January 2022

Treating Children With Physical Disabilities: Development Of A Video-Based Education Resource Using Simulated Participants

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TREATING CHILDREN WITH PHYSICAL DISABILITIES: DEVELOPMENT OF A VIDEO-BASED EDUCATION RESOURCE USING SIMULATED PARTICIPANTS

A Thesis Submitted to the Yale University School of Medicine
In Partial Fulfillment of the Requirements for the Degree of Doctor of Medicine

by

Alexandra Carolyn Ruth Kimmel 2022
Treating children with physical disabilities: development of a video-based educational resource using simulated participants

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Abstract

Introduction: Children with physical disabilities (CWPD) represent an important population that has historically experienced inadequate and insensitive care across medical settings. A lack of comfort and knowledge about CWPD is common among health professionals and trainees. We created and evaluated a new educational resource enhanced by videotaped clips of a model pediatric outpatient visit for a CWPD and his mother, both portrayed by simulated participants.

Methods: We created a curriculum working group composed of multiple stakeholders, including patients with disabilities, parents of children with disabilities, and physician experts in treating disabilities. Using recommendations from the curriculum working group, we developed a didactic resource that interspersed 9 short video clips (with a cumulative duration of 27 minutes) into a 50-minute workshop given to students in the healthcare professions. We delivered the session virtually, using synchronous videoconferencing with Zoom. Learners completed assessments at baseline and after the
didactic intervention that measured satisfaction, knowledge, and attitudes. We compared learners’ attitudes to published norms on existing instruments. Our primary outcome measure was change in the *Attitudes to Disabled Persons - Original (ATDP-O)* scale.

Results: Forty-nine healthcare students participated: 29 (59%) from medicine, and 21 (41%) from physician assistant or nursing programs. The workshop proved a good fit for virtual delivery and was highly rated by students. Baseline attitudes did not differ from published norms, but ATDP-O scores improved between baseline and endpoint: from 31.2 ± 8.9 to 34.8 ± 10.1 (paired-t = 3.28, p = 0.002, Cohen’s d = 0.38).

Conclusion: This video-based educational resource proved easy to implement in the virtual classroom, was well received by learners, and led to measurable improvements in perceptions and attitudes toward CWPDs. All the didactic materials we developed are available to view, download, or adapt by end-use instructors.
Acknowledgements

I would like to thank Dr. Andres Martin for being open to the ideas and willing to amplify the voice of a medical student who had never previously been involved in medical education or curriculum development, but set out to change the medical school curriculum. I have learned so much from your example of how to be an extraordinary scholar, clinician, and mentor while still managing to take the time to listen and care for the input of every single member of your team. I am so honored to have been able to work with you.

To Dr. Erin Nozetz, thank you for bringing your incredible expertise as a pediatrician for children with complex care needs and as an educator to this project. This project could not have become incorporated into the curriculum without you. Your willingness to endure many meetings, to entertain new project ideas, and to devote your time and passion to this topic as we have continued to expand the curriculum on disability, both within our institution and across the nation, has been so inspiring.

I would also like to thank Dr. Oluwaferanmi Okalami for not only providing incredible insight for this project and sharing his own experience, but for blazing the trail in the medical community for physicians and patients with disabilities. Thank you for allowing me the opportunity to share this project and collaborate with medical students at other institutions. It has been a humbling honor to work with such a giant in the field of disability.

To Dr. Jaideep Talwalkar, thank you for the extensive contributions you made to the development of the videos and to the writing of this project. I am so appreciative of the guidance and expertise in medical education that you have provided to this project and your suggestions critically enhanced the quality of the didactic resource, from conception to execution.

Thank you to my parents, James and Christine, for your unending support and for the incredible examples you have set as professionals, as mentors, and as the most loving of people. I truly would not be where I am today without you, and I cannot express how much I appreciate everything you have done for me. Thank you to my brother, Adam, for inspiring me with your bravery, your intelligence, and your understanding. You will always be my best friend. To my amazing partner, James, you have changed my life. I am in awe of your brilliance, your compassion, and your patience. I could not ask for a better collaborator for life.

Most importantly, to my closest friend, Mary, I can never say thank you enough. This project would not exist without you. Since we were kids, I have been so impressed by your talent, your kindness, and your drive. You have taught me so many things, not just about disability but about true friendship. It has been one of the greatest privileges of my life to be able to work on this project with you. Thank you for letting me be your friend.
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Introduction

Project Inspiration

In June 2017, I was on my way to work when I saw a video posted on social media of my best friend of many years, Mary, in a hospital bed. I immediately messaged Mary to see what had happened and to make sure she was okay. At that point in time, she had been struggling for several years with Celiac disease and I expected her visit to the hospital be related to her episodic severe stomach pain. I certainly did not expect a response from her mother informing me that Mary had suffered a spinal stroke the night before and was now paralyzed.

On reading that message, a numbness washed over me. Mary had just started her dream job a little over a week ago. We had both graduated college only a month prior, ready to take on the challenge of post-graduation life in Philadelphia. Now, as I sat at my work cubicle, I realized that both of our lives had been forever changed.

Mary was being treated in the neurological intensive care unit at a hospital in downtown Philadelphia. I was working just a short subway ride away at a different hospital as a research coordinator in, of all things, pediatric stroke. But, I am sad to say, that I initially decided against visiting Mary in the hospital. I was extremely worried I would say or do the “wrong thing” and I felt that I had no idea how to help her. I had never in my life been in close contact with a person who was paralyzed. I felt I would only make things worse for Mary and that she would somehow be better off without me.

Even though I had decided to stay away, I could not shake the feeling that I needed to be there for Mary, even if I wasn’t sure how to do so. After discussions with my own family, I pushed through my fear and left work early to take the subway down to
see her. I will never forget the first moment I walked into her hospital room. She was lying in bed looking pale, limp, and exhausted. But, she looked up at me and smiled in the same way she always had. She may have looked different, but she was still my best friend.

After she was discharged from the hospital, Mary spent the next several months as an inpatient in a rehabilitation hospital. I visited her every week, often eating meals in the hospital cafeteria and even slept overnight in her room, watching and movies and eating popcorn just as we used to do during sleepover parties in high school. She threw herself wholeheartedly into recovery, dedicating all her energy into physical and occupational therapy. Less than three months from her stroke, Mary regained close to full function of her left arm. However, she remained otherwise paralyzed from roughly below the neck and it became very clear that she would require use of a wheelchair in her everyday life.

