1 Updated: November 16, 2020

2 This article is the Author's Accepted Manuscript version (accepted version, post-peer review,
3 prior to typesetting by the journal) accepted by *Pedagogy in Health Promotion*, a SAGE journal.
4 This manuscript is shared through the Green Open Access Self-Archiving Policy of SAGE
5 Publishing, allowing the Accepted Manuscript to be posted as a downloadable copy on any non-
6 commercial website.
7
8 Please do not cite this document without the authors' permission. Instead, please access and cite
9 the official article:
10
11 James, T. G., Sullivan, M. K., & Varnes, J. R. (In press). Improving representation of people
12 with disabilities in health education. *Pedagogy in Health Promotion.*
13

14 **Improving Representation of People with Disabilities in Health Education**

15

16 Tyler G. James, M.S, CHES®* [1], Meagan K. Sullivan, M.P.H., CPH[2],

17 & Julia R. Varnes, Ph.D., M.P.H., MCHES®[1]

18

19 *Correspondence regarding this article should be sent to Tyler G. James.

20 Twitter for Tyler G. James: @tylergjames_

21 Affiliations:
22 1. Department of Health Education and Behavior, University of Florida, Gainesville, FL,
23 USA.
24 2. Florida Disability and Health Program, Department of Health Services Research,
25 Management, and Policy, University of Florida, Gainesville, FL, USA.
26

27 Disclosures: Tyler G. James is a member of the Editorial Board for the journal *Pedagogy in*
28 *Health Promotion*. The authors of this article were not supported by specific grant funding. The
29 opinions within this article of those of the authors and do not necessarily represent their
30 employers or their employers' funding agencies.
31

32

33

34 Abstract

35 Over the past two decades there has been increasing recognition of the importance and merits of
36 increasing representation of historically underrepresented minorities in the health professions.
37 However, people with disabilities are less discussed in these efforts. Over one-in-four of U.S.
38 Americans have a disability; yet, it seems these individuals are less represented in the field of
39 health education. This commentary discusses the merits of increasing representation of people
40 with disabilities in the health education/promotion profession and calls for preparation programs
41 and professional organizations to reduce systemic barriers and facilitate increased representation.
42

43 Keywords: *Diversity and inclusion; underrepresented population; people with disabilities.*

44

45 **Improving Representation of People with Disabilities in Health Education**

46 Health professions have recognized the importance of increasing representation of
47 minority professionals in their fields: increased innovation, better patient safety and health
48 outcomes, and social justice. This recognition led to calls to action to increase gender and
49 racial/ethnic diversity within these fields, wherein representation is indeed increasing (Boatright
50 et al., 2018; Phillips & Malone, 2014). Over 22% of U.S. Americans have a disability (Courtney-
51 Long et al., 2015); yet, people with disabilities (PWDs) are frequently excluded from diversity
52 and inclusion efforts. Unfortunately, PWDs are underrepresented in many health professions
53 including, it seems, the health education and promotion (HE/P) profession.

54 PWDs in the U.S. experience a range of health disparities including poorer financial and
55 disability-related access to medical professionals (Bauer et al., 2016; Drainoni et al., 2006;
56 Graham & Mann, 2008); higher prevalence of health risk behaviors and conditions including
57 obesity, diabetes, and cardiovascular disease (McKee et al., 2011; McPhee et al., 2019); and,
58 poorer and communication with healthcare providers (Kushalnagar et al., 2018; Streur et al.,
59 2019). In response to these disparities, Healthy People 2020 and Healthy People 2030 (U.S.
60 Department of Health and Human Services, 2013, 2020) call for efforts to improve the health of
61 PWDs. Unquestionably, the field of HE/P has a responsibility to address these health disparities
62 up-stream by developing prevention programs and policies. HE/P best practices (e.g.,
63 community-participatory programs; Green & Kreuter, 2005) call for engaging communities and
64 culturally tailoring these programs and services. However, PWDs often experience barriers to
65 engagement due to society's denial of PWDs personal experiences, widespread infantilization,
66 and assumptions of homogeneity and helplessness (e.g., East & Orchard, 2014; Mertens, 2009);
67 resulting in disempowerment.

Inarguably, increasing the representation of PWDs in the HE/P profession can lead to innovation and better individual and community health outcomes. Further, although it is not the responsibility of PWDs to serve as ambassadors or otherwise focus on disability health-related issues, increased representation of PWDs in the HE/P profession will serve to passively and actively combat stereotypes and disentangle biases. This could result in increased recognition of the importance of engaging PWDs in planning efforts and service delivery; thus, improving health outcomes for PWDs. To address underrepresentation of PWDs in the field, we must be proactive in taking steps to reduce systematic exclusion from professional preparation and development opportunities in both higher education and professional organizations.

Recommendations for Higher Education

There has been a marked increase in the prevalence of college students with disabilities in the past 20 years (National Center for Education Statistics, 2000, 2019). Still, students with disabilities face systematic barriers to accessing and successfully completing college (Lyman et al., 2016). Higher education programs and instructors must ensure that their educational curriculum is accessible to students with disabilities.

