

Evaluating a novel disability education and awareness event for health professions trainees

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ABSTRACT:

Background: People with intellectual and developmental disabilities (IDD) are at high risk for unmet healthcare needs and face barriers to equitable care, yet few health professions students receive adequate training to meet these needs.

Objectives: An interactive panel discussion with Special Olympics Pennsylvania (SOPA) athletes and staff was planned and implemented so that health professions students/trainees would gain knowledge of IDD, health barriers, SOPA resources, and volunteer opportunities.

Methods: Panelists included two SOPA athletes and their mentors; questions solicited responses about personal healthcare experiences (Fall 2019). Attendees completed a mixed-methods post-event survey capturing event satisfaction, reflections, and interest in learning more about patients with IDD.

Results: Sixty individuals attended, and 43 (72%) completed post-event evaluation. Attendees reported high satisfaction (88%), desire for future trainings (100%), and interest in learning about communicating (88%), providing care (88%), and addressing IDD health barriers (91%).

Conclusions: Collaborative community panels could be effective in engaging healthcare students in discussion about caring for patients with IDD.

KEYWORDS: Medicine, Community health partnerships, Community-Based Participatory Research, Health disparities, Disabled Persons

Background and Objectives

About 7.3 million people in the United States have intellectual and developmental disabilities (IDD)¹, yet few medical or health professions programs provide adequate education on serving patients with IDD¹⁻³. People with IDD have an estimated 20-year decreased life expectancy compared to the general population and are higher risk for poor health, sexual assault, and having unmet healthcare needs.²⁻⁴ Currently, the Liaison Committee on Medical Education does not have a formal requirement for curriculum on IDD.⁵ Lack of adequate training for physicians and health professionals to provide equitable care to patients with IDD is a public health issue⁴⁻⁷; thus, well-planned, dynamic medical education curricula on IDD has the potential to yield competent, socially conscious, and equitable medical and allied health providers in the future.

While literature on this topic is sparse, the few studies that have been done show that health professionals have a relatively narrow understanding of what it means to live with IDD and the associated health needs.^{4,6,8} An important factor associated with a more positive attitude towards individuals with IDD and willingness to care for these individuals was direct interaction.⁸ An attitude shift through interaction highlights an invaluable opportunity in health professions training to better meet healthcare needs for those with IDD and reduce health disparities.

First, health professions trainees must be introduced to the IDD population and their needs. To promote health trainee education on this topic, we planned, implemented, and evaluated an interactive discussion panel event presented by Special Olympics Pennsylvania (SOPA) athletes and staff and attended by health professions students and trainees at an urban, private university in Northeastern, USA. The goal of this panel was to enlighten students about

persons with IDD, enumerate on the health barriers they face, and showcase the resources and volunteer opportunities that Special Olympics offers. We also assessed post panel trainee knowledge on IDD and interest in working with SOPA. Spearheaded by medical school faculty in the Department of Community and Family Medicine at Thomas Jefferson University and the Vice President of Mission Integration at SOPA, this event was a jumping off point for an enduring relationship between healthcare professionals and SOPA. We describe the development of this panel event and pilot feedback.

Methods

Partnership

SOPA aims to “provide year-round sports training and competition in a variety of sports,” with greater goals of promoting advocacy, leadership, innovation, and inclusion from and for children and adults with intellectual and developmental disabilities.⁶ An important pillar of this mission includes addressing and providing collaborative solutions to major medical problems facing its athletes. In addition to national and statewide health initiatives, SOPA is committed to engaging the local medical communities of their athletes.⁷ In developing this partnership, the lead physician in this pilot study, a family doctor passionate about caring for persons with IDD and long-time SOPA volunteer, wanted to explore interactive ways for medical trainees to better understand this patient population. In 2019, they “cold called” the local SOPA offices to discuss collaboration and immediately encountered enthusiasm from SOPA. SOPA leadership was interested in collaboration and eager to engage both SOPA athletes and medical trainees alike. During initial brainstorming meetings, SOPA programming and project leaders shared their

mission and values, their upcoming events and activities, and need for increasing the volunteer pool; while the physician shared the desire to better engage students in the IDD community through volunteering as well as the overarching goal to better understand how patients with IDD and their families feel about the current healthcare system. Both partners expressed desire to address healthcare gaps and barriers people with IDD face, and adamantly agreed that community wellness engagement and interactive “learning by doing” efforts, both providers and people with IDD could begin to feel more comfortable with each other.