Mary was able to return home roughly four months after her stroke and continued intensive physical and occupational therapy as an outpatient. In some ways, adjusting to life at home was harder for her than living at the hospital. She remained positive, however, and slowly began to attempt some of the activities she had previously enjoyed, now with the assistance of her power wheelchair or her smaller wheelchair that required someone to push her.

I was by her side as we both learned what it means to have a disability and use a wheelchair while navigating environments and situations that were previously so easy and familiar. After learning how to strap her wheelchair into her family’s minivan, Mary and I were able to go to the movie theater, wine tastings, or on walks in the park. But we also became aware of the ways in which the built environment we lived in was truly
created for the abled. A simple trip to the movies meant choosing a theater by ensuring there would be access to ramps and elevators. The minivan, while an amazing invention, was often difficult to park due to its size and far too often we would pull into a parking lot and find that someone had parked across the line next to a handicap space, making it impossible to pull out the side ramp of the van so that Mary could exit. She often did not want to bring her power chair to the theater because the back of the chair was tall, and she worried it would block the views of others in the theater. Taking her push chair for the day meant that if I needed to step away briefly, she would be left stranded without the ability to move herself. These many considerations have yet to account for the mental stress for Mary that would come with every outing from the possibility of having to ask employees for alternative routes of access or simply from the stares and stigma of others.

By the time I entered Yale School of Medicine roughly a year after Mary’s stroke, I had learned so much about physical disability in the community setting and I was eager to learn about disability in the healthcare setting. However, while many sessions in the preclinical curriculum were dedicated to explaining the diseases that cause disability and the biological basis of disability, the teaching of the social and practical implications of disability was limited. The standout session was a panel in the second-year curriculum that featured a practicing radiologist who uses a wheelchair, and while it was powerful, it became clear that limited time would otherwise be spent on teaching students about disability. As future providers, my classmates and I were not spending time learning how to foster a strong doctor-patient interaction with patients with disabilities, let alone engaging with the social, ethical, and historical contexts of disability in medicine. With
collaboration from Dr. Andres Martin and Dr. Erin Nozetz, we set out to improve the education at Yale School of Medicine on patients with disabilities.

Background

Over sixty million people in the US have some form of disability, comprising 26% of the general population;\(^1\) those with serious physical disabilities impacting mobility represent half of the total. During 2008-2010, there were 2.9 million children with one or more disabilities, or 4% of all US children under the age of 18.\(^2\) Despite such high prevalence, patients with disabilities have historically experienced inadequate and insensitive care from physicians across medical settings, including primary care.\(^3,4\) Patients with physical disabilities are less likely to receive the same quality of primary care as their able-bodied counterparts.\(^5,6,7\) Surveys of patients with disabilities have shown many lack access to primary care and even during visits are less likely to be asked about health promotion, including functional assessments, inquiries about emotional status, or screening for physical or sexual violence.\(^8,9\) Similar disparities in quality of primary care exist for children with physical disabilities (CWPD), particularly in the areas of screening, prevention, and chronic illness management.\(^10\) There have been improvements in the primary care of CWPD using a family-centered care model,\(^11,12\) but many areas of dissatisfaction persist.\(^13\)

Primary care physicians have demonstrated widely varying levels of comfort in treating CWPDs and many report lack of knowledge and skill as contributing factors.\(^14,15,16,14,17,18\) This lack of comfort among healthcare providers has been observed by patients with disabilities and accounts for low quality of care and difficult healthcare
experiences for patients with disabilities and their families.\textsuperscript{19,20,21,6} A similar lack of comfort and knowledge about patients with disabilities prevails among trainees across healthcare fields, including medical students.\textsuperscript{22,23,24,25,26}

Medical students have less comfort and more negative attitudes towards people with disabilities, as compared to other patient groups.\textsuperscript{23,27} Such negative attitudes are in turn reflective of perceptions by society at large toward people with disabilities—stigmatized views at times reinforced by the medical field.\textsuperscript{28} For instance, quality-of-life measures tend to confound health with function, suggesting that disabled and non-disabled individuals differ in quality of life, when they in fact differ mostly in function. The “ableist conflation” equates disability with suffering and death, and “flattens communication about disability to communication about pain, suffering, hardship, disadvantage, morbidity, and mortality”.\textsuperscript{29}

Other studies have highlighted the fear and anxiety of healthcare students with the challenge of caring for patients with disabilities. Further illustrating the need for improving medical school education on disability, a 2009 survey showed that only 61% of medical school deans reported their graduates as being competent to treat patients with disabilities, and about 56% of medical students felt unprepared to treat patients with disabilities.\textsuperscript{30} Multiple factors, ranging from female gender to personal experience with disability, have been shown to predict increased comfort of medical students.\textsuperscript{24} However, authors of these same studies have identified the most modifiable factors to be experience and education with patients with disabilities, calling for educational interventions to ameliorate fear and increase positive attitudes in order to improve the quality of care of
these patients. In other words, a potent counterfactual and remedy to biased narratives and stigma is “an immersion in the personal testimonies of disabled people.”

In 2005, the Surgeon General issued a call for improved care for people with disabilities, including the development of medical school curricula to teach clinicians about best practices. In response, some medical schools and residency programs have developed targeted curricula focusing on treating patients with disabilities. One noteworthy yet resource-intensive approach consists of a multi-year curriculum that incorporates clinical training and simulations. Others have found that even a 30-minute lecture and patient panel can increase medical student knowledge and comfort levels. A Task Force on Disability Education of Medical Students was formed in 2016 and recently provided recommendations to address the problem of insufficient medical education on the treatment of patients with disabilities. These recommendations urged the development of improved competency-based teaching in medical schools.

Despite these efforts, most medical curricula lack educational content focused on children with physical disabilities. To address this gap, we developed an educational resource that incorporates embedded videos featuring simulated participants (SPs) designed for implementation in the curriculum at Yale School of Medicine. We then measured the impact of this intervention on healthcare students’ knowledge and comfort treating CWPDs.
Statement of Purpose

To develop tips for providers on treating patients with disabilities using the expertise and input of various stakeholders in the disability community and to create and evaluate a new educational resource enhanced by videotaped clips of a model pediatric outpatient visit for a child with physical disabilities for inclusion in the curriculum of the Yale School of Medicine

Methods

Student Contributions

I have been involved in every part of this thesis project, from conception to execution of the research. Working in collaboration with Dr. Martin, I conceived of the idea to create a workshop that would teach medical students about disabilities using video clips of simulated patients as a model. I performed the background literature search to assess the state of medical education on disability and to identify educational resources available from other institutions. Through this literature search, I identified several existing approaches from other institutions, ranging from a patient panel to direct interactions with simulated patients. However, I also discovered few resources focused on the treatment of children with physical disabilities and identified this as an area for potential improvement and the focus of this thesis project.

