Structural Barriers to Student Disability Disclosure in US-Allopathic Medical Schools

Lisa M Meeks1,2,3, Ben Case1,2, Erene Stergiopoulos4,5, Brianna K Evans5 and Kristina H Petersen6

1Department of Psychiatry, The University of Colorado, Aurora, CO, USA. 2Department of Family Medicine, The University of Michigan Medical School, Ann Arbor, MI, USA. 3Center for a Diverse Healthcare Workforce, University of California, Davis, School of Medicine, Sacramento, CA, USA. 4Department of Psychiatry, University of Toronto, Toronto, ON, Canada. 5Department of Biochemistry & Molecular Biology, New York Medical College, Valhalla, NY, USA.

ABSTRACT

INTRODUCTION: Leaders in medical education have expressed a commitment to increase medical student diversity, including those with disabilities. Despite this commitment there exists a large gap in the number of medical students self-reporting disability in anonymous demographic surveys and those willing to disclose and request accommodations at a school level. Structural elements for disclosing and requesting disability accommodations have been identified as a main barrier for students with disabilities in medical education, yet school-level practices for student disclosure at US-MD programs have not been studied.

METHODS: In August 2020, a survey seeking to ascertain institutional disability disclosure structure was sent to student affairs deans at LCME fully accredited medical schools. Survey responses were coded according to their alignment with considerations from the AAMC on report on disability and analyzed for any associations with the AAMC Organizational Characteristics Database and class size.

RESULTS: Disability disclosure structures were collected for 98 of 141 eligible schools (70% response rate). Structures for disability disclosure varied among the 98 respondent schools. Sixty-four (65%) programs maintained a disability disclosure structure in alignment with AAMC considerations; 34 (35%) did not. No statistically significant relationships were identified between disability disclosure structures and AAMC organizational characteristics or class size.

DISCUSSION: Thirty-five percent of LCME fully accredited MD program respondents continue to employ structures of disability disclosure that do not align with the considerations offered in the AAMC report. This structural non-alignment has been identified as a major barrier for medical students to accessing accommodations and may disincentivize disability disclosure. Meeting the stated calls for diversity will require schools to consider structural barriers that marginalize students with disabilities and make appropriate adjustments to their services to improve access.

KEYWORDS: Disability, structural barriers, disclosure, disability resource provider, medical education, resources, AAMC, best practices

Introduction

Medical leaders emphasize the importance of increasing diversity in medical education, including individuals with disabilities.1-6 Despite this emphasis on inclusion, students with disabilities face significant and well-documented barriers. In particular, barriers arise when the structures for student disclosure and provision of accommodation are uninformed. An uninformed system is one where the arbiter of decision-making is absent knowledge of medical education curriculum and assessment requirements, best and emerging accommodation practices across multiple settings and assessment styles, and relevant disability law and case law involving medical education. When uninformed structures are in place, students face additional burdens.5,17-9 Indeed, studies show that students with disabilities often avoid disclosing their disability and requesting accommodations for fear of bias, stigma, and misperceptions about performance.7,8,10-14 These concerns are fueled by the need to substantiate requests with confidential documentation.1,9 This is especially concerning when students are subject to support structures that foster conflicts of interest and uninformed decision-making, which may erode trust in the process.1,3,9

Fears regarding disclosure are partially evident in the disconnect between confidential self-disclosure of disability status in de-identified demographic surveys and individual disclosures and accommodation requests within medical schools. For example, the Association of American Medical Colleges (AAMC) collects de-identified data from all graduating medical students across a range of topics in the graduation questionnaire (GQ). In 2020,
the GQ included novel disability-related questions; a total of 7.6% of students identified as having a disability, with a little over half (52.6%) reporting receiving accommodations from their school.13 Of the 47.4% who did not receive accommodations, the majority (74.1%) reported not requiring accommodations, while approximately one-quarter (23%) reported not requesting accommodations for reasons other than not needing them.15

Although 7.6% of students anonymously self-reported a disability on the 2020 GQ. Only 4.6% formally reported a disability and requested accommodations from their medical schools.15,16 This 3% gap may be partially attributable to the structural barriers identified in the 2018 AAMC report on disability.1 Among the structural barriers to disability inclusion, the AAMC report identified [1] conflicts of interest in the disclosure process, and [2] a lack of specialized knowledge about clinical accommodations among disabilities resource professionals (DRP), the individuals who adjudicate disability-related determinations for institutions.1 In addition to identifying barriers, the report provided an appendix of considerations for schools to guide efforts towards improving disability inclusion, including specific guidance regarding the structure of student disability disclosure1 (Table 1).