With SOPA’s large 2019 Fall Festival approaching, the partnership team decided the best way to promote volunteering and engagement was to work with a campus medical student group to present during their group meeting. Working with this group, the team decided that both traditional didactic presentation and panel discussion with SOPA athletes could be the most influential. The purpose of the event was two-fold: introduce caring for patients with IDD; and inform trainees about SOPA volunteer opportunities (single day and longitudinal), how they can use their healthcare skills when volunteering, and strategies to maximize interactions with SOPA athletes. Also, two SOPA athletes and their families attended and shared their healthcare and SOPA experiences directly with attendees. Wanting to be inclusive and interprofessional, we also invited other faculty, students, and residents from other healthcare areas, such as nursing, physical therapy, occupational therapy, and physical medicine and rehabilitation.

Interactive Panel Event and Attendees

The in-person, on campus session was open to all health professions students, residents, and fellows at a private, urban university in Philadelphia, PA in Fall 2019. Event information was emailed to healthcare trainees who were currently enrolled as students, using university

provided listserv; it was promoted through the XX Cares for Kids special interest group email and media channels. The email detailed event specifics, including that the event was completely optional, and dinner was provided.

In total, N=60 health professions students and trainees attended the event, while N=43 attendees completed a 10-item, mixed-methods, post-event evaluation survey. The community-academic team, composed of the lead physician-scientist, SOPA leaders, and a quantitative scientist from the physician-scientist's home department, planned the two-hour event to consist of three overarching segments:

1. Introduction and overview of working with patients with IDD. This 20-minute segment, presented by a physician who is board-certified in both Family Medicine and Developmental Medicine, discussed adults with IDD as a vulnerable population, described healthcare disparities faced by adults with IDD, and addressed strategies for communicating with people with IDD including using person-first language.
2. Overview of Special Olympics. This 20-minute segment included an overview of the events, activities, and programs hosted by Special Olympics and a step-by-step presentation of how to register as a volunteer. This segment was designed in collaboration with and presented by the Vice President of Mission Integration at SOPA. Volunteer opportunities presented included those requiring the skills of healthcare students and professionals, such as the Healthy Athletes and Healthy Habits programs and Competition Emergency Medical Support.^{8,9}

3. Interactive discussion with Special Olympics athletes. This one-hour segment was a question-and-answer panel discussion with two Special Olympics athletes and their mentors or parents, moderated by an Assistant Professor in the Jefferson College of Nursing. During the session, athletes and their mentors discussed realities of training, competition, and the Healthy Athletes program that provides free health screenings and education. Athletes and their mentors or parents shared about disparities they faced in accessing and maintaining healthcare across health disciplines. Student attendees had the opportunity to ask questions of the panelists.

Measures

A short 10-item, mixed-methods post-event feedback survey was developed by the aforementioned community-academic partnership. Items were based on general event feedback surveys and adapted to reflect the topic of the event (people with IDD). (See Appendix) Attendees self-reported their program and training level. One item captured overall event satisfaction, measured on a 5-point Likert scale (1=very dissatisfied to 5=very satisfied). Three close-ended items, measured on a 5-point Likert scale (1=not interested to 5=very interested), captured interest in learning more about: communicating with patients with IDD, providing health care to persons with IDD, and addressing barriers to care people with IDD face. One-item captured interest in attending future trainings or workshops (coded yes/no). Three open-ended questions were also included: “*Are there any other topics related to patients with IDD that you would like to learn more about?*”, “*What did you enjoy most about this event?*”, and “*What surprised you the most?*”.

