**Step-by-Step Guide to Teaching Medical Students to Care for Patients with Autism Spectrum Disorders**

Medical education programs are increasingly expected to address underserved or vulnerable populations and teach undergraduate medical students to be culturally competent. Including content on patients with disabilities can address these curricular elements. A **critically important element** of teaching patient care to vulnerable populations is giving students **hands-on experience** with the underserved population, in our case people with autism spectrum disorders (ASD). This guide provides sample objectives that can be met with such an encounter, a list of types of encounters that can be arranged, and specific suggestions on how to recruit volunteers for your encounter.

The following steps will guide your program development:

1. **Create objectives for the encounter**

Curricular elements that include patients with autism spectrum disorders or other disabilities can support the Liaison Committee on Medical Education (LCME) goals of cultural competence, diversity, or meeting the needs of underserved/vulnerable populations. Consider including one or more of the following objectives in your undergraduate medical education curriculum:

1. Teach medical students how to care for patients with autism spectrum disorders and other developmental disabilities.
2. Improve students’ understanding of and competence in providing family-centered care to underserved patients.
3. Improve medical students’ attitudes and knowledge of persons from diverse cultural backgrounds including disability.
4. Increase the number of physicians with skills and attitudes that welcome persons with disabilities into their practices.
5. Empower individuals with developmental disabilities to become advocates for their own care.
6. **Choose type of encounter or combination of encounters**

Undergraduate medical programs address diversity in a variety of ways: didactic instruction, community service encounters, clinical clerkships, standardized patient (SP) encounters, panel discussions with patients, advocates, and family members; in addition to home visits where students interact with individuals with disabilities outside of a healthcare setting.

* 1. **Didactic instruction**

Lectures can be an efficient way to teach students about health and healthcare disparities, diversity, and patient care issues. Incorporating video content that features people with disabilities and their families can make lectures more engaging and impactful. Online didactic material is available and examples can supplement hands-on patient encounters. [Click here](http://nisonger.osu.edu/disabilityconted2.htm) **for “Healthcare Access for Persons with Developmental Disabilities,” a one-hour training on** health issues and barriers to health care for people with developmental disabilities (including intellectual disability, autism spectrum disorders, and cerebral palsy).

**The Centers for Disease Control and Prevention’s** [Learn the Signs. ACT Early](http://www.cdc.gov/ncbddd/actearly/index.html) **materials** help healthcare professionals gain knowledge and skills to improve early identification, diagnosis and care of children with ASD.

In 2005 University of South Florida clinical educators implemented a disability-related course for all third-year medical students. This six-week course incorporates didactic instruction, training sessions, and clinical experiences during the primary care clerkship (Woodard, Havercamp, Zwygart, & Perkins, 2012).

Symons, McGuigan, and Akl (2009) at the University of Buffalo School of Medicine and Biomedical Sciences developed a four-year curriculum to educate medical students about disabilities. The curriculum uses several approaches such as classroom instruction, home visits and clinical experience to achieve three overarching goals: build knowledge of disabilities, improve attitudes and commitment to disability, and foster skills to provide patient-centered care.

* 1. **Standardized patient**

Including patients with disabilities in standardized patient (SP) encounters is an effective way to provide training on vulnerable populations including autism spectrum disorders (ASD) and other disabilities. Standardized patients are individuals who are specifically trained to participate in mock doctor-patient encounters. SPs are trained to recreate physical, emotional, and medical history and responses of an actual patient. These activities can improve students’ interpersonal communication skills, which are the cornerstone in patient interviewing. For SPs with disabilities, the encounter could be simply a “new patient exam”; this may be easier for volunteers with cognitive impairment that might interfere with their ability to memorize and act-out a case.

Clinical educators at the University of South Carolina created a ninety-minute workshop for third-year medical students to improve skills, awareness and clinical consideration of patients with disabilities. Persons with disabilities are used as standardized patients for this interaction (Brown, Graham, Richeson, Wu, & McDermott, 2010). Medical students are taught how to safely transfer patients from their wheelchairs to examination tables. Students are required to complete a fifteen-minute visit with a patient who has a disability including physical exam. Tufts University School of Medicine introduces medical students to the “Chris Walker case” during their third-year clerkship in Family Medicine. This case uses individuals with physical disabilities and/or blindness to portray a patient with shoulder discomfort. Students are required to perform a patient interview including medical and social history (Minihan et al., 2004).

The Ohio State University Nisonger Center, with funding from the Health Resources and Service Administration, implemented a curriculum to train third-year medical students to care for patients with autism spectrum disorders. This encounter took place during the ambulatory care clerkship and we worked closely with the Director of Ambulatory Clerkships in the College of Medicine to facilitate these encounters. One element of this innovative curriculum involved training adults with ASD to function as standardized patients in a mock interview scenario with medical students. We used this presentation to introduce adults with ASD to the standardized patient program. During each rotation, two adults with ASD were interviewed by medical students, who were encouraged to build rapport and establish a relationship with the SP in a “new patient” scenario. The clinical scenario entailed an interview, medical history, but no physical exam at the request of several volunteers with ASD. Following each encounter, we conducted a facilitated small-group discussion. Finally, students were asked to write a reflection on what they learned and the relevance of the experience to their practice as a physician.

