

# Building More-Inclusive Institutional Research for Disabled Populations in the Campus Community

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## About the Authors

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## Abstract

Traditional institutional research systems may limit who is counted and how they are counted because of limitations associated with disability classification, self-disclosure of disability status, and accessibility limitations inherent within some data-collection methods. As postsecondary institutions work toward improving access for disabled groups, the ways in which they collect and report information related to this population becomes even more important. The purpose of this article is therefore to explore current issues faced by institutional research offices when conducting research that includes or is about disabled people, and to propose questions for institutional research professionals to consider. After providing an overview of disabled subpopulations on campus, we focus on four areas: (1) identifying and discussing or defining disabled individuals, (2) ensuring the ethical and equitable treatment of disabled individuals, (3) using accessible methods of data collection, and (4) reporting on disabled populations and disseminating results. We provide a supplementary resource for institutional research professionals in an appendix. This appendix includes questions to consider during the planning and research development phases, as well as the data analysis and dissemination phases.

**Keywords:** institutional research, disability, inclusion, accessibility

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## INTRODUCTION

According to the World Health Organization (WHO; 2024), 1.3 billion people across the world, or roughly 16% of the world's population, have a significant disability. Compared to a decade ago, the number of disabled people has increased. This increase is a result of a variety of factors, including an increased world population, advances in medicine and health care worldwide that have increased life expectancy, and greater awareness—and subsequent diagnosis—of cognitive, mental health, and other health disabilities (WHO, 2024; Young, 2023). It is important to note that a 16% worldwide disability rate is likely an underestimation due to lack of reporting, lack of diagnosis despite meeting disability criteria, and variation of disability criteria and definitions across the globe (Lauer & Houtenville, 2018; McDermott & Turk, 2011). Although no statistics clearly and consistently outline how many disabled students, faculty, and staff are enrolled or work in higher education, there are some approximations from different sources, mainly about students. For example, the U.S. National Center for Education Statistics (2023) noted that roughly 21% of U.S. undergraduate students identify as disabled, and Parsons and colleagues (2020) noted that 14% of Canadian undergraduates identify as disabled. Similar to concerns about underestimations regarding world rates of disability, the same can be said for determining the number of disabled students, faculty, and staff on campus, where lack of reporting and variation of disability criteria and definitions also impact rates.

Providing accurate, contextualized, and useful data about students, faculty, staff, and other postsecondary populations is central to college and university improvement and to the mission of institutional research (IR) professionals and offices (Association for Institutional Research [AIR], 2019).

With regards to disability specifically, however, institutional researchers sometimes limit who is counted and how they are counted because of vagaries in disability classification, self-disclosure of disability status, and accessibility limitations inherent to some data-collection methods. In fact, Hurtado and colleagues noted the need for consideration of disabled populations in institutional assessments as early as 2002. Unfortunately, limited data have been collected about disabled populations at institutional, state, provincial, national, and international levels since that time, and much of it is of questionable quality (Blaser & Ladner, 2020). As a result, decisions that have implications for disabled students, faculty, and staff are made without current data, and it is unclear sometimes whether disabled people are being considered at all (Leake, 2015).

As postsecondary institutions continue to work toward improving access for disabled groups on campus, the ways in which they collect and report information related to this population becomes even more important. To date, postsecondary disability has received little attention within the IR literature (Madaus et al., 2018; Vaccaro et al., 2015). Although some recommendations for collecting institutional data on disability exist (see Cox & Nachman, 2020; Madaus et al., 2020), only Vaccaro et al. (2015) have focused on this topic in IR journals. Given the scarcity of work in this area, the purpose of this article is to explore current issues faced by IR offices when conducting research that includes or is about disabled people, and to propose questions for institutional researchers to consider. After providing an overview of disabled subpopulations on campus, we focus on four primary areas: (1) identifying and discussing or defining disabled individuals, (2) ensuring the ethical and equitable treatment of disabled individuals, (3) using accessible methods of data collection, and (4) reporting on disabled populations, and dissemination of results.