Typically, accommodations for course materials are provided through a college's disability resource center (DRC) after (1) the student has provided medical documentation of the disability; and (2) consulting with the student on reasonable accommodations. Unfortunately, a sub-population of students exist who are unable to provide documentation for various reasons including lack of healthcare access, stigma, and feeling vulnerable (Lyman et al., 2016; Marshak et al., 2010). For students who do engage with DRCs, navigating access is a continual process requiring multiple meetings with DRC professionals to revise accommodations and ensure the classroom environment is accessible. Further, DRC policies and guidelines differ by institutions

91 – presenting access barriers for students with disabilities as they progress through their
92 education.

93 Implementing Universal Design for Learning (UDL) strategies in the classroom can
94 ensure that all students have equal access to course materials, without mandates from DRCs.
95 UDL strategies include using: (1) multiple modalities to provide course content (e.g., podcasts,
96 visual presentations, and textbooks); (2) multiple strategies to present content (e.g., case studies,
97 hands-on activities, and guest speakers); and (3) a variety of assessment methods, without
98 relying solely on written assessments (CAST, 2018).[1]

99 Access to the learning environment and content is critical. However, social norms may
100 influence if a student with a disability seeks or uses classroom accommodations. Thus, training
101 students, faculty, and staff on disability awareness and cultural competency is critical – not only
102 for ensuring students, visitors, and staff with disabilities feel welcome, but also to influence
103 future health promotion work with PWDs. Professional preparation programs should consider
104 integrating a *social aspects of disability* course in their student curriculum, and hosting disability
105 awareness trainings. For example, the University of Florida's College of Public Health and
106 Health Professions partners with the Florida Disability and Health Program, jointly funded by the
107 Centers for Disease Control and Prevention (CDC) and the Florida Department of Health, to
108 provide disability awareness training to undergraduate and graduate students. There are 19 CDC-
109 funded disability and health programs nationwide, and many provide these types of training. An
110 additional benefit of these trainings is that faculty and staff can also receive training on
111 protections for students with disabilities and how to appropriately communicate with students.

[1] Resources for learning more about these strategies are available from the Universal Design for Learning Center (https://medium.com/udl-center), the Center for Applied Special Technology (http://udlguidelines.cast.org/), and the U.S. Department of Education.

Recommendations for Professional Organizations

Each of the authors has separately experienced or witnessed HE/P professional organizations limiting access to, or having barriers to engaging in, professional development opportunities. Deaf and hard-of-hearing health educators have been denied access to effective communication through sign language interpreters or captions at plenary sessions; professionals with mobility disabilities have faced physical barriers accessing meeting rooms and stages; and professionals who are blind/low vision may encounter barriers to accessing presentation content. Not only are inaccessible programs placing our professional organizations at increased liability (for failing to comply with federal mandates), it is in direct violation of the Code of Ethics of the Health Education Profession (Coalition of National Health Education Organizations [CNHEO], 2020) and also hinders our efforts to recruit and retain members with disabilities. Thus, we call for partners within the CNHEO to facilitate a multi-pronged approach.

First, HE/P organizations should collaborate with disability advocacy organizations and organizations that serve health professionals with disabilities. These partnerships would help demonstrate the field's dedication to increasing representation of PWDs and providing opportunities for members of both organizations to engage in meaningful dialogues regarding the provision of health education to PWDs. Additionally, these partnerships could help facilitate trainings to professional organization staff and officers of their responsibility to comply with accessibility laws.

Secondly, HE/P organizations and their members must recognize the two legal and ethical responsibilities of providing accessibility to professional meetings and events. First, organizations must ensure that reasonable accommodations are provided when requested. We have interacted with first-time meeting attendees who have no intention of remaining involved in

the organization due to inaccessibility. Secondly, organizations should adopt accessibility standards for presenters to ensure content is accessible. For example: (1) standards for instructional material (e.g., PowerPoint and posters) to be visually accessible; (2) train moderators to remind attendees to use the microphone when asking questions; and, (3) assign program planning committee members the responsibility of collecting, organizing, and fulfilling reasonable accommodations.

Summary

Higher education programs and health education organizations can, and should, be doing more to promote recruitment and retention of health educators with disabilities. Increasing the representation of PWDs in the HE/P profession will help increase innovation and improve the health of PWDs. We provided two strategies for higher education programs and two strategies for professional organizations that will improve accessibility to instructional and professional development content, thus reducing systematic exclusion of PWDs in the field which is a primary barrier to increasing representation. Our hope is that these strategies can encourage reflection and action by these two stakeholders on how they may be unintentionally harming priority populations, and how they can actively support PWDs entering the field.

References

Bauer, S. E., Schumacher, J. R., Hall, A., Marlow, N. M., Friedel, C., Scheer, D., & Redmon, S. (2016). Disability and physical and communication-related barriers to health care related services among Florida residents: A brief report. *Disability and Health Journal*, *9*(3), 552–556.