For this encounter, we used adults with ASD who were able to speak and represent themselves in a healthcare visit. Student feedback was very positive; medical students recognized the importance of learning about providing health care to vulnerable populations and were glad to have an opportunity to meet patients with developmental disabilities. In addition to this encounter, students requested exposure to patients who were more severely affected by autism, to children with ASD, and to an experienced clinician example of providing medical care to patients with ASD.

* 1. **Clinical clerkship**

Students at Rutgers University Robert Wood Johnson School of Medicine visit [Matheny Medical and Educational Center](http://www.matheny.org/medical_education.htm) during their third year to learn how to interact and care for individuals with disabilities as a part of their clerkship rotation. Additionally, third-year medical students take part in a developmental disability seminar during their pediatric rotation facilitated by [The Elizabeth M. Boggs Center on Developmental Disabilities.](http://rwjms.rutgers.edu/boggscenter/student/DD_seminar.html)

The School of Medicine at the University of Massachusettsoffers an [interclerkship](http://www.umassmed.edu/ome/interclerkships/index.aspx) for third-year medical students entitled “Working with Persons with Disabilities in the Clinical Setting,” and a Population Health Clerkship for second-year medical and nursing students focused on the healthcare needs of individuals with disabilities.

* 1. **Panel discussions**

Panels can be an effective way to expose students to a number of patient care issues from the patient or family perspective. Participants can be individuals with disabilities, parents, family members, advocates, and medical professionals. The role of the facilitator is to create a dialogue that is both informative and engaging.\*

\***Note**: *Because panel discussions are not scripted, panel members may surprise the class and moderator with what they share. For example, it is not uncommon for families with children on the autism spectrum to explore Complementary or Alternative Medicine. This presents an opportunity for the faculty member to discuss with the students how to respond to the family who expresses interest in treatments that are not evidence-based. This discussion should be held before or after the panel presentation.*

Ideas for panel discussion:

* Impact of diagnosis
* Misconceptions and stigmas associated with diagnosis
* Acute healthcare experiences
* Best experience with medical professional
* Worst experience with medical professional
* Medications, therapy, community services
* Transition to adult services
* Educational services
* Caregiver wellness
* Community resources for patients and families
* Healthcare financing, cost of services

The Ohio State University Nisonger Centerfacilitates panel discussions on the healthcare needs of children and adults with ASD. Our panels consist of a facilitator (a developmental-behavioral pediatrician) and 4-6 panel members made up of people with ASD, parents and other family members. Although previous panel participants with ASD were able to speak and respond to questions, the parents were able to offer a glimpse into life with children who are severely affected by ASD. We also added two videotaped physical exams of patients with ASD performed by a developmental-behavioral pediatrician. These exams were used to demonstrate the effectiveness of interpersonal communication, person-first language, and the benefits of a medical home approach to primary care.

* 1. **Home visits**

Home visits can have a profound impact on students and are effectively used by clinician educators to teach medical students continuity of care. Home visits have been used as part of geriatric clerkships to educate students on the psychosocial components of chronic illness and to improve attitudes toward vulnerable populations.

[Mount Sinai Visiting Doctors Program](http://www.mountsinaifpa.org/patient-care/practices/visiting-doctors-program/about-us) is the largest academic-based home visit program in the nation. Third-year medical students take part in a one-week, home-based clinical rotation in the Visiting Doctors Program. Students conduct physical examinations and assessments, focusing closely on social and cultural determinants of health within the home environment (Ornstein, Hernandez, DeCherrie, & Soriano, 2011). Students at [Weill Cornell Medical College](http://weill.cornell.edu/education/curriculum/third/pri_car.html) participate in a half-day home visit experience as a part of their third-year primary care clerkship, where they learn the art of psychosocial histories and chronic illness care management. [University of Connecticut](http://cbe.uchc.edu/education/curriculum/index.html) medical students participate in a home care and health assessment program as part of their second-year experience.

* 1. **Community service encounters**

[Florida International University Herbert Wertheim College of Medicine](http://www.fiu.edu/research/newsroom/2011/neighborhood-help.html) has an innovative service-learning program through its community outreach initiative, NeighborhoodHELP. This program is considered the cornerstone of students’ medical education at Florida International University. During students’ second year they take part in their service-learning study, which includes a home visit component. Using interdisciplinary teams from public health, social work, nursing, and law, students monitor and track the health of families. Additionally, students will work with community partners and primary care physicians to develop and implement care plans for families throughout their matriculation.

* 1. **Additional web-based tools and resources**

The University of California-San Francisco has created a program within The Department of Family and Community Health with the goal of improving health outcomes for individuals with developmental disabilities across the lifespan. The Office of Developmental Primary Care offers clinical services, advocacy, research and training opportunities. Their [website](http://developmentalmedicine.ucsf.edu/odpc/) offers a wealth of resources for self-advocates, clinicians, researchers, and trainees.