# OVERVIEW OF DISABLED SUBPOPULATIONS ON CAMPUS

Hansen and colleagues (2022) reflect on how their Institutional Research and Decision Support office developed an equitable framework for their work. They note, “Applying an equity lens required that we—at a minimum—continue to disaggregate data to help decision-makers understand inequities in access and outcomes by faculty, staff, administrator, and student groups (e.g., first generation, gender, historically marginalized, under-resourced, low-income, nontraditional, transfer)” (p. 96). As a collective, disabled students, faculty, and staff are a Like group that has been marginalized, in part due to a tendency to aggregate data across disability diagnoses or profiles. Furthermore, even when disabled people are disaggregated by disability diagnosis or profile, many disabled faculty and staff members are often overlooked (Higbee & Mitchell, 2009). Although disabled students are undeniably important, rarely are disabled faculty and staff the focus, unless it relates to enacting accommodations, disability-related classroom climate, universal design for instruction and learning (UD-IL), or disability-related professional development. This is also true of research on disability (Madaus et al., 2018). It is therefore important that IR professionals explore disability from the positions of multiple campus subpopulations (e.g., specific disability diagnoses or profiles; students, faculty, or staff), and that they also consider to what extent these subpopulations are being examined.

## Students

As it relates to disabled students, research efforts have largely focused on providing accommodations

for access via disability resources offices (Madaus et al., 2018). Despite the importance of research on accommodations, it is only one aspect of the disabled student experience in higher education. Moreover, if one believes that college completion is the outcome measure of greatest import, the predictive ability of accessing accommodations is limited (Newman et al., 2021). Although an exhaustive list of potential topics to explore related to disabled students is not possible, some include campus belonging, engagement in high-impact educational experiences, post-college outcomes, online versus on-campus educational outcomes, and academic service use (e.g., writing centers, career services).

## Faculty and Staff

As noted, far less is known about disabled faculty and staff compared to what is known about disabled students. Evans et al. (2017) suggest that, when conversations about disabled faculty and staff do take place, they are typically about preventing workplace injury and managing return to work or accommodations. Although it is meaningful to examine disabled faculty and staff as a collective group and to position this group as employees on campus, consideration should also involve examining these groups separately, because of their distinct roles on campus.

A small body of literature has specifically examined disabled staff on campus, such as student affairs professionals (Brewster et al., 2017; Daddona & Harold, 2018; Higbee & Mitchell 2009). More often, the focus is on experiences of compassion fatigue and burnout within this group (Anderson, 2021; Mullen et al., 2018; Walker et al., 2023). While the literature about staff is quite limited, a growing body of work has supported the development of a greater understanding of the rate of disability and

the experiences of disability among faculty members. In the Canadian context, Statistics Canada (2020) data from the Survey of Postsecondary Faculty and Researchers revealed that the disabled faculty/ professors, instructors, teachers, or researchers<sup>1</sup> are among the groups that experience the highest levels of harassment, ableism, and unfair treatment within the postsecondary environment. Much of the literature pertaining to disabled faculty has focused on ableism within the academy (Brown, 2021; Dolmage, 2017), as well as mental health challenges and disabilities (Kerschbaum et al., 2017; Price, 2011).

Although a thorough examination of the topics related to disabled faculty is outside the scope of this article, suggestions for areas of inquiry or variables that IR professionals might consider include faculty accommodations (American Association of University Professors, 2012), barriers to academic employment (Levitt et al., 2023), burnout, and disclosure. Although some literature about disabled faculty and staff exists, it is fairly limited in comparison to literature about disabled students. Furthermore, discussion and literature about disabled faculty and staff within the realm of IR is essentially nonexistent. There is a need within the IR literature and practice to disaggregate disability data according to students, faculty, staff, and other subpopulations on campus. Due to the limited understanding of disabled higher education employees at the international, national, and institutional levels, many research questions exist that can be explored by IR professionals to support educational missions. A few broad questions that might be of particular interest include, “Do differences exist between retention and promotion rates of disabled faculty and staff and nondisabled faculty and staff?,” “Do salary disparities exist between disabled

and nondisabled faculty and staff?,” and “Do student evaluations of disabled faculty differ significantly from their evaluations of nondisabled faculty?” Answers to these questions have potential to inform decision-makers as they develop equitable and inclusive policies and procedures.

