Case Study: University of Louisville School of Medcine

Special Olympics Health MADE POSSIBLE BY Golisano

CDC CENTERS FOR DISEASE CONTROL AND PREVENTION

THE PROBLEM

People with intellectual disabilities are at increased risk for poor health outcomes and are a high priority population for reducing health disparities.[1,2,3] The lack of health care provider training on disability has been highlighted in recent literature as a key, modifiable determinant of the health disparities experienced by people with intellectual disabilities.[4,5,6]

BACKGROUND

The National Curriculum Initiative in Developmental Medicine (NCIDM) supports multiple medical schools to implement curriculum about health care for people with intellectual disabilities through a multi-year partnership between the American Academy of Developmental Medicine and Dentistry and Special Olympics International, with resources from a cooperative agreement funded by the Centers for Disease Control and Prevention. The University of Louisville School of Medicine (ULSOM) was selected as part of the first cohort of NCIDM Medical School Partners.

SOLUTION

To integrate the voices of people with intellectual disabilities into the medical school curriculum, ULSOM chose to engage in a Photovoice project designed to highlight advice from people with intellectual disabilities to medical students and include their perspectives about health. ULSOM and University of Louisville School of Public Health and Information Sciences faculty worked with self-advocates from Special Olympics Kentucky's Athlete Leadership Program for about ten months, supporting them in completing a Photovoice project. Photovoice is a qualitative technique in which participants take photos related to a central theme and narrate their photos in a later interview.[7] The athlete leaders presented the findings that emerged from their photos and interviews to all second-year medical students (n=166) during 2-hour, interactive discussion sessions. Additionally, through partnering with Lee Specialty Clinic, a multidisciplinary clinic serving adults with intellectual disabilities, an ongoing elective for fourth-year medical students now provides future physicians with the opportunity to work with people with intellectual disabilities.

CHALLENGES

The successful coordination of multiple community partners was a challenge in terms of the time commitment it requires. Additionally, within a medical school environment, grant funding is often required for faculty to be able to dedicate time towards developing new curriculum content. Also, a passionate internal champion is essential, both for initial curriculum development and for sustainability. Relationships with key community partners are a necessary first step to developing curriculum that actively involves self-advocates. These relationships must be established and maintained to create experiences that are meaningful to students and feasible to community partners.

BENEFITS

Students gained knowledge and competence regarding the health care of people with intellectual disabilities. Of the second-year medical student participants, 94% agreed that the session helped them better understand the health issues of adults with intellectual disabilities. Reflecting on the session, students reported, "I feel like it gave me a much better idea of the

challenges facing adults with intellectual disabilities" and "It was useful to hear from the patient's perspective in an open, nonjudgmental atmosphere."

Fruitful collaboration and strong working relationships between the university, Special Olympics Kentucky, and Lee Specialty Clinic allowed ULSOM to create expansions of previous grant-funded activities and to create new curriculum efforts moving forward.

LESSONS LEARNED

- Networking with colleagues through organizations like the American Academy of Developmental Medicine and Dentistry is a helpful way to learn from other medical schools engaging in this type of curriculum work.
- Relationships with community partners, such as state-level Special Olympics Programs, are essential for interfacing with the community of people with intellectual disabilities and their supporters. Volunteering at community partners' events is a great way to start forming sustainable, key relationships for involving self-advocates in curriculum efforts.
- Involving self-advocates in curriculum efforts teaches students lessons that simply cannot be presented by any otherteacher.
- Respectful involvement includes working with people with intellectual disabilities to ensure they are prepared and confident going into the experience. In this case, most self-advocates were initially nervous about speaking in front of a large group of medical students, so the team worked closely with them for several months to make sure everyone had a positive experience.
- Medical schools should engage faculty and physicians in the community in curriculum efforts to provide students with experiences with patients with intellectual disabilities in a variety of settings, including academic medical centers and mainstream community settings.
- Buy-in from faculty and staff in the university's Medical Education Office is vital, as they facilitate adding content to existing curriculum and help ensure sustainability.
- It is important to include foundational content in disability studies and disability frameworks in addition to content specific to intellectual disability.
- An initial, small project is an important stepping stone towards more in-depth curriculum efforts.

ADDITIONAL RESOURCES

- For more information on NCIDM: https://aadmd.org/page/ncidm-medical-student-education
- University of Louisville press release: http://uoflnews.com/releases/uofl-leading-national-effort- to-improve-lifelong-care-for-people-with-intellectual-developmental-disabilities/

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[1] Office of the Surgeon General (US), National Institute of Child Health and Human Development (US), Centers for Disease Control and Prevention (US). *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation: Report of the Surgeon General's Conference on Health Disparities and Mental Retardation*. Washington (DC): US Department of Health and Human Services; 2002. http://www.ncbi.nlm.nih.gov/books/NBK44346/. Accessed December 1, 2017.

[2] Ervin DA, Hennen B, Merrick J, Morad M. Healthcare for Persons with Intellectual and Developmental Disability in the Community. *Front Public Health*. 2014;2.

[3] Havercamp SM. National Health Surveillance of Adults with Disabilities, Adults with Intellectual and Developmental Disabilities, and Adults with No Disabilities. *Disabil Health J*. 2015;8(2):165-172.

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[6] Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities (NCBDDD) Health Surveillance Work Group. *U.S. Surveillance of Health of People with Intellectual Disabilities: A White Paper*.; 2009. https://www.cdc.gov/ncbddd/disabilityandhealth/pdf/209537-A_IDmeeting-short-version12-14-09.pdf. Accessed May 30, 2018.

[7] Catalani C, Minkler M. Photovoice: A Review of the Literature in Health and Public Health. *Health Educ Behav*. 2010;37(3):424-451.