Conflicts of interest

A major structural barrier to student disability disclosure occurs when there is a conflict of interest in the process of requesting accommodations.1,17 One mechanism for conflict of interest occurs when individuals who hold an evaluative role, or a role in student promotion, review student’s primary documentation as part of the request for accommodations.1,7,9 Those who participate on committees that adjudicate disability determination may also have a conflict of interest1,18 and may not have a full knowledge of best practices or relevant laws related to the provision of appropriate accommodations for students with disabilities.19 In these scenarios, students may hesitate to disclose a disability, fearing potential bias or discrimination in the evaluative process.1,7,10,12 Students may also have heightened concerns when the medical school Dean of Students serves as the arbiter of accommodation determination. In these cases, students may elect non-disclosure, knowing that the dean of students is involved in evaluations critical to the students’ future, including the Medical School Performance Evaluation (MSPE). Taken together, these conflicted disability disclosure structures may disincentivize students from disclosing their disability to seek accommodations.1,3,7,9

Uninformed decision-making

Even if faculty are not privy to primary documentation, the disability disclosure process may still serve as a structural barrier if it is not informed by [1] best practices for didactic and clinical accommodation, [2] full knowledge of the curriculum and assessments, [3] command of the board exam requirements for accommodation and [4] relevant disability and case law.19-21 Indeed, the process of determining appropriate accommodations in medical school requires a nuanced understanding of medical education curriculum and the clinical learning environment including the federal regulations for determining whether an accommodation results in a patient safety concern or direct threat, and an understanding of the assistive and adaptive technologies that reduce barriers to clinical care for students with disabilities.1,3,9,17,22 Medical schools that utilize an undergraduate campus, non-health-science-specific DRP risk making uninformed decisions.1,9,20,21,23 DRPs that are not familiar with medical education curriculum, particularly clinical curriculum, and who were not trained specifically for health professions education may not be aware of best practices or case law governing the provision of accommodations within medical education. In these cases, the resulting uninformed decisions have consequences for medical education programs and students alike.

For example, uninformed decisions can result in over-accommodation, potentially eroding the program’s academic rigor or fundamentally altering the medical school curriculum. Conversely, inexperienced decision-making can lead to under-accommodating students which may result in a failure to remove disability-related barriers. When disability-related barriers remain in place, students may struggle to fully engage in the program, leading to academic failure.

Proximity to medical school curriculum, faculty, and a nuanced understanding of clinical accommodations are essential for robust decision making. Therefore, concerns arise when medical schools utilize a central campus disability office, in the absence of a liaison or DRP housed within the medical school. In the absence of this tethered structure, DRPs may be
physically and operationally separated from the medical school campus. This separation of offices can impede proactive communication with administration, students, and faculty, all necessary for responding quickly and with authority to acute issues.\textsuperscript{3,5} Indeed, legal scholars have advised medical schools to make use of specialized expertise to inform decision-making and best support students with disabilities.\textsuperscript{24} Despite legal\textsuperscript{19,24} guidance on the topic, students report that medical school disability structures vary greatly such that they experience significant differences in the availability and expertise of services when disclosing disability and requesting accommodation.\textsuperscript{1}

**Trust**

The relationship between students and their medical school is critical. Unfortunately, when DRPs lack knowledge of medical education and clinical accommodations, a student’s trust in the school to meet their disability-related needs can be undermined.\textsuperscript{7,8,10,12,13} Indeed, a lack of expertise among DRPs may send an implicit message that accommodating disability-related barriers and commitments to disability inclusion are not a high priority. Moreover, it implicitly communicates that medical students cannot be disabled and do not require accommodations, as evidenced by the lack of service and personnel to support the specific needs of this population. Sadly, the lack of medical education-informed DRPs sends a covert message about the appropriateness of including students with disabilities in medical school, perpetuating long-standing ableist views.\textsuperscript{7,13} In so doing, these messages inform the climate around disability disclosure and stigma, and run counter to the stated commitments to diversity, equity and inclusion by medical education associations writ large.\textsuperscript{4-6,26}