After deciding on this focus for the workshop, I began to identify potential members of a curriculum working group who could provide their thoughts on important elements of the project to highlight, as described below. I recruited members of advocacy organizations for children with disabilities as well as physician and research experts in disability. I met with each member of the curriculum working group individually to
obtain their perspectives and recommendations for the most important points about treating children with physical disabilities that should be included in healthcare student education. Using extensive notes taken during each discussion, I synthesized the principles most emphasized into the “Top Ten Things Patients with Disabilities Want Their Doctors to Know” section of the results presented in this thesis. I also used these principles as the basis for important points to highlight in the video clips as well as the slide deck developed for the workshop.

I decided to use the video clips to depict a model well-child outpatient visit for a child in a wheelchair and his mother, portrayed by simulated patients. I created the characters of Jacob—a twelve-year-old boy with bilateral paralysis of his lower extremities after a case of transverse myelitis—and his mother, Martha. I wrote a draft of the script for the video using the principles I identified from the curriculum working group. With the feedback and suggestions of Dr. Jaideep Talwalkar and Dr. Erin Nozetz, I finalized the script, which consisted of five scenes corresponding with significant segments of an outpatient visit: rooming the patient, obtaining a history of present illness, taking a health history, performing a physical exam, and closing the visit.

Dr. Martin, as the Director of the Simulated Participant Program, recruited the actors for the videos from a local improvisation theater group that had previously worked with the Simulated Participant Program. He also obtained approval for the child actor in the videos to be the first child actor to ever work as a simulated participant at the Yale School of Medicine. We also recruited Dr. Nozetz to act as the physician in the videos. After casting the actors, Dr. Martin worked with the staff of the Simulated Participant
Program and the Yale Simulation Center to reserve the simulation rooms and to hire a video production crew to film the videos.

Filming of the videos occurred in September 2020 in full compliance with the Yale university guidelines on COVID-19. Dr. Martin and I directed the actors and the film crew, as well as approved of each section of takes to ensure that the important teaching points in each section were sufficiently covered. Once filming completed, the videographer Travis Carbonella of New Haven, CT edited the raw footage into the final video clips used in the workshop. The videos can be accessed using the QR code and URL links provided in Appendix 1.

![Image from filming of the video component of the educational resource, September 2020](image)

**Figure 1.** Image from filming of the video component of the educational resource, September 2020

Filming of the addendum video “Interview with a Disability Advocate” occurred in December 2020. My brother, Adam Kimmel served as the videographer, director, and
editor of the video. I recruited my friend and member of the curriculum working group, Mary Salisbury, to participate as the disability advocate and I served as the interviewer.

Figure 2. Still image from “Interview with a Disability Advocate” addendum video

With the help of Dr. Martin, I created a Qualtrics survey with multiple instruments to evaluate healthcare students’ attitudes, knowledge, and satisfaction with our workshop. I identified multiple validated instruments for evaluating the attitudes of healthcare students towards patients with disabilities. I also created multiple-choice questions using content we planned to cover in the workshop to evaluate students’ knowledge of patients with disabilities.

I then submitted an application to the Yale IRB committee for exemption of the project from review. Once the study was deemed exempt by the IRB, I obtained approval for the project from the Yale School of Medicine Teaching and Learning Center, as we planned to include Yale medical students in our study population.

Working with Dr. Nozetz and Dr. Martin, I created a PowerPoint slide deck that interspersed the video clips with additional considerations for the care of children with physical disabilities, including information on topics such as transverse myelitis, the
Americans with Disabilities Act, and the SSHADESS assessment for adolescents. We also developed additional group discussion questions based on the content of the video clips to help students engage more actively with the material. The final product is a roughly fifty-minute workshop that uses the video clips, slide deck, and discussion questions to help students approach the interaction with and care of children with physical disabilities. The workshop is adaptable to both the traditional lecture format with a large-group or to small “buzz group” workshops. I created a facilitator’s guide that details how to use the videos and slide deck in each format.

We decided to conduct the study of the workshop during a voluntary evening session in February 2021. I recruited study subjects by sending emails advertising the event to the members of the Yale School of Medicine Pediatrics Interest Group and Physical Medicine and Rehabilitation Interest Group. I also sent emails to students in the Yale Physician Assistant Program, the Yale School of Nursing, and the Quinnipiac School of Medicine Child Psychiatry Interest Group. Dr. Martin supplied funding to provide gift cards to Grubhub in the amount of fifteen dollars each to students who signed up for the workshop.

The study of the workshop was conducted over the online synchronous videoconferencing platform Zoom and one hundred healthcare professions students were in attendance. Dr. Nozet led the workshop while I was responsible for managing the videos and the slide deck. Students completed the Qualtrics survey I designed with Dr. Martin both before and after the workshop. After completion of the workshop and the survey, the session transitioned to a discussion with a panel of patients with disabilities.
and disability advocates. I organized and recruited the members of the panel, which included several of the members of the curriculum working group.

After conclusion of the session, Dr. Martin obtained the data from the Qualtrics survey and completed the statistical analysis. In collaboration with the other members of the curriculum working group including significant edits from Dr. Martin and Dr. Jaideep Talwalkar, I wrote all material presented in this thesis.

Ethics approval
The study was deemed exempt from review by the Yale Human Investigations Committee (Protocol # 2000028161). Participation was voluntary, responses were anonymous, and individual survey results were not accessible to faculty responsible for any course evaluations.

Curriculum Working Group
In keeping with the tenets of participatory research\textsuperscript{38} and the notion of “nothing about me without me”,\textsuperscript{39} the curriculum was designed in conjunction with a working group of multiple stakeholders. The group included disability advocates, adult patients with physical disabilities, and parents of CWPDS, as well as faculty with complementary expertise in caring for CWPDS, clinical skills education, and curriculum design using simulated participants.