## IDENTIFYING AND DISCUSSING OR DEFINING DISABLED INDIVIDUALS

### Defining Disability

The language around disability is constantly evolving. Disability can be conceptualized in different ways, depending on context such as country, since there are differences in political and cultural characteristics. Furthermore, there can be differences in definitions within countries, depending on who or which group is being cited. In the United States, definitions of disability are provided within Section 504 of the Rehabilitation Act (U.S. Department of Education, 1973) and the Americans with Disabilities Act (ADA) (1990). According to the ADA,

The term “disability” means, with respect to an individual—(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment. (Sec. 12102)

Furthermore, according to the ADA (1990), an individual with a disability is someone who,

1 . This group also includes those who are sessionals and part-time lecturers. It excludes teaching assistant and research assistant positions that are part of an academic program.

with or without reasonable modifications to rules, policies, or practices, the removal of architectural, communication, or transportation barriers, or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity. (Sec. 12131)

In Canada, to define disability one might turn to some different sources such as the Accessible Canada Act (2019), the Accessibility for Ontarians with Disabilities Act (AODA) (AODA, 2005, S.O. 2005, c.11), the Employment Equity Act, and sources such as Statistics Canada and the Social Sciences and Humanities Research Council. In many cases, researchers will draw on the definition within the Accessible Canada Act, which became law in 2019 and is aimed at creating a barrier-free Canada, particularly for disabled people. The Act defines *disability* as

any impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment—or a functional limitation—whether permanent, temporary or episodic in nature, or evident or not, that, in interaction with a barrier, hinders a person’s full and equal participation in society. (Sec. 2)

Although comparing various formal and legal definitions of disability is not within the scope of this article, we do want to highlight that considering whether and how to define *disability* within IR work is important. The decision to include a definition and then to use a specific definition, perhaps based on legal understanding of disability, is going to include or exclude certain participants.

We reviewed a small sample of higher education student surveys that are often used to examine students within the campus context. We found that none of these surveys included a definition of disability. With that being said, we encourage IR professionals to consider including some form of a definition, so that participants are aware of how the researchers have conceptualized the term.

## Person-First vs. Identity-First Language

An example of the way in which language can be contested pertains to the use of person-first and identity-first language (Wooldridge, 2023). Person-first language means that the individual is acknowledged before the disability or condition (e.g., person with a disability, person with autism<sup>2</sup>). The argument is that, with person-first language, the individual is being recognized as a whole person who has value and worth before their condition. As Brown (2011) points out,

From that...perspective, you would think we would support the use of person-first language, because we want to be seen as people with equal rights, value, and worth to non-Autistic people. But we don't. Because when people say "person with autism," it does have an attitudinal nuance. It suggests that the person can be separated from autism, which simply isn't true. (para. 8)

With identity-first language, disability is brought to the forefront (e.g., disabled person, autistic person). With this approach, there is an opportunity for disabled individuals to claim *disability* as an identity and source of pride, to diminish the negative connotations that the term disability has traditionally held (Wooldridge, 2023). Brown (2011) argues that,

2. The autistic community has also not yet reached consensus regarding the capitalization of the word *autism* as related to person-first and identity-first language. Professionals are encouraged to research and use the conventions preferred by those with the lived experience in the community they wish to know more about.

when we say “Autistic person,” we recognize, affirm, and validate an individual’s identity as an Autistic person. We recognize the value and worth of that individual as an Autistic person—that being Autistic is not a condition absolutely irreconcilable with regarding people as inherently valuable and worth something. (para. 18)

These different approaches mean that the preferred use of language can differ from person to person, illustrating the nuances within this population. Recognizing that there are differences in preferred language can allow IR professionals to then make changes in their work that acknowledges this complexity. For example, when collecting data about disabled students, faculty, and staff, or when disseminating findings related to them, IR professionals can include an acknowledgement clarifying this complexity of person-first versus identity-first language, and indicate what their approach to language will be in the data collection and dissemination. Will they be using person-first or identity-first language? Are the different approaches being used interchangeably? If one approach is selected, why? To model this behavior, the authors of this article elected to use identity-first language to acknowledge disability as an identity and cultural group. It is acknowledged that the disability community has different perspectives on the use of identity-first language and the authors respect these perspectives.

