul style="list-style-type: none"> • Talk directly to the disabled person. • Avoid directing the conversation at whomever may be accompanying them to the appointment. • Communicate as you would with a non-disabled patient: Speak in the same manner, tone and volume. • Effective communication lets disabled patients know you are attuned to their concerns and needs which increases the likelihood of seeking care and following through with recommendations. • Communication may be supported by an interpreter, communication board, or other tools. 	<ul style="list-style-type: none"> • What is your preferred method of communication? • Do you need any accommodations for communication? • I'm sorry, I don't think I understood you. Let me try explaining this in a different way.
P	Promote Participation and Patient-Centered care	<ul style="list-style-type: none"> • Promote patient autonomy by engaging with the patient, even if they are accompanied by someone or are non-speaking/non-verbal. • Consider the use of shared or supported decision-making. • Respect boundaries. Adaptive and assistive devices, such as wheelchairs and service animals, are an extension of a person with a disability. You should not touch these devices or attempt to help a disabled person without first asking for consent or permission. 	<ul style="list-style-type: none"> • Are you comfortable with everyone here being present for our discussion? • What is the best way to help you? • Do you need assistance with dressing or getting onto the table? • May I move your belongings for you?
T	Take Time for a Thorough medical history and physical exam	<ul style="list-style-type: none"> • Perform a comprehensive physical exam. Avoid examining a patient in their wheelchair as this may lead to an incomplete exam. • Disparities in physical, sexual, reproductive, and mental health are stark for disabled patients. Do not skip any parts of the history or exam. • As with non-disabled patients, variable clinical encounter lengths are inherent to medical practice. 	<ul style="list-style-type: none"> • Do you need a lift to help you transfer to the exam table for the physical exam? • What is the best way for me to do this [exam maneuver]? • Is there any [exam maneuver] or body area I should avoid? Is there anything I should be aware of before I perform [exam maneuver]?

Overview: The ADEPT CARE Protocol

Letter	Recommendation	Description & Problem Representation	Sample Questions/Statements
C	Consider disability-related Conditions	<ul style="list-style-type: none"> • People with disabilities are disproportionately exposed to risk factors for preventable health conditions, manifesting in increased prevalence of chronic conditions, such as cardiovascular diseases, diabetes, obesity, and depression. • These co-existing conditions are further exacerbated by physical inactivity and mental health conditions, which have increased prevalence amongst the disabled community and are major risk factors for chronic disease. • Both disabled men and women are at a higher risk of experiencing sexual violence, sexual coercion, and unwanted sexual experiences. • Some Disabled people may be more vulnerable to abuse due to the need for personal assistant and personal caregiving. • Healthcare providers are mandatory reporters for abuse or neglect. 	<ul style="list-style-type: none"> • Have you ever felt unsafe with a caregiver or other person in your life? • Has anyone physically hurt you? • Has anyone forced you to have sexual activities? • Has anyone ever prevented you from using an assistive device? • Has anyone you depend on refused to help you?
A	Ask about Access needs and Accommodations in the home and community	<ul style="list-style-type: none"> • When assessing social determinants of health and social needs for people with disabilities inquire about the accessibility of community-based resources and accommodations. • Transportation barriers affect access to society, physical activity sites, grocery stores, pharmacies, social support, and more. • The cost of home modifications illustrates financial and physical accessibility barriers. 	<ul style="list-style-type: none"> • What accommodations [modifications, supports] do you have at home? • Do you have home modifications? • Tell me about the community where you live. • Do you have personal care assistance? • How long have you had your current [assistive device]? • Tell me about your exercise routine.
R	Review the treatment plan and Respond to feedback	<ul style="list-style-type: none"> • Review the treatment plan to assess the patient's understanding and solicit feedback on how to provider better care. • When a disabled patient corrects you or offers feedback, actively listen and change your behavior accordingly. • Provide after-visit summaries and follow up information in a format that is accessible to the patient. 	<ul style="list-style-type: none"> • I want to make sure that I was clear today. Can you please summarize what we just went over in our visit and what the plan is going forward? • How would you like me to give you the after-visit instructions? • What questions do you have for me about what we went over during your visit today?
E	Ensure accessible follow-up and referral	<ul style="list-style-type: none"> • Consider the accessibility of any patient education materials and/or referrals. • Recognize the importance of interprofessional care for disabled patients. • Collaborate and communicate with other providers to optimize care. • Ensure that the patient has a method to communicate with your clinic that is accessible to them in case questions arise. 	<ul style="list-style-type: none"> • I will call the imaging facility to let them know what accommodations you require for your mammogram. • I confirmed that this specialist has an accessible practice. • Let us talk more about this [health program] in your local community that may be accessible to you.