The curriculum working group was formed by direct recruitment of members of the disability community as well as experts in the fields of disability advocacy, complex care, pediatrics, medical education. The list of members of the working group are as follows: Mary Salisbury, disability advocate and proud wheelchair user; Tesha Tramontano-Kelly, Executive Director of the Connecticut Family Support Network and
parent of a child with disabilities; Laura Knapp, Transition Coordinator of the Connecticut Parent Advocacy Center and parent of a child with physical disabilities; Kelly and Justin Cohen, parents of a child with physical disabilities; Dr. Lisa Honingfeld, PhD, Vice President for Health Initiatives at the Child Health and Development Institute of Connecticut; Dr. Oluwaferanmi Okanlami, MD MS, Assistant Professor of Family Medicine, Physical Medicine & Rehabilitation, and Urology, Director of Services for Students with Disabilities, and Director of Adaptive Sports and Fitness at the University of Michigan Medical School and proud wheelchair user; Dr. Erin Nozet, Assistant Professor in General Pediatrics at the Yale School of Medicine with expertise in the care of children with special health needs and in medical education; Dr. Jaideep Talwalkar, Associate Professor of Internal Medicine and Director of Clinical Skills, Medical Education at the Yale School of Medicine; and Dr. Andres Martin, MD MPH, Riva Ariella Ritvo Professor in the Child Study Center and Professor of Psychiatry and Director of the Simulated Patient Program, Teaching and Learning Center of the Yale School of Medicine.

Development of Tips for Providers

Individual interviews were conducted with each member of the curriculum working group. Each member was asked the standardized question: “What do you think medical students should know about taking care of patients with disabilities?” Extensive notes were taken during the interviews and used to identify ten themes across all responses that could be synthesized into tips for healthcare providers from members of the disability community.
Educational Resource

We created an educational resource with four objectives for learners: 1) Identify key areas of differences and similarities in the outpatient care of a child in a wheelchair, as compared with the care of a child without physical disabilities; 2) Develop a framework for how to talk about disability with CWPD; 3) Use a family-centered model for interacting with CWPD and their families; and 4) Recognize important aspects and modifications of the physical exam of a CWPD.

The resource includes video clips, factual information, handouts, and discussion prompts to stimulate conversation among learners during a 50-minute workshop on treating CWPDs. The slide deck, facilitator guide, and video clips for the workshop are accessible using the QR codes and links in Appendix 1.

The video clips depict a detailed, model primary care visit conducted by one of the coauthors (EN), a pediatrician experienced in treating CWPD. The patient and parent in the video depictions are hired professional actors familiar working in medical settings. We followed accepted best practices for SPs,\textsuperscript{40} taking particular care to abide by the additional practical, legal, and ethical considerations for working with underage actors.\textsuperscript{41} The actors were recruited from a local community acting group. We were unable to find a child actor with a disability within the time constraints of the project, necessitating our hiring of an able-bodied child instead.

The video-based component consists of nine clips plus a supplemental interview with a disability advocate who uses a wheelchair. The different video components, described in Table 1, are available through a dedicated web-based platform.
Table 1. Video clips for child with physical disability didactic resource

<table>
<thead>
<tr>
<th>Clip</th>
<th>Scene / content</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a</td>
<td>Rooming the patient</td>
<td>0 50</td>
</tr>
<tr>
<td>1b</td>
<td>Opening the interview</td>
<td>2 23</td>
</tr>
<tr>
<td>2a</td>
<td>Talking about disability</td>
<td>3 13</td>
</tr>
<tr>
<td>2b</td>
<td>Taking a history</td>
<td>4 3</td>
</tr>
<tr>
<td>3a</td>
<td>Transition to physical exam</td>
<td>1 10</td>
</tr>
<tr>
<td>3b</td>
<td>Discussion of puberty</td>
<td>5 6</td>
</tr>
<tr>
<td>3c</td>
<td>Physical exam</td>
<td>2 28</td>
</tr>
<tr>
<td>4</td>
<td>Family-centered care</td>
<td>3 34</td>
</tr>
<tr>
<td>5</td>
<td>Closing the visit</td>
<td>2 40</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>25 27</strong></td>
</tr>
</tbody>
</table>

**Addendum**  Interview with disability advocate  8 55

*Note:* All clips are available for viewing or download at Figshare using QR code and link found in Appendix 1

![Still image from the “Rooming the Patient” video clip](image)

Figure 2. Still image from the “Rooming the Patient” video clip
Participants and Data Collection

Participants were healthcare students enrolled in the Yale Schools of Medicine or Nursing. We recruited volunteer learners via emails sent to relevant interest groups, as well as to the online physician assistant (PA) and nursing school programs. We conducted the workshop during the COVID-19 pandemic, delivering content virtually through the video-conferencing platform Zoom (San Jose, CA). Students were given 10 minutes before and after the session to complete the surveys described below. We collected information securely into Qualtrics (Provo, UT).

Outcome Measures

We selected survey and free-response items to assess change in participant attitudes toward, and knowledge of CWPD, as well as to evaluate student satisfaction with the workshop.
To assess attitudes, participants completed the *Disability Attitudes in Health Care (DAHS)*\(^4\) at baseline. The DAHS is a 17-item instrument used to measure baseline attitudes unrelated to curricular content or to previous experiences with disability and has good internal consistency (Cronbach α, 0.74). We obtained the norms for the instrument were Table 2 of the original publication. Participants also completed the *Attitudes to Disabled Persons - Original (ATDP-O)*\(^3\) at baseline and endpoint. The ATDP-O is a widely used instrument that has been shown to have good internal consistency (Cronbach α, 0.91) and sensitivity to change. The ATDP-O has 20 items, for which respondents indicate how strongly they agree or disagree on a six-point Likert scale with statements about individuals with disabilities; some of the items are reverse-coded to prevent response acquiescence bias. We followed the scoring and norms for the ATDP-O instrument from Table 6 of the original publication by Yuker *et al* (1970). Finally, for a more textured assessment of attitudes, we asked learners before and after the workshop to provide the first three words or short phrases “that come to mind when hearing ‘child on a wheelchair’”.

To assess knowledge, we asked participants to answer five multiple-choice questions written by the working group and corresponding to content information covered in the workshop. Finally, to assess satisfaction with the workshop, we asked participants to rate the session using six items on a Likert scale, as well as one optional free-text response field in which to express any thoughts, feedback, or suggestions.

*Statistical Analysis*

We analyzed data using SPSS version 25 (Armonk, NY). We compared responses from baseline to endpoint using paired-t tests and Cohen’s *d* effect sizes. We used word cloud
generator software (wordclouds.com; Zygomatic Inc., Vianen, The Netherlands) to visually depict participants’ word choices before and after the workshop. We manually coded the words into three emotional valence categories (Kitay et al, 2020; Fuehrlein et al, in press).
Chapter One: Ten Things Patients with Physical Disabilities and Their Caregivers Want Their Healthcare Providers to Know

1. “Talk directly to me. Having a disability does not mean I am incapable of speaking for myself.”