## Models of Disability

There are several different models or approaches to conceptually viewing disability. One is the medical model, which views the disability as a part of the person who requires medical care or treatment. From this perspective, disability is viewed as something

that needs to be treated or fixed. While the medical model views disability as something wrong with the individual, the social model of disability views disability as something that has been socially or environmentally created. Other models also exist. For example, the International Classification of Functioning, Disability and Health uses a biopsychosocial model that considers the role of biological, individual, and social factors. There is also the relational model and the human rights model.

The point here is that the approach or model of disability that is informing the work of IR professionals will have several implications. For example, some participants might not identify with disability in the way that a medical model lends itself to. This means that IR professionals could be analyzing and interpreting data that do not fully capture the disabled population on campus. This is one factor that contributes to the underestimate of disabled campus populations.

## Asking Questions about the Presence and Type of Disability

Institutions frequently collect information from and about faculty and staff through a variety of methods including course evaluations, applications, performance evaluations, focus groups, institutionally developed surveys, and national surveys (e.g., Higher Education Research Institute Faculty Survey, National Faculty and Staff Health Assessment, National Study of Postsecondary Faculty). Of note is that, apart from the National Faculty and Staff Health Assessment, the national surveys do not inquire about disability as a demographic. More curious is that even the National Faculty and Staff Health Assessment asks about only a limited number of diagnoses (e.g., diabetes, migraines).

For this article, we reviewed a sample of five higher education student surveys, three from the United States and two from Canada. We found that questions about the presence of disability or impairment were consistently present, but that there

were different ways of asking these questions. We found that these surveys also consistently asked about the type of disability or impairment; these questions were asked in different ways as well. These disability-related questions are presented in Table 1.

**Table 1. Examples of Disability-Related Questions and Response Options in a Sample of Higher Education Student Surveys**

| Survey Instrument   | Question Stem(s)   | Response Options   |
|---|--|--|
| National College Health Assessment (NCHA) through the American College Health Association (ACHA) <sup>3</sup>         | This part of the survey will help us understand your personal characteristics. There may be limitations to the response options provided, and the response categories offered may not represent your full identity nor use the language you prefer. We care about all identities and experiences and ask that you indicate which choice best describes you.<br><br>Do you have any of the following? | <ul style="list-style-type: none"> <li>• Attention-Deficit/Hyperactivity Disorder (ADD or ADHD)</li> <li>• Autism spectrum disorder</li> <li>• Deaf/hearing loss</li> <li>• Learning disability</li> <li>• Mobility/dexterity disability</li> <li>• Blind/low vision</li> <li>• Speech or language disorder</li> </ul>   |
| Canadian Graduate and Professional Student Survey (CGPSS) through the Canadian Association of Graduate Studies (CAGS) | Do you self-identify with any disability or impairment?<br><br>Please specify which one(s) (select all that apply)   | Yes/No/I prefer not to respond <ul style="list-style-type: none"> <li>• Sensory (vision or hearing)</li> <li>• Mobility</li> <li>• Learning (e.g., ADHD, dyslexia)</li> <li>• Mental health (e.g., depression, bipolar)</li> <li>• Autism spectrum (e.g., autism, Asperger’s)</li> <li>• Chronic (e.g., Crohn’s, colitis, multiple sclerosis)</li> <li>• A disability or impairment not listed above, please specify</li> <li>• I prefer not to respond</li> </ul> |

3 . We have included the question that is in the demographics section at the end of the survey. Earlier in the survey, there are other relevant questions such as under the “Chronic Conditions” section, which asks this question: “Have you ever been diagnosed by a health-care or mental health professional with any of the following ongoing or chronic conditions?” The 40-response options list a range of conditions, including many that are mental health-related and others that are asked about in the demographic section.