**Litigation**

When decision-making is uninformed, faculty are privy to a student’s disability documentation in inappropriate ways, or a conflict of interest persists in the accommodations process that hinders a student’s access to the program, it can lead to litigation and Office for Civil Rights (OCR) complaints.\textsuperscript{27-29} Complaints and litigation consume an enormous amount of resources, including faculty time and effort, cost for legal representation, and time spent supporting the discovery and deposition processes. Complaints and litigation are usually the last resort for students and can be mitigated when medical school faculty employ and work in partnership with a DRP who is cognizant of best and promising practices, mitigating the possibility that decisions are uninformed while removing concerns regarding conflict of interest.

Despite knowledge that these structural barriers exist, no study to date has investigated the current student disability disclosure structures utilized in US-MD schools. This study sought to identify the prevalence of various disability disclosure structures at US-MD schools and the extent to which these structures align with the considerations outlined in the 2018 AAMC report.

**Methods**

This study used survey data to assess the student disability disclosure structures across all US-MD accredited schools. We identified 156 US-MD accredited schools listed on the LCME website. In keeping with previous studies we excluded schools with a provisional or preliminary accreditation, those on probation, or those with exempt status (N = 15), for a total of 141 eligible participants.\textsuperscript{16,30-32} As part of a larger study on medical education, we surveyed the Deans of Students on the disability disclosure structure within their program. We contacted Deans via email and invited them to complete the survey. Two follow-up reminders were sent at 2-week intervals. Respondents selected a structure for disability disclosure from 6 options or elected other and described the model at their institution (Table 2). The University of Michigan Medical School institutional review board exempted the study.

In the first phase of analysis, basic counts were conducted for each of the 6 categories of disability disclosure structure. Responses were coded into 2 groups: alignment and non-alignment with AAMC report considerations.\textsuperscript{7} Though variation in expertise may exist within some structures of service, schools were considered aligned when they retained a medical school or health science-specific disability professional void any conflict of interest, or when they used their undergraduate campus disability office and employed a health science-specific liaison who is specially trained in the clinical programs and adjudicates all decisions for health professions schools. Schools that relegated disability decisions to a dean or assistant dean of students, committee determination, the undergraduate central campus disability office absent a liaison who specializes in clinical programs, or a disability resource professional who maintained dual roles resulting in a conflict of interest (e.g., maintained an evaluative or supervisory role with students) were coded as non-aligned.

In the second phase of analysis, survey results were linked to the 2018 AAMC Organizational Characteristics Database. Data included: medical schools’ region, ownership, financial characteristics, and class size. All organizational data, except class size, were categorical. One investigator (BC) developed categories for class size using national medical school cohort means and ranges as a guideline. Class size categories were defined as small (<100 students), average (100-200 students) and large (≥200 students). Descriptive statistics were used to summarize results. Chi-square tests were run, and p values assessed on the dichotomized disclosure structure data and organizational data. Data analysis used IBM SPSS Statistics Version 26.

**Results**

Disability disclosure structures were collected for 98 of 141 eligible schools (70% response rate). Of respondents, 64 (65%) programs maintained a disability disclosure structure in
alignment with AAMC considerations; 34 (35%) did not. Structures for disability disclosure varied among the 98 respondent schools. Within aligned schools, only 9 (9%) employed a medical school specific DRP—the lead recommendation from the report, while 16 schools (16%) employed a confidential health-science DRP, the preferred model for robust disability service that offers the most benefit to students and programs. Fifty-seven respondents relied on the larger undergraduate university central campus disability office, 39 (40%) with a health-sciences-specific liaison, and 18 (19%) without a health-science specific liaison. Twelve schools (12%) delegated the responsibility of disability review and determination to the student affairs office or dean of students, and 4 (4%) utilized an internal committee (Table 2). No statistically significant relationships were identified between the structure of disability disclosure and an organization's region, ownership, reporting structure, or class size.