My physical disability does not mean that I also have a mental disability. Talking to my caregiver or parent in the room instead of me makes me feel unseen. I want to know you care about my perspective on my own health and that I can make my own decisions about my body, just like any other able-bodied patient.

Sit down, look me in the eye, and do not be afraid to comfort me the way you would any other patient. I will come back to doctors who treat me with respect and are willing to interact with me as an equal, rather than being put off by differences in my physical abilities.

2. “Every disability is different.”

People with the same type of disabilities can have very different levels of function. For example, two people with an injury at the same level of their spinal cords might be able to move or feel things in different parts of their bodies from one another. One disability does not automatically equal another.

Please don’t assume that just because someone has a physical disability, they can’t do something. I might surprise you with the ways I am able to adapt and overcome my physical limitations. Ask me if I need help before assuming that I do. When you ask me questions, I know that you care to learn about me and my unique abilities.

3. “My disability shouldn’t be the ‘elephant in the room.’”
Sometimes doctors seem to think that it is more polite not to talk about my
disability. I live with my disability every day and know it is there. It is an
important part of my health and I want to talk about it—but I don’t want it to be
the only thing we talk about.

Don’t be afraid to ask me about my abilities and how I accomplish my
day-to-day activities. If I need help with my daily activities, it’s also important to
ask me how I feel about that. For example, you could ask: “Somebody helps you
go to the bathroom. How does that work for you?” Listen carefully to how I talk
about my disability and take cues from what I say. If you use the language I use to
talk about my disability, it makes me much more comfortable and shows me that
you’re listening to me.

4. “If you don’t know something about my disability, be honest and be willing to
ask.”

I know that there are many forms of disabilities and that every person with a
disability is different. I don’t expect you to know everything about what my
disability is or what it means for my life. It’s okay to sit down with me or my
caregiver and ask questions to learn about my condition.

For example, some of us have “sensory issues,” which can mean many
different things that are important to our experience of healthcare. If I am meeting
you for the first visit and you don’t know what “sensory issues” means for me, I
am happy if you are honest and ask me. I like it when doctors ask me questions
like: “Let’s walk through this together, how can we help you to make this a good
experience?” or “Is this your first time in the situation?” or “What works best for you?”

5. “Please take the time to make your office welcoming, from entrance to exit.”

For some of us, it is a huge undertaking to even get in the car to go to the doctors’ office. Long flights of stairs and small rooms with no space to turn a wheelchair around are just a few of the things that can make a visit to the office even more stressful. Small accommodations go a long way for my comfort. Rooms with movable furniture and space for my chair next to the bed, signs with instructions and pictures that are easy to understand, and staff members who know the most accessible routes through the office so that I don’t have to figure that out by myself are all things that go a long way. It is also always nice to be mindful of where you sit. For instance, if I have limited ability to turn my body or have a decreased vision or hearing on one side, please sit in a place that allows me to look at you and speak with you comfortably.

The anxiety of entering the doctors’ office can also occur from interacting with front desk staff. When I must look up and might not be able to see the staff because of the height of the front desk, it can make me feel small and insignificant. Sitting in a waiting room surrounded by other patients who are able-bodied can also make me uncomfortable. Offering appointments early or late in the day and training office staff to know that my visit will likely take additional time can be very helpful. The doctors’ office can be a very stressful place for me and I might need a little extra support.
6. “Sometimes I want you to be the expert and sometimes I want you to recognize that I am the expert.”

Doctors can be an important model for how to approach the many health needs that I have. Encourage me and my family to be organized, to keep track of my many appointments and the details of my care plans, and to write down my questions and concerns ahead of time so that I can better understand your recommendations. You can also be an important source of reminders that I have many strengths. Please stay informed of the resources that are available to help me. I am the expert in my body, but I am still seeking advice from you.

If I or my caregiver have a concern, please listen. I live with my disability every day and know the unique aspects of my body very well. Listen to our gut instincts—if I or my caregiver think something is wrong, it probably is. My body and my health are complex. Please do not make snap judgements or dismiss my concerns based only on the information in a textbook.

7. “My disability is not my entire life.”

A teenager with a disability is still a teenager! I have interests, hobbies, and relationships outside of my disability that still play an important role in my health. Doctors often get so focused on my disability that they forget to ask me the questions they would ask their other able-bodied patients. Please make sure to ask me about my social relationships, physical activity, occupation, schoolwork, drug use, or sexual development. Even if I have a disability I might still have many questions about puberty or how to eat healthy and lose weight, for example.

8. “My mental health is just as important as my physical health.”
Don’t just emphasize my physical wellness. My mental health is equally important. Living with a disability can be very difficult. Going to the movies or out to eat, for example, might cause me anxiety because I worry about other people staring at me. School and work can be even more stressful for me because I might need accommodations that can be difficult to get, or I might feel that the people around me are judging me for needing accommodations in the first place. For some of us, having a body that doesn’t fit other people’s definition of “normal” can have a negative effect on our mental health and it might cause anxiety or depression.

If I am depressed or anxious, it might also have nothing to do with my disability. I might be struggling with my mental health because of my job, or my relationship, or any number of reasons. Just because I have a physical disability does not mean I am mentally unwell. No matter what the reason is, I will always appreciate if you care about my mental health as much as you care about my physical health.

9. “The physical exam can be an uncomfortable part of the visit for anyone, but it can be even more difficult for me.”

I may be very uncomfortable with the physical exam and your understanding and accommodations can make a big difference for me. I or my caregiver will know the best way for me to transfer to the exam table. Please ask me what would work best and have additional staff available if some additional assistance is needed to lift me onto the table. Getting into a gown might be both physically difficult and stressful for me, so please allow me the privacy to do so without feeling rushed.
I might have more pain or anxiety with sitting or lying on the table that other patients. Small gestures can go a long way to help, like offering me a pillow to support my legs or offering me some assistance with laying back or rolling onto my side. Please always tell me what you are going to do before you do it. Most people don’t like to be touched without warning, and for me it can be even more scary or uncomfortable. I might have sensory issues that make being touched or moved even more difficult. Letting me know what you are going to do and why can be very helpful. Asking “What can I do to make this exam more comfortable for you?” can make a big difference.

10. “Caring for me is more similar than it is different.”