| Survey Instrument  | Question Stem(s)  | Response Options   |
|--|---|--|
| <p>1st-year Students Survey through the Canadian University Survey Consortium (CUSC)</p> | <p>Do you have any of the following disabilities/impairments?</p>   | <ul style="list-style-type: none"> <li>• Mobility/dexterity</li> <li>• Hearing</li> <li>• Speech</li> <li>• Vision (e.g., blindness, low vision)</li> <li>• Learning/memory (e.g., learning disability)</li> <li>• Other physical disability</li> <li>• Neurodivergence (e.g., autism spectrum, attention deficit disorder)</li> <li>• Mental health</li> <li>• Chronic conditions (e.g., multiple sclerosis, Crohn's, autoimmune)</li> <li>• Other (please specify)</li> </ul>  |
| <p>Student Experience in the Research University (SERU) through the SERU consortium</p>  | <p>Do you have any conditions or disabilities that significantly affect your experience as a student at [university name], including how you learn or perform academically, interact with others, or access campus?</p> | <p>Yes/No for each of the following:</p> <ul style="list-style-type: none"> <li>• Physical disability or condition (e.g., mobility limitation, sensory condition)</li> <li>• Learning disability or condition (e.g., dyslexia, speech disorder)</li> <li>• Neurodevelopmental/cognitive disability or condition (e.g., autism, attention deficit/hyperactivity disorder, brain injury)</li> <li>• Emotional or mental health concern or condition (e.g., depression, anxiety, posttraumatic stress disorder)</li> <li>• Other disability or condition. Please specify</li> </ul> |



| Survey Instrument   | Question Stem(s)  | Response Options  |
|---|---|---|
| <p>National Survey of Student Engagement (NSSE) through the Center for Postsecondary Research</p> | <p>Do you have a disability or condition that impacts your learning, working, or living activities?</p> <p>Which of the following impacts your learning, working, or living activities? (Select all that apply)</p> | <p>Yes</p> <p>No</p> <p>I prefer not to respond</p> <p><b>Sensory disability</b></p> <ul style="list-style-type: none"> <li>• Blind or low vision</li> <li>• Deaf or hard of hearing</li> </ul> <p><b>Physical disability</b></p> <ul style="list-style-type: none"> <li>• Mobility conditions that affect walking</li> <li>• Mobility condition that does not affect walking</li> <li>• Speech or communication disorder</li> <li>• Traumatic or acquired brain injury (TBI)</li> </ul> <p><b>Mental health or developmental disability</b></p> <ul style="list-style-type: none"> <li>• Anxiety</li> <li>• Attention deficit or hyperactivity disorder (ADD or ADHD)</li> <li>• Autism spectrum</li> <li>• Depression</li> <li>• Post-Traumatic Stress Disorder (PTSD)</li> <li>• Another mental health or development disability (schizophrenia, eating disorder, etc.)</li> </ul> <p><b>Another disability or condition</b></p> <ul style="list-style-type: none"> <li>• Chronic medical condition (asthma, diabetes, Crohn's disease, etc.)</li> <li>• Learning disability</li> <li>• Intellectual disability</li> <li>• Disability or condition not listed</li> </ul> |

## Presence of Disability

Although not an exhaustive list of student surveys, there are a few things of note that would be of interest to IR professionals. First, with regards to the Canadian Graduate and Professional Student Survey, there is acknowledgement that participants are self-identifying, and there is use of the terms *disability* or *impairment*. This broadens the approach to disability toward a social model. A participant could select “yes” because of the inclusion of the word *impairment*, and they might not have responded affirmatively if only the word *disability* was used. Second, inclusion of the term *self-identify* in this survey is noteworthy because some instruments might include a question stem such as, “Have you been diagnosed with any of the following conditions?” Incorporating language that centers the participant in decision-making of their experience is more in line with a social model of disability.

It is important to note that definitions and questions about disability are situated within historical contexts. Although there is evidence that there is some movement away from the medical model of disability on some items, other common instruments or those developed within IR offices may not have been revised. An example of this shift in language is with the disability items on the National Survey of Student Engagement (NSSE). In a blog post, Zilvinskis et al. (2021) describe how a small team went through an updating process to address these items. The initial disability question asked, “Have you been diagnosed with any disability or impairment?” With this item, using the term *diagnosed* is more in line with a medical approach to disability where a medical professional must determine whether the person meets criteria to be diagnosed with a disability. The new question, “Do you have a disability or condition that impacts your learning, working, or

living activities” is more in line with a social model.

IR professionals must therefore consider who they are including and excluding in their research based on decisions about how they define disability, which model of disability they are using, and whether they are using person-first or identity-first language. All these considerations will impact how data are collected, analyzed, reported or disseminated, and interpreted.