Analysis

SAS version 9.4 was used for analyses. Frequencies were calculated. Open-ended responses were analyzed using a content-analysis approach. Authors reviewed responses to open-ended questions and iteratively identified within-question themes that emerged. As this was brief, pilot-event feedback, only descriptive statistics were used and no additional behavioral measurement approaches were employed. This study was exempt by the Thomas Jefferson University Institutional Review Board (#20G.226).

Results

Attendees were physical therapy (n=14, 33%), medicine (n=12, 28%), and occupational therapy (n=11, 26%) students and trainees. Overall, 88% of attendees (n=38) were very satisfied with the event. All respondents noted interest in attending future trainings/workshops (n=43, 100%), and were very interested in learning more about communicating (n=35, 81%), providing care (n=38, 88%), and addressing barriers to care (n=39, 91%) for patients with IDD. Table 1 describes attendees' backgrounds, event satisfaction, and interest in learning more about session topics.

Table 1. Special Olympics Fall Panel Quantitative Evaluation (N=43)

Program ^a	n (%)
Medicine	12 (27.91)
Student (n=8)	
First Year – MS1	5 (41.67)
Second Year – MS2	1 (8.33)
Third Year – MS3	1 (8.33)
Fourth Year – MS4	1 (8.33)
Resident (n=3)	
Physical Medicine and Rehabilitation – PGY3	1 (8.33)
Physical Medicine and Rehabilitation – PGY4	1 (8.33)
Pediatrics – PL3	1 (8.33)
Fellow (n=1)	
Sports Medicine Fellow – PGY4	1 (8.33)
Physical Therapy ^b	14 (32.56)
Occupational Therapy ^b	11 (25.58)
Medical Laboratory Science ^b	3 (6.98)
Nursing ^b	2 (4.65)
Couples and Family Therapy ^b	1 (2.33)
Overall satisfaction with event^c	
Very satisfied	38 (88.37)
Satisfied	5 (11.63)
Neither satisfied or dissatisfied	0 (0.00)
Dissatisfied	0 (0.00)
Very dissatisfied	0 (0.00)
Interested in learning more about...communicating with patients^d	
Very interested	35 (88.37)
Interested	8 (11.63)
Fairly interested	0 (0.00)
Slightly interested	0 (0.00)
Not interested	0 (0.00)
Interested in learning more about...providing care^e	
Very interested	38 (88.37)
Interested	5 (11.63)
Fairly interested	0 (0.00)
Slightly interested	0 (0.00)
Not interested	0 (0.00)
Interested in learning more about... addressing barriers to care^f	
Very interested	39 (90.70)
Interested	2 (4.65)
Fairly interested	2 (4.65)
Slightly interested	0 (0.00)
Not interested	0 (0.00)
Want to attend future trainings/workshops^g	
Yes	43 (100.00)
No	0 (0.00)

^aQuestion asked: "What program are you in?" ^b Respondents did not specify in which degree program they were enrolled. ^c Question asked: "Overall, how satisfied are you with this event?" ^d Question asked: "How interested are you in learning more about: How to communicate with patients with IDD?" ^e Question asked: "How interested are you in learning more about: How to provide care to patients with IDD?" ^f Question

asked: "How interested are you in learning more about: How to address barriers to care for patients with IDD?"⁸ Question asked: "Would you attend future trainings or workshops about providing care for patients with IDD?"

Four themes emerged related to topics attendees wanted to learn more about: strategies to improve care, IDD education, Special Olympics organization and events, and patient challenges. Table 2 shows themes from open-ended questions. Of the 20 respondents who provided feedback on other topics they would like to learn more about, 55% (n=11) expressed interest in wanting to learn about care strategies: *"specific tips for conversation/proper approach to patients w/ special needs."* Seven respondents (35%) also indicated they would, in general, like further education about IDD: *"I'd love to hear more about the range of severity/ impact of IDD/ variety developmentally amongst pts."*

Three themes were identified related to overall event enjoyment: conversations with the athletes, Special Olympics overview, and overview of IDD and healthcare (n=43 responses). Attendees overwhelmingly enjoyed the conversation with athletes (n=39, 91%): *"I loved hearing from the athletes themselves -- I was so moved and inspired."*