It’s important to me that you treat me with the same care that you treat your other patients. I want you to be my partner in taking care of my health and to know you’re on my team. You don’t need to change your approach just because I might use a wheelchair or need other accommodations. I may be physically different from other patients, but at the end of the day I want the same care and kindness from my doctors as any able-bodied patient.
Chapter Two: Assessment of the Video-Based Educational Resource Using Simulated Participants

Forty-nine healthcare students completed the survey: 29 (59%) from medicine, and 21 (41%) from physician assistant or nursing programs. Students came from across the spectrum of their 2- to 4-year programs, though we did not collect individual-level to protect participant anonymity. The baseline characteristics of the students are summarized in Table 2.

<table>
<thead>
<tr>
<th>Table 2. Basic Characteristics (n = 49)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Profession</strong></td>
</tr>
<tr>
<td>Medicine</td>
</tr>
<tr>
<td>Physician Assistant</td>
</tr>
<tr>
<td>Nursing</td>
</tr>
<tr>
<td><strong>Ever involved in the care of a child with a physical disability</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td><strong>Have a friend or relative who is a child or a parent of a child with a physical disability</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td><strong>Has a physical disability</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>

Baseline scores on the DAHS did not differ from published norms: 67.2 ± 3.9 vs 66.5 (single sample t = 1.25, ns). ATDP-O scores improved between baseline and endpoint: from 31.2 ± 8.9 to 34.8 ± 10.1 (mean difference = 3.6 [95% confidence interval = 1.4 - 5.8], paired t = 3.28, p = 0.002, Cohen’s $d = 0.38$). Table 3 summarizes item-level changes before and after the intervention.
Table 3. Change on the Attitudes to Disabled Persons Original (ATDP-O) after training intervention (n = 49)

<table>
<thead>
<tr>
<th>Item</th>
<th>Prompt</th>
<th>PRE</th>
<th>SD</th>
<th>POST</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Parents of disabled children should be less strict than other parents</td>
<td>2.8</td>
<td>0.4</td>
<td>2.9</td>
<td>1.2</td>
</tr>
<tr>
<td>2</td>
<td>Physically disabled persons are just as intelligent as non-disabled ones</td>
<td>2.6</td>
<td>0.6</td>
<td>2.8</td>
<td>0.8</td>
</tr>
<tr>
<td>3</td>
<td>Disabled people are usually easier to get along with than other people</td>
<td>2.5</td>
<td>0.9</td>
<td>2.7</td>
<td>1.0</td>
</tr>
<tr>
<td>4</td>
<td>Most disabled people feel sorry for themselves</td>
<td>2.5</td>
<td>1.2</td>
<td>2.5</td>
<td>0.9</td>
</tr>
<tr>
<td>5</td>
<td>*Disabled people are the same as anyone else</td>
<td>2.3</td>
<td>0.7</td>
<td>2.4</td>
<td>1.1</td>
</tr>
<tr>
<td>6</td>
<td>*There shouldn't be special schools for disabled persons</td>
<td>2.2</td>
<td>0.9</td>
<td>2.4</td>
<td>0.7</td>
</tr>
<tr>
<td>7</td>
<td>*It would be best for disabled persons to live and work in special communities</td>
<td>2.1</td>
<td>1.2</td>
<td>2.2</td>
<td>0.9</td>
</tr>
<tr>
<td>8</td>
<td>It is up to the government to take care of disabled persons</td>
<td>2.1</td>
<td>1.5</td>
<td>2.0</td>
<td>1.4</td>
</tr>
<tr>
<td>9</td>
<td>Most disabled people worry a great deal</td>
<td>1.9</td>
<td>1.3</td>
<td>1.9</td>
<td>1.2</td>
</tr>
<tr>
<td>10</td>
<td>*Disabled people should not be expected to meet the same standards as non-disabled people</td>
<td>1.8</td>
<td>1.1</td>
<td>1.9</td>
<td>1.1</td>
</tr>
<tr>
<td>11</td>
<td>*Disabled people are as happy as non-disabled ones</td>
<td>1.7</td>
<td>1.4</td>
<td>1.9</td>
<td>1.4</td>
</tr>
<tr>
<td>12</td>
<td>*Severely disabled people are no harder to get along with than those with minor disabilities</td>
<td>1.6</td>
<td>1.5</td>
<td>1.8</td>
<td>1.4</td>
</tr>
<tr>
<td>13</td>
<td>It is almost impossible for a disabled person to lead a normal life</td>
<td>1.5</td>
<td>1.7</td>
<td>1.5</td>
<td>1.9</td>
</tr>
<tr>
<td>14</td>
<td>You should not expect too much from disabled people</td>
<td>1.3</td>
<td>1.6</td>
<td>1.4</td>
<td>1.1</td>
</tr>
<tr>
<td>15</td>
<td>*Disabled people tend to keep to themselves much of the time</td>
<td>0.8</td>
<td>1.8</td>
<td>1.3</td>
<td>1.7</td>
</tr>
<tr>
<td>16</td>
<td>Disabled people are more easily upset than non-disabled people</td>
<td>0.5</td>
<td>1.5</td>
<td>0.9</td>
<td>1.9</td>
</tr>
<tr>
<td>17</td>
<td>*Disabled persons cannot have a normal social life</td>
<td>0.4</td>
<td>1.8</td>
<td>0.7</td>
<td>1.4</td>
</tr>
<tr>
<td>18</td>
<td>*Most disabled people feel that they are not as good as other people</td>
<td>0.3</td>
<td>1.7</td>
<td>0.6</td>
<td>1.6</td>
</tr>
<tr>
<td>19</td>
<td>*You have to be careful of what you say when you are with disabled people</td>
<td>0.2</td>
<td>1.5</td>
<td>0.6</td>
<td>1.5</td>
</tr>
<tr>
<td>20</td>
<td>*Disabled people are often grouchy</td>
<td>0.2</td>
<td>1.5</td>
<td>0.4</td>
<td>1.6</td>
</tr>
<tr>
<td>Total</td>
<td>Range: 0 - 60 (higher scores = more positive / less stigmatized attitudes)</td>
<td>31.2</td>
<td>8.9</td>
<td>34.8</td>
<td>10.1</td>
</tr>
</tbody>
</table>

Note: adapted from Yuker et al., 1970. Values range from 0 to 3 at the item level, with higher scores indicating more positive / less stigmatized attitudes; asterisks denote reverse scoring. Items are presented ranked by baseline scores, from highest to lowest. Total score change between time points: paired t = 3.28, p = 0.002, Cohen's d = 0.38.

Figure 1 provides a visual rendering of all words written in by learners before and after the workshop. Words are weighted by frequency and highlighted in colors, each of
three representing a different emotional valence: red, negative; blue, positive; white, neutral. The results of the knowledge assessment are summarized in Table 4.