## Type of Disability

Similar to how the disability-related question can be asked in different ways, so too can questions about disability type. The “Response Options” column in Table 1 presents options for participants to consider for each of the five student surveys we reviewed. There are a few observations of note: The developers of the NSSE have grouped types of disability under four broad headings. This illustrates that the instrument developers not only have considered the specific disabilities they want to include, but also have considered how they might aggregate those disabilities into the broader four categories—potentially for analysis. During the planning and research development phases, they have considered how individuals using the collected data will group responses for the analysis phase. This differs from the 1st-year Students Survey, where its developers have used nine categories of disabilities. This difference is significant because it allows for different questions to be answered: In the 1st-year Students Survey, there is a heading for “Mental Health,” which differs from the NSSE instrument where “Mental Health or Developmental Disability” are grouped under one heading, with multiple response options within that heading. If someone on campus is interested in within-group differences across different types of mental health

diagnoses, the 1st-year Students Survey does not allow for that level of analysis, while the NSSE instrument does. Again, whether it is important to be able to disaggregate mental health conditions during analyses depends on the objectives of the research and the audience. The final point with regards to these surveys is whether examples of different disabilities have been provided. “Are students, faculty, and staff with different conditions going to view themselves within these types of disabilities, or are they going to have to select ‘other?’” Decisions about how to ask questions about disability type should be informed by ongoing discussions within the IR field, departmental or institutional priorities, and theoretical or research-based evidence of promising practices.

IR professionals should consider whether disaggregation by disability type is a level of analysis that is needed. We advocate for a critical, inclusive approach to IR in which multiple identities are acknowledged and prioritized throughout IR practices. Any existing or new instruments or protocols should be carefully reviewed for questions about disability type. Questions that IR professionals might consider are, “Do we ask a demographic question about type of disability?,” “What are the response options?,” “How will we analyze the data in the case of low counts?,” and “What are the practical implications of conducting analyses based on type of disability?”

By approaching data collection, analysis, and presentation or interpretation with an understanding that there are within-group differences according to disability type, IR professionals will be in a better position to support an evolving understanding of their institution’s disabled population and contribute to the growing need for a more comprehensive understanding of this group.

## ENSURING THE ETHICAL AND EQUITABLE TREATMENT OF DISABLED INDIVIDUALS

The ethical treatment of all research participants is critical to the work of IR professionals, as evidenced by the promulgation of and regular revisions to the AIR Statement of Ethical Principles (AIR, 2019). Although these ethical principles serve as a guide for conducting research in an ethical manner in a broad way, it is critical for professionals to understand the nuances of ethically conducting research with disabled participants.

### Vulnerable Populations

Research ethics trainings have long discussed ensuring the protection of vulnerable populations. Among the populations considered vulnerable are those who have “impaired decision-making capacity” (Protection of Human Subjects, 2018, S46.111, #3, p. 11) and those who have “attributes such as... disability” (Panel on Research Ethics, 2022, chap. 4, SA, Art. 4.1). But what makes these groups vulnerable? According to the National Bioethics Advisory Commission (2001), “Vulnerability, in the context of research, should be understood to be a condition, either intrinsic or situational, of some individuals that puts them at greater risk of being used in ethically inappropriate ways in research” (p. 85). The Commission continues by noting that populations are vulnerable “because they have difficulty providing voluntary, informed consent arising from limitations in decision-making capacity ...or situational circumstances..., or because they are especially at risk for exploitation (as in the case of persons who belong to undervalued groups in our society)” (p. 85). Essentially, a prospective

participant's comprehension of consent forms, ability to review consent forms in accessible formats, segregation from (e.g., hospitalization) and discrimination by society (e.g., ableism), and/or potential for being unduly influenced due to needs (e.g., life-saving medical services, funds for medical bills or interventions) all make them vulnerable (Gehlert & Mozersky, 2018). Each of these potential reasons for being part of a vulnerable population should be considered when researching disabled people, because any of those reasons could be present. Not all disabled people are vulnerable. To be clear, a person's disability is not what makes them vulnerable. Rather, it is the inaccessibility, inequity, and noninclusivity of a society, including research endeavors, that produces the vulnerability.