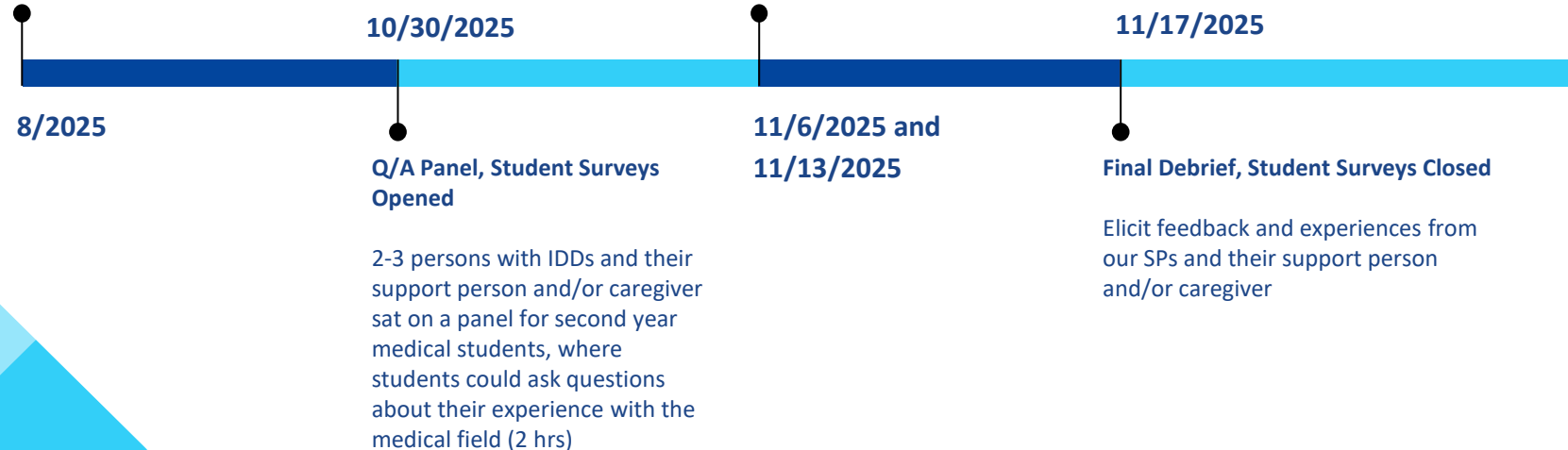
The History of ADEPT-CARE

2021	Original “ADAPT-CARE” at UCONN
2022	Pilot of ADEPT-CARE as PSCOM MS1 Elective Initiation of MS2 Curriculum
2023	ADEPT-CARE Phase 2 Videos
2025-Onward	Continuation of Phase II (MS2) curriculum with adaptations each year

Implementation at PSCOM: Overview

SP Recruitment

PA Revs All-Starz, PSCOM Special Olympics, E-mail Listserv, Community-Placed Flyers and forum usage



OSCE Sessions

2 hour block where students interacted with 2 different standardized patients (SPs) with disabilities and their support person and/or caregiver

Ethics Session

Student and Doctor led session reviewing medical ethics involving persons with IDD

11/17/2025

Final Debrief, Student Surveys Closed

Elicit feedback and experiences from our SPs and their support person and/or caregiver

Implementation at PSCOM: Panel Discussion

Q/A Panel

Video-directed session where students watched several minutes of an 18-minute long video, discussed questions with their classmates, and then heard perspectives from SPs and their support person, with an open Q/A at the end of the session

Start video at 8:30am

1:25 time stamp: What are some experiences you've had thus far in medical school where you've interacted with a patient with a disability or staff member with a disability? What are the barriers you've observed?

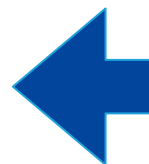
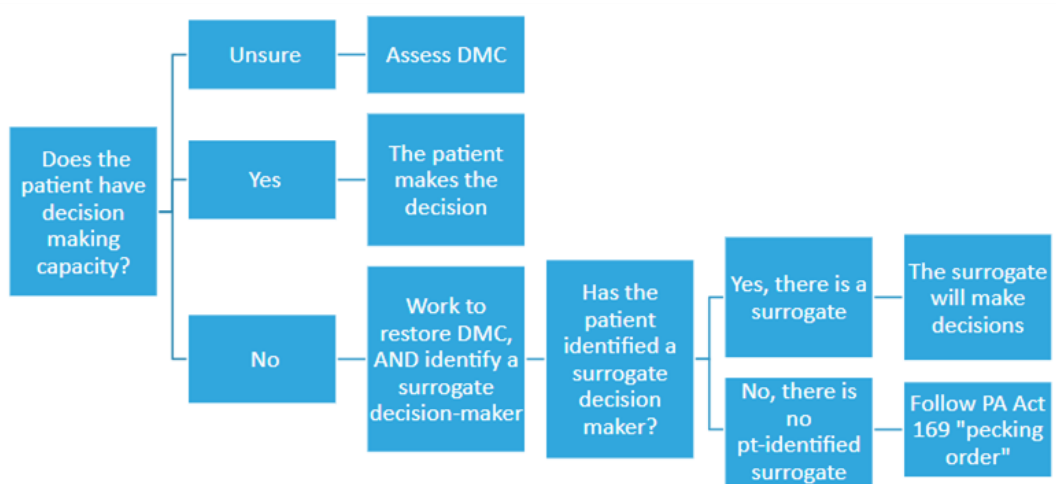
- Use this an opportunity to mention that some disabilities are invisible, you may have interacted with many more people with disabilities than you realize
- **Talking points for panelists to consider:**
 - o Speak to your experiences with the accessibility of the clinical environment: waiting rooms, exam rooms, medical equipment, etc.
 - o What does dignity mean to you in a health care setting?
 - o What subtle or invisible barriers do you think students/providers often overlook when caring for patients with disabilities?