Figure 4. (Panel A, Before)
Figure 4. (Panel B, After)
Participants rated the workshop highly on the post-session survey. Free responses were uniformly positive, and representative verbatim quotes included: “Thank you for doing this: I wish it could be part of our pre-clinical skills course”; “Short videos with commentary following was a great way to address the material”; “This was extremely insightful and definitely something that was lacking from our education. Please continue to share these opportunities with students at the school of nursing, we really appreciate being included”; and “As a sibling of someone with a disability, I really appreciate the balance between treating someone in their unique situation while also normalizing their experiences and letting them have a voice.”

Table 4. Change on knowledge assessment questions after training intervention (n = 49)

<table>
<thead>
<tr>
<th>Prompt</th>
<th>PRE</th>
<th>POST</th>
<th>McNemar test</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the name of the civil law passed in 1990 prohibiting discrimination against individuals with disabilities in public spaces?</td>
<td>n correct: 43, % correct: 88</td>
<td>n correct: 48, % correct: 98</td>
<td>0.063</td>
</tr>
<tr>
<td>Which of the following statements about acute transverse myelitis in children is NOT correct?</td>
<td>n correct: 39, % correct: 80</td>
<td>n correct: 43, % correct: 88</td>
<td>0.289</td>
</tr>
<tr>
<td>A “medical home” is defined as…</td>
<td>n correct: 29, % correct: 62</td>
<td>n correct: 42, % correct: 86</td>
<td>0.002</td>
</tr>
<tr>
<td>Which of these statements is true of urinary retention in patients with transverse myelitis?</td>
<td>n correct: 11, % correct: 22</td>
<td>n correct: 18, % correct: 37</td>
<td>0.167</td>
</tr>
<tr>
<td>During a skin assessment, you observe an area of open skin that has formed a tender, painful ulcer on the coccyx of a child who uses a wheelchair. Which stage of pressure ulcer did you observe?</td>
<td>n correct: 22, % correct: 45</td>
<td>n correct: 20, % correct: 41</td>
<td>0.611</td>
</tr>
</tbody>
</table>
Discussion

Our novel video-enriched curriculum resulted in improved attitudes about caring for children with physical disabilities and was met with high student satisfaction. Participation in the virtual workshop resulted in healthcare students’ positive shift in attitudes and preconceived notions. The improvement was not only statistically significant, but clinically meaningful as well—as reflected by a medium effect size of 0.38. Students also exhibited a shift in views, moving from approaching CWPDs as “different” and “challenging” to seeing them “normal” and “resilient,” indicating a reduction in stigmatized views. Learners gained a sense that the interpersonal approach to patients with physical disabilities need not differ greatly. Indeed, such an insight is by design at the crux of the workshop; namely, that the treatment of patients with disabilities should at its core be interpersonally the same as that for able-bodied patients, while recognizing and maintaining respect for inherent differences. This message was felt by the member of our curriculum working group who identify as part of the disability community to be perhaps the more important lesson to impart to healthcare students. However, there are multiple considerations unique to the care of CWPDs that we identified and highlighted in the workshop, that we have compiled as key points in Table 5.
<table>
<thead>
<tr>
<th></th>
<th>Clinical considerations in the care of children with physical disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Ensure the physical setting meets the child's accessibility needs</td>
</tr>
<tr>
<td>2</td>
<td>Be ready to make appropriate accommodations, adjustments, or referrals</td>
</tr>
<tr>
<td>3</td>
<td>Sit down in order to address the child at eye level; don't hover over</td>
</tr>
<tr>
<td>4</td>
<td>Address the child and not only the parent or caregiver</td>
</tr>
<tr>
<td>5</td>
<td>Address lifestyle questions, including SHADES (Sexual Health and Disability Education)</td>
</tr>
<tr>
<td>6</td>
<td>Is the clinical setting a medical home? If not, is there one worth referring to?</td>
</tr>
<tr>
<td>7</td>
<td>Take note of the language the patient and family use to speak about their abilities and disability</td>
</tr>
<tr>
<td>8</td>
<td>Don’t hesitate to ask directly about disability</td>
</tr>
<tr>
<td>9</td>
<td>Establish a clear understanding of baseline functioning and needed supports (e.g. wheelchair, feeding tube, etc.)</td>
</tr>
<tr>
<td>10</td>
<td>Consider the role of care coordination in child's overall care</td>
</tr>
<tr>
<td>11</td>
<td>Include developmental and nutritional history; address anticipatory guidance</td>
</tr>
<tr>
<td>12</td>
<td>Ensure family is aware of relevant legislation and rights, particularly ADA[^1], which prohibits discrimination and sets minimal standards for building accessibility</td>
</tr>
<tr>
<td>13</td>
<td>Considerations for the physical exam: be intentional and planful about moving to exam table; do not conduct in wheelchair; establish a thorough baseline of function, particularly on first visit; skin exam is particularly important (with special attention to pressure ulcers)</td>
</tr>
<tr>
<td>14</td>
<td>What to do if you make a mistake: we are all human; recognize the error, apologize, and move on</td>
</tr>
<tr>
<td>15</td>
<td>Puberty and sexuality: open channels of communication; normalize, normalize, normalize</td>
</tr>
<tr>
<td>16</td>
<td>Family-centered considerations: recognition of individual strengths; each family is unique; listen thoughtfully to parent concerns; don’t be afraid to ask the hard questions</td>
</tr>
<tr>
<td>17</td>
<td>The most important take-aways: there are more similarities than differences; it’s OK to ask; it’s OK to make a mistake; the principles of providing quality, compassionate patient care are the same as with non-disabled patients</td>
</tr>
</tbody>
</table>


---

Participating students voluntarily attended the workshop outside of classroom time and may represent a biased sample. Students with greater interest in the subject
matter might have been more likely to attend, have more knowledge and less stigmatized views at baseline, and report higher satisfaction. However, in spite of this likely bias in sampling, we documented improvements in attitudes after participation in the workshop.

The changes we found in knowledge were not as clear as those for attitudes. The only item with a significant change pertained to the definition of a medical home. We bumped into a ceiling effect for two of the other questions, for which correct responses at baseline were already at over 80%. The correct answer may have been too subtle for one of the questions (staging of pressure ulcers), and the content not addressed clearly enough for the fifth question.