### **Informed Consent Requires Accessibility**

According to the Belmont Report, informed consent, or understanding a research study and choosing to participate without being unduly influenced to do so, is critical to respecting prospective participants and their autonomy (U.S. Department of Health, Education, and Welfare, 1979). Although many investigations conducted by IR professionals do not require informed consent, the investigations that do require informed consent need to consider issues of accessibility. When prospective participants cannot access and understand information about the study and their rights—whether due to physical, sensory, or cognitive inaccessibility—informed consent has not been secured. For example, prospective participants who are blind or dyslexic (which is a disability that impacts reading) who are provided with consent materials in only a paper format, might not be able to read about and understand the study and their rights as participants. As such, informed consent is not obtained. Ensuring accessibility of the informed consent materials and the associated process is a precursor to receiving consent.

### **Subjects of vs. Participants in Research**

Disabled people have long been subjected to research as the subjects of that research in society. Despite college and university researchers investigating this population external to the academy from a medicalized perspective, very little research has explored disabled students, faculty, and staff within higher education (Madaus et al., 2018). Higher education is only beginning to develop a body of literature on this topic. For too long, disabled voices have been marginalized by higher education, and, as a result, very little is known about how best to educate, supervise, train, and serve them. What makes expanding this body of research even more challenging is that very few within higher education understand what is and is not known about disabled people within higher education. What questions should we be asking? What information would serve the needs of college and university faculty and staff in serving disabled people? This is where the opportunity exists to partner with disabled people in the creation of research.

Disabled people are regularly subjected to educational, psychological, medical, and physical assessments. The assessment is being done *for* the disabled person. Rarer are research projects and assessments that are participatory in nature and work in collaboration *with* disabled people. In higher education, community-engaged research with disabled populations is needed. This would be where disabled people (e.g., students, faculty, and/or staff) are serving as co-researchers in the identification of research topics and questions, instrument design, data collection and analysis, and dissemination (Bromley et al., 2015). These populations are leveraging their expertise (i.e., their lived experience and knowledge associated with disability) to help address questions that

they and their community want to answer. They support allies, who are researchers who do not have disabilities but who are working to create more-accessible, more-equitable, and more-inclusive educational environments, and who understand the questions and interpret the data—qualitative and quantitative—using more-complete and more-representative approaches.

## USING ACCESSIBLE METHODS OF DATA COLLECTION

The use of accessible methods of data collection is critical to research ethics and validity. When data collection methods and materials are inaccessible to a disabled person, is it ethical to ask them to participate? Despite IR professionals' desire to have representative data, what might be the emotional implications of inaccessible research experiences for disabled participants? For example, is it ethical to ask a blind participant to take a survey that does not allow for the use of a screen reader and text-to-speech software? This is an important issue to consider, and the solution is not to exclude disabled participants but instead to ensure that research experiences are proactively designed in accessible, equitable, and inclusive ways.

Although social justice, the ethical treatment of participants, and a desire to have representative data should be the primary reasons for ensuring the accessibility of the research methods used, accessible methods likely improve the validity and reliability of the findings. Significant questions about validity arise when participants are unable to access, whether cognitively, physically, or sensorily, data collection materials and/or intervention materials. Certainly, most IR professionals have encountered

participant data that they suspect is inaccurate (e.g., if a participant has selected the same response option for all questions on a survey). When it comes to disabled participants, inaccessible materials may, in some cases, result in unintentional responses that are inaccurate. For example, a student who has a mobility impairment that results in involuntary arm movement might accidentally select a response on an electronic form or might not be able to provide a complete response to an open response question without accessibility features enabled or available. Thus, the following suggestions are offered to improve practice.