1. **Recruit volunteers with autism spectrum disorders**

Contact your local autism organizations and community support groups – they may be very interested in helping you find individuals and families willing to help teach medical students about autism. Also, speak with colleagues within your organization and community who care for patients with developmental disabilities – they may know resources and families in the autism community. For more information about such organizations, please see the national and statewide resource lists.

1. **Correspond with volunteers regularly to improve attendance**

We contact volunteers initially in person or by phone and follow up by email. Here is a series of communications in email form that you can use to help panel attendance.

**Sample Panel Email Correspondence  
6 weeks before panel  
Email 1: Recruitment**

Greetings, **(Insert name)**,

I hope this note finds you well. It was a pleasure meeting you at the Autism Society event. I am writing to tell you about a new project being implemented at our center. The **(Insert Center name)** at **(Insert University name)** is hosting a panel entitled, Educating Medical Students about Autism Spectrum Disorders (ASD). This will take place on **(Insert date and time)**. The overarching goal of this panel is to improve medical students' attitudes and knowledge of persons with disabilities and to increase the number of physicians providing services to individuals with intellectual and developmental disabilities (IDDs). We want to provide educational opportunities to build competence and understanding in caring for patients with ASD for medical students. Our objective is three-fold: to give medical students essential information about providing care to individuals with ASD, to empower persons with disabilities to become advocates for their health care, and to improve patient transition from pediatric to adult medical care services.

Please let me know whether or not you are interested and available to participate in this panel on **(Insert date and time).** I will follow up with a phone call next week. In the meantime, please reply to this email or call me at **(your telephone number)**. I look forward to talking with you about this opportunity! Your participation will help in the improvement of medical education for future health care in the treatment of autism spectrum disorders.

**4 weeks before panel**

**Email 2: Invitation**

Greetings, panel members!

Thanks again for your interest in teaching medical students about autism spectrum disorders! We are emailing you to give you more information about the panel, Educating Medical Students about Autism Spectrum Disorders (ASD). This will take place on **(Insert date/time)**. It will be located in the medical center in **(Insert location).**

Please arrive at **(Insert time)**, as the panel will begin promptly at **(Insert time).** You are more than welcome to arrive early; we will have consent forms for you to sign before the panel begins. We will be filming this panel for future reference and to use in educating medical students.  The forms you sign will serve to recognize and approve this.

The panel facilitator will begin the workshop with a 15–20-minute introduction on providing health care to individuals with autism. We would like to you to prepare a brief, 2-minute introduction, outlining your connection to ASD. Once the panel begins, **(s/he)** will ask you and other panel members a series of questions related to autism. This will help the medical students understand more about autism spectrum disorders and your experiences.

**The discussion topics below may help you think about stories that you may want to share on (Insert date):**

* Experience and impact of receiving an ASD diagnosis
* Acute healthcare experiences with ASD (e.g., emergency care)
* Diagnosis and treatment of co-occurring conditions
* Worst experience with a healthcare provider
* Best experience with a healthcare provider (e.g., medical home)
* Intersection of other services (county board, school)
* Transition to adult healthcare services

Please respond by 12:00 (noon) **(Insert date)** to confirm your participation. If you have any questions or want to meet before to practice, please contact me at **(Insert phone number)** or by email at **(Insert email)**. We look forward to your participation.

**2 weeks before panel  
Email 3: Confirmation**

Greetings, panel members,

Hope this note finds you well. We are excited to have you as part of the panel to educate medical students about autism spectrum disorders. This is just a reminder that you will meet us on **(Insert date/time/location)**. We will need you to sign consent forms; if you need more time for this, then please come around **(arrival time).**

Also, please let us know if you have any additional questions. We look forward to your participation.

**1 week before panel  
Email 4: Reminder**

Greetings, panel members,

We are emailing you to give parking information for the Educating Medical Students about Autism Spectrum Disorders (ASD) panel. As you know, the panel will take place on (**Insert date and time**). It will be located in (**Insert Location**).

Please arrive at **(Insert time)**, as the panel will begin promptly at (**Insert time**). You are more than welcome to arrive early; we will have consent forms for you to sign before the panel begins. We will be **filming this panel for future reference** and to use in educating medical students.  The forms you sign will serve to recognize and approve this.

You will find a campus map attached that shows you where to park **(Insert name of parking structure)**. The address for the garage is **(Insert address)**; you can find more information by clicking the hyperlink.

If you have any questions or want to meet before to practice, please contact me at **(Insert Phone number)** or by **email** at **(Insert email)**. We look forward to seeing you on **(Insert date)**.

**One week after panel  
Email 5: Thank-You**

Greetings, **(Insert name)**,

On behalf of the **(Insert Center name)** and the Educating Medical Students about Autism Project, we thank you so much for participating in this week’s panel! Your contribution to this project will help prepare future physicians to care for patients with autism spectrum disorders. We truly appreciate your effort and want you to know how much you have helped medical education! We hope you will continue be part of our panelist pool. Once again, thank you for taking time to speak on the panel; we value your dedication to increasing autism awareness among medical students. We look forward to working with you again soon.

Thanks,

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