Restart latest 8:45am

4:18 time stamp: How can you as a medical student help support access needs being met?

- Talk about UM accommodations tab
- Dr. Cooper to talk about a patient with an amputation and needing a straw and how there's not a great place to document that
- ADA requirements of reasonable accommodations
- **Talking points for panelists to consider:**
 - o Can you remember a time when your access needs were not met during a medical visit? Can you think of a time when they were? How did this shape your experience and make you feel throughout the visit?
 - o Can you think of small actions that have made or can make a big difference in accessibility for you?

Implementation at PSCOM: Ethics Session



Implementation at PSCOM: OSCE Sessions

OSCES

Students practiced history taking and physical exams on persons with IDD (ages 6 to 26) and their support person during 15 minute increments over a 2 hour period.

There was a large, student-led debrief session at the end of the sessions.

Timeline

“ADEPT-CARE for Patients with Intellectual and Developmental Disabilities”
70 students, groups of 4

8-8:15 Round 1 (2/4 students go)

8:15-8:20 Debrief Round 1 (students + SPs)

8:20-8:35 Round 2 (other 2/4 students go)

8:35-8:40 Debrief Round 2 (students + SPs)

8:40-8:50 Break/Transition

8:50-9:10 Round 3 with new SP, efficiency style, all 4 students should do a part of H&P

9:10-9:20 Debrief Round 3 (students + SPs)

9:20-9:25 Medical Students Transition to LRA

9:25-9:35/40 Post-Survey (medical students)

9:35/40-9:50 Student Large Group Debrief

Previous Results at PSCOM

What has been done?

Grant Applications: previous funding through Alliance for Disability in Health Care Education and the Woodward Center for Excellence in Health Sciences Education (Penn State College of Medicine), currently funded through Children's Miracle Network until 7/2027

Research: Pilot Results (manuscript published), Assessing generalizability with other health professional students (data collected), Assessing efficacy and generalizability with practicing healthcare professionals (data analyzed)

Raising Awareness Through Oral Presentations: (Arc of PA 2023, DAC Med conference 2022, American Academy for Cerebral Palsy and Developmental Medicine Annual Meeting 2022)

Promoting Inclusive Medical Education through Posters Presentations: AAMC Conference, AMA Abstract, Association of Academic Psychiatry Medical Student Council May Journal Club (all 2023)

Promoting PSCOM ADEPT-CARE Curriculum for Medical Students: Ongoing!

Results (2024-2025)

88%

Of students responded that they were confident in their abilities to assess a patient with IDD after the ADEPT-CARE training, compared to just **21%** of students prior to training in 2025.

65%

Of students responded that they were confident in their ability to provide accommodations to patients with disabilities following this course, compared to **34%** pre-ADEPT CARE in 2025.

43%

Of students felt they had received adequate training to provide care for patients with disabilities following training in 2024, compared to **9.8%** prior to training.

Direct Student feedback:

- “Preventive care for IDD should be adapted, not omitted; consistent caregiver/family collateral best captures baseline cues and changes.”
- “I really appreciate having dedicated sessions to become more informed about how to treat patients with IDD.”
- “After the osce session, I feel more comfortable interacting with diverse patient populations including those with IDD. “
- “I feel like it needs to be incorporated from the beginning, not just a small 2 week blip in a course.”

Pending Results & Further Analysis

- 2025 survey data has undergone only a preliminary review
- 2025 6-month follow up survey currently collecting responses
- Manuscript including 2024 data analysis currently underway
- Medical Student recruitment underway to select student leaders for future years

Standardization
of SP feedback
during OSCEs

Continued data
Collection +
Analysis

Future
Collaboration with
other
organizations

Next Steps

Resource list for
future + current
medical providers

Manuscript writing
+ submission for
publication

Continued quality
improvement for
curriculum
sustainability

Summary

- Goal: To implement the ADEPT-CARE protocol as a educational tool for medical students to incorporate into patient encounters for people with IDD.
- The ADEPT-CARE curriculum benefits all who are involved based on survey feedback from students as well as SPs.
- Fills a reported gap in medical education → directly address students' discomfort performing an H&P with disabled patients.
- ADEPT-CARE has the potential to be an easily understandable teaching tool.
- Could be effectively and flexibly implemented into medical education in multifaceted way, as supported by current medical student feedback.
- Addressing greatest reported barriers to “real-life” implementation would benefit from collaboration of multiple stakeholders for system-wide changes.

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- ❖ Dr. Amanda Cooper, MD, PSCOM Faculty and Milton S. Hershey General Surgeon
- ❖ Dr. Rebecca Volpe, PhD, PSCOM Ethics Committee
- ❖ Medical Student Volunteers

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Thank You!

Questions?