Themes related to what surprised attendees included: health disparities experienced by persons with IDD, breadth and reach of Special Olympics, and panelists' perspectives and backgrounds (n=35 responses). Many attendees were unaware of health disparities (n=19, 54%), expressing surprise *"that so many PCPs won't treat pts with IDD,"* and that Special Olympics spans beyond athletic participation (n=16, 46%), e.g., *"how much medical care Special Olympics offers."*

Table 2. Open-Ended Feedback Response Themes and Select Supporting Quotes

Are there any other topics related to patients with IDD that you would like to learn more about? (n=20)	
Strategies to improve care ^{ab}	N=11 (55%)
<ul style="list-style-type: none"> • <i>“How to set up a physical environment so that it is more inclusive/ accessible of patients with IDD”</i> • <i>“Specific tips for conversation/proper approach to patients w/ special needs”</i> • <i>“How to approach mental health d/o in patients w/ IDD. How can we as providers create a welcoming environment to discuss depression/anxiety etc.?”</i> 	
Further education about IDD ^{bc}	N=7 (35%)
<ul style="list-style-type: none"> • <i>“I would like to understand the common comorbidities associated with patients with IDD.”</i> • <i>“I’d love to hear more about the range of severity/ impact of IDD/ variety developmentally amongst pts.”</i> • <i>“I’d be interested in hearing about any emotional therapy resources there are for patients with IDD”</i> 	
Special Olympics organization and events ^{ac}	N=3 (15%)
<ul style="list-style-type: none"> • <i>“Future opportunities other than the Fall Festival”</i> • <i>“The events and opportunities volunteers can participate in to learn more about that particular patient population.”</i> • <i>“What are the most common medical issues that present during the event?”</i> 	
Challenges experienced by patients	N=2 (10%)
<ul style="list-style-type: none"> • <i>“Additional barriers/challenges faced outside of healthcare”</i> • <i>“I would like to know more about their experiences and hear what they would like in a healthcare professional”</i> 	
What did you enjoy most about this event? (n=43)	
Conversation with athletes ^{dc}	N=39 (91%)
<ul style="list-style-type: none"> • <i>“I loved the athletes’ input and hearing their points of view in regards to healthcare.”</i> • <i>“I loved hearing from the athletes themselves -- I was so moved and inspired.”</i> • <i>“The athletes panel at the end and hearing the impact of their special olympics organization on their lives”</i> 	
Special Olympics overview ^{de}	N=6 (14%)
<ul style="list-style-type: none"> • <i>“Learning about the program”</i> • <i>“The video about why special olympics for those with ID is so important and helpful”</i> • <i>“The panel and description of events coming up”</i> 	
Overview of IDD and healthcare ^e	N=2 (5%)
<ul style="list-style-type: none"> • <i>“Being able to learn about working with people w/ IDD”</i> • <i>“I really enjoyed the balance of presentation and panel.”</i> 	
What surprised you the most? (n=35)	
Health disparities experienced by people with IDD ^{fg}	N=19 (54%)
<ul style="list-style-type: none"> • <i>“I was surprised by how big of a problem lack of resources is for individuals with IDD.”</i> • <i>“Life expectancy can be shorter than someone without an IDD due to health care availability and also interactions with health care providers”</i> • <i>“That so many PCPs won’t treat pts with IDD”</i> 	
Multitude of opportunities offered through Special Olympics ^f	N=16 (46%)
<ul style="list-style-type: none"> • <i>“How many Special Olympics events there are and how much of an impact that it has on the lives of the athletes.”</i> • <i>“How much medical care Special Olympics offer”</i> • <i>“Leadership programs available to sports participants”</i> 	
Panelists’ perspectives ^g	N=5 (14%)
<ul style="list-style-type: none"> • <i>“It never crossed my mind that we could make a doctor’s visit longer.”</i> • <i>“How interesting hearing their opinions are”</i> • <i>“Matthew’s^h youtube channel! So awesome”</i> 	