Boatright, D. H., Samuels, E. A., Cramer, L., Cross, J., Desai, M., Latimore, D., & Gross, C. P. (2018). Association between the liaison committee on medical education’s diversity standards and changes in percentage of medical student sex, race, and ethnicity. *JAMA*, *320*(21), 2267–2269. https://doi.org/10.1001/jama.2018.13705

CAST. (2018). *Universal Design for Learning Guidelines version 2.2*. http://udlguidelines.cast.org/

Coalition of National Health Education Organizations. (2020). *Code of ethics for the health education profession*.

Courtney-Long, E. A., Carroll, D. D., Zhang, Q. C., Stevens, A. C., Griffin-Blake, S., Armour, B. S., & Campbell, V. A. (2015). Prevalence of disability and disability type among adults—United States, 2013. *MMWR. Morbidity and Mortality Weekly Report*, *64*(29), 777.

Drainoni, M.-L., Lee-Hood, E., Tobias, C., Bachman, S. S., Andrew, J., & Maisels, L. (2006). Cross-disability experiences of barriers to health-care access: Consumer perspectives. *Journal of Disability Policy Studies*, *17*(2), 101–115.

East, L. J., & Orchard, T. R. (2014). Somebody else’s job: Experiences of sex education among health professionals, parents and adolescents with physical disabilities in Southwestern Ontario. *Sexuality and Disability*, *32*(3), 335–350.

176 Graham, C. L., & Mann, J. R. (2008). Accessibility of primary care physician practice sites in
177 South Carolina for people with disabilities. *Disability and Health Journal*, *1*(4), 209–214.
178 Green, L. W., & Kreuter, M. (2005). *Health program planning: An educational and ecological*
179 *approach.* (4th ed.). McGraw-Hill.
180 Kushalnagar, P., Hill, C., Carrizales, S., & Sadler, G. R. (2018). Prostate-Specimen Antigen
181 (PSA) screening and shared decision making among deaf and hearing male patients.
182 *Journal of Cancer Education*, 1–8.
183 Lyman, M., Beecher, M. E., Griner, D., Brooks, M., Call, J., & Jackson, A. (2016). What keeps
184 students with disabilities from uing accommodation in postsecondary education? A
185 qualitative review. *Journal of Postsecondary Education and Disability*, *29*(2), 123–140.
186 Marshak, L., Van Wieren, T., Ferrell, D. R., Swiss, L., & Dugan, C. (2010). Exploring barriers to
187 college student use of disability services and accommodations. *Journal of Postsecondary*
188 *Education and Disability*, *22*(3), 151–165.
189 McKee, M. M., Schlehofer, D., Cuculick, J., Starr, M., Smith, S., & Chin, N. P. (2011).
190 Perceptions of cardiovascular health in an underserved community of deaf adults using
191 American Sign Language. *Disability and Health Journal*, *4*(3), 192–197.
192 McPhee, P. G., Gorter, J. W., MacDonald, M. J., & Martin Ginis, K. A. (2019). The effects of an
193 individualized health-risk report intervention on changes in perceived inactivity-related
194 disease risk in adults with cerebral palsy. *Disability and Health Journal*, 100868.
195 https://doi.org/10.1016/j.dhjo.2019.100868
196 Mertens, D. M. (2009). *Transformative research and evaluation*. The Guilford Press.

197 National Center for Education Statistics. (2000). *Postsecondary students with disabilities:*
198 *Enrollment, services, and persistence* (NCES 2000-092). National Center for Education
199 Statistics, U.S. Department of Education. https://nces.ed.gov/pubs2000/2000092.pdf
200 National Center for Education Statistics. (2019). *Digest of education statistics: 2018* (NCES
201 2020-009). National Center for Education Statistics, U.S. Department of Education.
202 Phillips, J. M., & Malone, B. (2014). Increasing racial/ethnic diversity in nursing to reduce
203 health disparities and achieve health equity. *Public Health Reports*, *129*(Suppl 2), 45–50.
204 Streur, C. S., Schafer, C. L., Garcia, V. P., Quint, E. H., Sandberg, D. E., & Wittmann, D. A.
205 (2019). "If everyone else is having this talk with their doctor, why am I not having this
206 talk with mine?": The experiences of sexuality and sexual health education of young
207 women with spina bifida. *The Journal of Sexual Medicine*, *16*(6), 853–859.
208 https://doi.org/10.1016/j.jsxm.2019.03.012
209 U.S. Department of Health and Human Services. (2013). *Healthy people 2020 topics and*
210 *objectives A to Z*. HealthyPeople.Gov. https://www.healthypeople.gov/2020/topics-
211 objectives
212 U.S. Department of Health and Human Services. (2020). *Healthy People 2030 Objectives*.
213 HealthyPeople.Gov. https://health.gov/healthypeople/objectives-and-data/browse-
214 objectives
215