Discussion
There is a gap between the number of students who self-identify as having a disability and those willing to disclose and request accommodations at the school level, with structural barriers serving as a potential driver of this gap. Our study found that 35%, or just over 1/3 of responding medical schools employed structures of disability determination that do not align with AAMC considerations and actively disadvantage medical students with disabilities. In particular, 16% of schools maintained a structure that contained a conflict of interest (decisions by committee or student affairs deans), while 19% utilized a structure with a potential for uninformed decision-making, delegating decision-making to non-medical school personnel with no specialized liaison. Only 9% of schools in our study employed a medical school-specific DRP, removing the majority of barriers noted in previous studies. These findings point to a need for ongoing education to medical school administrators to ensure that they appreciate recognize the knowledge and expertise DRPs require to robustly adjudicate disability decisions in medical education.

Reassuringly, the majority of medical schools (65%) maintained a disability disclosure structure in alignment with AAMC considerations, though with some variation in the amount of integration. This finding may be in response to the growing population of students with disabilities in medical education16 and the commitment of medical education writ large to diversify medical school cohorts in an effort to and graduate physicians who reflect the general population of patients.1,2,4-6 The finding that disability disclosure structures were independent of institutions’ region, ownership, financial characteristics, and class size was also reassuring, suggesting that the decision to align with current recommendations is not resource dependent. If financial characteristics and class size do not pose barriers to alignment with AAMC recommendations, then medical schools may be able to easily realign practices and appropriately structure disability disclosure. One mechanism
for this is through the integration of a DRP into the medical school fabric to inform the experience for the student, the school, and to further the institutions’ ongoing efforts to promote inclusion.

Meeting the calls for diversity—to include disability—will require the dismantling of structural barriers that marginalize students with disabilities. Indeed, the structures of disability disclosure hold material consequences for students. First, students face ongoing and considerable stigma surrounding disability, which disincentivizes disclosure. Additionally, students’ fears about disclosing are perpetuated when their schools relegate disability disclosure to a representative with conflicts of interest, or one who does not have specialized knowledge of medical education, relevant disability laws, and clinical accommodations. Commitments to diversifying the knowledge base of the individual in this position. Hiring a DRP to provide services within the medical school is considered best practice; however, in order to be effective this individual must also be supported through professional development and training, be tied into national resources on the topic, and be well-supported and invited into the medical school as a member of the educational team.

Future research should investigate whether structural barriers are associated with disabled student performance and graduation, satisfaction in their educational experience, and the prevalence of students disclosing disability. This work should also focus on survey data drawn from student perspectives to understand the top learner-driven reasons for non-disclosure. Although the GQ findings support the existence of a gap between students’ willingness to self-identify disability on a confidential survey and disclosure to medical schools, it does not provide a mechanism for students to report structural barriers as a reason for non-disclosure. Data of this nature would assist in further interpreting our study findings and provide the means to test for a direct association between lack of disclosure and structural barriers. This represents a future direction for this work, including refining questions on the GQ to determine the driving forces of non-disclosure. Future studies should also include qualitative data from learners on the nuances of disclosure and their relationship with institutional structural characteristics, which would provide rich data to continue exploring this relationship.

Conclusion
To realize the stated goals of achieving diverse medical school classes, including the admission of qualified learners with disabilities, the structure for disability disclosure at medical schools must be well-informed and not place additional burdens on students. To address this, US-MD schools should designate medical school-specific DRPs with knowledge of disability law, medical education curriculum, and best practices to adjudicate disability-related decisions and support the implementation of accommodations, while serving as a confidential resource for students and faculty. Specialization is a valued part of the medical milieu; indeed for students with disabilities access to DRP’s who hold a nuanced understanding of disability in the context of medical education should be equally valued. Schools must move beyond considering the AAMC report and take action.

Authors’ Note
In this article, the authors intentionally switch between person-first (e.g., “person with a disability”) and identity-first language (e.g., “disabled person”). This recognizes and respects the variation in preferred language among persons with disabilities.

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LMM and BC had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Concept and design: LMM, KHP, Acquisition, analysis, or interpretation of data: LMM, BC, KHP, ES. Drafting of the manuscript: LMM, KHP, BC, ES and BKE. Critical revision of the manuscript for important intellectual content: LMM, KHP, BC, ES and BKE. Statistical analysis: LMM, BC. Administrative, technical, or material support: BC and BKE. Supervision: LMM.

ORCID iDs
Lisa M Meeks 1 https://orcid.org/0000-0002-3647-3657
Erene Stergiopoulos 2 https://orcid.org/0000-0002-8039-872X

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