Learners expressed overall satisfaction with the workshop and rated the session highly on all items, including that the workshop contributed to their learning and addressed gaps in their education. Free responses were also uniformly positive, with students expressing that the workshop covered “something that was lacking from our education” and that it “should be incorporated into training for everyone.” Multiple students highlighted the format of videos interspersed with discussion as a “superb, realistic, and useful” method for teaching the material and stated they “would love to attend more of these types of simulations with patients with other types of disabilities.” The video clips presented multiple springboards for rich discussion, including aspects of the model visit that did not completely reflect best practices. One such point is that the guardrail on the side of the patient’s bed was not raised during the physical exam in order to maximize patient safety. Another is that while the physician in the video is a model for interacting with a child with a physical disability, even as an expert there were instances in which she assumed the patient would be unable to perform a task before asking, such
as during discussion of transfer to the exam table, when the physician asked how best to assist before confirming if any assistance was in fact needed.

Limitations

We recognize several shortcomings. First, we acknowledge that one of our two professional actors was an able-bodied child, a shortcoming we made explicit at the end of the workshop (and in the addendum interview). We were not able to recruit a CWPD to serve as a SP, but are committed to doing so in future iterations, following guidelines for “authentic representation” set forth in an influential white paper advocating for the employment in television of actors with disabilities.46

Second, we filmed the workshop in the midst of the COVID-19 pandemic. In order to ensure safety, all participants wore face masks. Masks did not affect the sound quality, but they limited some facial expressions and non-verbal communication. At the same time, they provided a “time stamp” to the pandemic year during which produced these enduring videos.

Next steps

Our materials focus on the experience of a single child who uses a wheelchair during an outpatient clinic visit. Even as this workshop enhanced healthcare students’ attitudes of CWPD, we consider this but a first step in the development of a curriculum that properly prepares students to provide quality, compassionate care for patients with all forms of disabilities. Our work is aligned with the transformative potential of “disability-conscious medical education, training, and practice,”47 which draws on insights from intersectional disability justice activism.48 However, we do not address the many other forms of disability, including physical, cognitive, or emotional. A natural next step will be to
develop additional curated materials that focus on the treatment of patients with cognitive or emotional disabilities, as well as those with concurrent physical and cognitive disabilities. We recognize the disability community is broad and varied, and how the materials we developed for this study represent only a start at improving medical education efforts designed to increase the quality and sensitivity of healthcare delivered to patients with physical disabilities.

We also recognize the importance of direct student exposure to, and engagement with patients with disabilities, given that “only when healthcare providers, educators, and students are routinely and meaningfully exposed to the perspectives of people with disabilities can they develop a consistent proficiency in diagnosing and treating ableism, in their profession generally, as well as in their own practice.” After the didactic and collection of endpoint measures, we had an additional, 30-minute, unstructured discussion with a panel of individuals with living experience with physical disability: two adults on wheelchairs and the parents of a child with physical disabilities. Since our goal was to evaluate the new didactic materials, we excluded the panel component from our pre/post outcome measures. However, we encourage incorporating, whenever possible, a patient and/or parent panel as a synergistic complement to the videotaped materials embedded in the workshop. For situations in which access to suitable volunteer panelists or disability advocates is not feasible, instructors can use the filmed discussion about one of the co-author’s experiences navigating the healthcare system as a person who uses a wheelchair.

Our workshop has been formally incorporated into the Yale pediatrics clinical clerkship curriculum required for all medical students. As more students participate in the
workshop, we hope to measure behavioral change, which we did not do in this initial study.

We have also sought to share our curriculum with other medical institutions. We presented the curriculum at Pediatrics Grand Rounds at both the University of California Los Angeles (UCLA) and Vanderbilt University. The curriculum has also been part of a plenary session presentation at the Association of American Medical Colleges Regional Medical Education Conference. We are also collaborating with our peers at UCLA to establish a national working group focused the development disability curricula for medical schools. The working group includes members from Yale, UCLA, University of Texas Medical Branch, Brown Alpert School of Medicine, the Pennsylvania State University School of Medicine, and the University of Michigan School of Medicine. Together we meet on a quarterly basis to exchange ideas and educational resources. We plan to continue cultivating these relationships, as well as actively seek and establish opportunities for collaboration with other medical institutions throughout the nation.

We are also expanding our efforts within the Yale School of Medicine curriculum to develop new materials that address other types of disability. This author has formed a group along with Dr. Erin Nozetz and two current second-year medical students (Harry Doernberg and Nora O’Neill) to create additional sessions for the medical school curriculum that focus on various aspects of disability. This author has developed a fifty-minute workshop similar to the workshop developed in this thesis that uses a mixture of video clips, slide content, and discussion questions to address some of the principles of treating patients with intellectual disabilities. The workshop focused on intellectual disabilities has been formally incorporated into the Across the Lifespan block of the
preclinical curriculum for second-year medical students and has been met with positive feedback.

Other sessions our group has developed include a case-based workshop in the Professional Responsibility course for first-year students that discusses some of the ethical considerations for obtaining informed consent from a patient with intellectual and physical disabilities. Our group has also assisted with modifying the existing patients with disabilities panel, which is part of the Clinical Skills curriculum for second-year students. Working with the leaders of the Clinical Clerkships, we recently assisted in creating a precede session for the current third-year students focused on the disability from a social and historical perspective.

We have also obtained approval to modify the syllabus for the Physical Exam Course as part of the Clinical Skills curriculum for first-year medical students with information on additional considerations and potential modifications to the physical exam for patients with intellectual and physical disabilities. Plans are also underway to develop a session for second-year medical students to practice interviewing simulated participants with intellectual disabilities. Through a partnership we established with Chapel Haven, a group home in New Haven for adults with intellectual disabilities, students will have the opportunity to visit the group home and interact with volunteers who will act as simulated participants. Another session we are currently developing will focus on the historical and social contexts of disability, with the hopes of incorporating it into the Introduction to the Profession curriculum that occurs at the start of the first year of medical school.

In the future, we plan to continue expanding the sessions on disability we are developing for the Yale School of Medicine curriculum. Our group is partnering with Dr.
Beverly Sheares and the YSM Office of Diversity, Equity, and Inclusion to incorporate disability more thoroughly into the curriculum. We also plan to create sessions focused on issues of health equity for patients with disabilities and the intersection between patients with disabilities and other underrepresented minorities, including race, ethnicity, and sexual orientation. We hope to someday establish a more formalized thread of disabilities studies that will be recognized by the medical school and woven even more extensively throughout the curriculum.
References


Appendix 1. Treating Children with Physical Disabilities Workshop Materials

Slide Deck

https://tinyurl.com/2p8szbvp

Facilitator’s Guide

https://tinyurl.com/cf6fkxtw

Video Clips

https://tinyurl.com/4a6wfuz3