^a One item was double-coded as “Strategies to improve care” and “Special Olympics organization and events.” ^b One item was double-coded as “Strategies to improve care” and “Further education about IDD.” ^c One item was double-coded as “Further education about IDD” and “Special Olympics organization and events.” ^d Two items were double-coded as “Conversation with athletes” and “Special Olympics overview.” ^e One item was triple-coded as “Conversation with athletes,” “Special Olympics overview,” and “Overview of IDD and healthcare.” ^f Four items were double-coded as “Health disparities experienced by people with IDD” and “Multitude of opportunities offered through Special Olympics.” ^g One item was double-coded as “Health disparities experienced by people with IDD” and “Panelists’ perspectives.” ^h Athlete’s name has been changed to protect the individual’s privacy.

Conclusions

As measured via pre and post assessment, this pilot panel demonstrated a feasible way to expand students' understanding of IDD and its related health barriers. Featuring clinicians and Special Olympics athletes, mentors, and staff, the event was an effective way to engage attendees in disability education. Attendees enjoyed hearing from the panelists; were surprised to learn about health disparities and barriers to care persons with IDD face; and reported wanting to engage in further training surrounding care of patients with IDD. This event model is aligned with previous studies demonstrating student engagement in programs where patients serve as medical educators.¹⁰⁻¹¹

Most attendees were unaware of health inequities experienced by persons with IDD, elucidating a critical gap in health professional training and curricula. According to the knowledge-attitude-behavior model, behavioral change typically occurs after knowledge and attitude changes.¹² Health disparities education has been found to impact trainee knowledge and attitudes¹³, with several studies demonstrating associations between physicians' implicit attitudes and clinical decision-making.¹⁴ This suggests that interventions impacting trainee knowledge, such as our event, are important first steps to influencing clinicians' equity-promoting behaviors.

Other pilot studies have seen increased awareness and acceptance through brief but thorough educational opportunities for health professions trainees. Educational interventions, such as standardized patients with IDD, lectures by healthcare leaders in IDD, and video narratives from patients with IDD, have all seen great success.^{3,9-11} A lack of standardized IDD curriculum and varying curricular requirements of different health professions may present educational barriers, yet our study and other pilot programs show that such educational opportunities are invaluable for both health profession trainees and individuals with IDD alike.

While most attendees self-reported they were surprised to learn of health disparities, we did not explicitly assess knowledge pre- and post-event; nor do we employ a comparison group as this was a descriptive synthesis of post-event feedback and self-assessment. Additionally, because event attendance was voluntary, attendees likely had positive notions about and/or interests in IDD. Still, our pilot evaluation demonstrated that many trainees enjoy learning from patients with IDD in this format. We plan to use attendee feedback to plan additional events that incorporate breakout discussions on topics such as physical and occupational therapies and socio-emotional wellbeing; ultimately, we also aim to develop more formal didactic sessions. Future studies should evaluate how events like this can affect long-term knowledge, attitudes, and clinical practice. Next steps should involve in-depth qualitative interviews to derive greater insight into specific trainee education gaps.

Given the rapid virtual transition to virtual education due to COVID-19, following the conclusion of this pilot event, many of the in-person community-based events involving the student/trainees and SOPA had to be put on pause during 2020. However, the community-academic partnership has remained constant and even grown to include a clinical social worker from the physician's academic department and a variety of medical students interested in care of persons with IDD. Over the four years of our partnership, our continued interdisciplinary efforts have led to increased participation of healthcare students at recent SOPA events, particularly Fall Fest, and the development and implementation of the Special Olympics selective, an elective block for fourth-year medical students that allows them to get to know SOPA athletes as individuals outside of the exam room. Moving forward, this partnership will push for continued engagement of the healthcare community and SOPA athletes, creating an environment that fosters and expands understanding with the goal of training holistic health professionals.

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Ethical approval

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Disclaimers

None.

Previous presentations

Preliminary version of these findings were presented at the American Academy of Developmental Medicine and Dentistry Conference (virtually June 2020), and at the Society of Teachers of Family Medicine Annual Spring Conference (Portland, OR, January 2020).

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