### Universal Design for Instruction and Learning

UD-IL has been used within the postsecondary classroom for decades and is more recently being used in postsecondary administration to proactively improve access, equity, and inclusion (Lalor & O'Ryan, 2023). As described by McGuire and Scott (2002), UD-IL

embodies an approach to instruction that anticipates diversity in learners as the norm and operates on the premise that the planning and delivery of instruction as well as the evaluation of learning can incorporate attributes that embrace heterogeneity in learners without compromising academic standards. (p. 27)

With some replacement of terms, IR professionals can adapt this approach to meet research needs. McGuire and Scott's (2002) statement can be revised to read that UD-IL

embodies an approach to [IR] that anticipates diversity in [participants] as the norm and operates on the premise that the planning

and delivery of [research recruitment, data collection, and dissemination] can incorporate attributes that embrace heterogeneity in [participants] without compromising [research] standards. (p. 27)

To achieve this norm of anticipating diversity in participants, UD-IL should be used proactively during the planning and research development phases. Orr and Hammig (2009) identified five core elements of UD-IL, four of which apply to the work of IR professionals: (1) backward design, (2) multiple means of presenting information, (3) inclusive and varied assessment, and (4) empathy and approachability. (Note that the fifth element of UD-IL relates to the delivery and/or instruction of learning materials rather than assessment and evaluation.)

### **Backward Design**

Backward design deals with objectives, and is critical to UD-IL. Essentially, backward design asks, “What is the specific, measurable objective of the research and what is needed to determine if that objective was met?,” “What method or methods are needed to answer the research question in a responsible and respectful way (e.g., quantitative, qualitative, single-subject, mixed methods)?,” and “What are the extraneous elements that might not directly pertain to the objective that may distract or detract from meeting the objective (e.g., the need to use math to answer a question about how often someone engages in an activity)?” With these questions answered, backward design then asks, “How can the extraneous elements be removed so that greater focus is given to the research objectives?”

### **MULTIPLE MEANS OF PRESENTING INFORMATION**

This element can be thought of as relating to marketing: “How can IR professionals more effectively recruit participants with varied abilities?” Although there is limited research about research recruitment methods in IR work, broader research suggests that most studies use a single method of recruitment (Buckley et al., 2023). Given what is known about accessibility of printed and audiovisual content, a variety of methods should be used when recruiting from diverse populations. IR professionals should consider using a combination of the following recruitment methods to reach prospective participants:

- Videos combining audio, images, and text sent by email. (Do not forget to caption videos.)
- Text messages.
- Low-text, high-visual contrast posters. (Remember to hang them at varied heights and in varied locations such as the stairwell and the elevator.)
- In-person verbal requests with visual aids.

Although most of these strategies are likely familiar to IR professionals, the incorporated reminders indicate that more in-depth consideration of accessibility is needed during the planning and research development phases.

### **INCLUSIVE AND VARIED ASSESSMENT**

Inclusive and varied assessment relates to ensuring that people of all abilities can participate in ways that are ethical and accessible to provide information of sufficient quality and validity. Far too much weight is given to single studies, evaluations, and assessments. The findings of a

single survey or a series of focus groups provide initial information, but should not be relied on and should always be approached with caution when it comes to generalization (Bandalos, 2018; Bekhet & Zauszniewski, 2012). This is critical when considering disabled people as some forms of data collection systematically exclude, marginalize, and discourage participation. For example, it would be difficult or impossible for some dyslexic participants to complete a text-based survey that does not allow for the use of text-to-speech technology. Although the importance of access has been discussed already, particular strategies include the following:

- Offer surveys in multiple formats (e.g., paper, electronic).
- Enable or incorporate accessibility features for electronic surveys (e.g., speech-to-text, text-to-speech, closed captioning, alternative text).
- Use software (e.g., Grammarly, Microsoft 365) to confirm that written materials are at less-advanced reading levels to improve access and comprehension. (Note that reading level might need to be more advanced due to the topic, such as when using specific terminology related to health, but language at a 7th grade reading level is recommended.)
- Ensure onsite data collection is physically accessible (e.g., elevator access, space for navigating a wheelchair) and sensory accessible (e.g., low odor).
- Use multiple methods to broaden opportunity for participation (e.g., surveys, interviews, focus groups).

These strategies might not provide 100% access to all participants, so it is important to indicate

on recruitment materials that reasonable accommodations can be provided to participants with documented disabilities.

## **EMPATHY AND APPROACHABILITY**

Given that disabled people, as a class, have long been targets of discrimination (Cotter, 2018; Singer & Bacon, 2020) and are frequently subjected to disability-related diagnostic assessment and performance appraisal (Jez, 2020), it is recommended that IR professionals lead with empathy and try to be mindful of how people in power, including researchers, may have treated them. Likely without malicious intentions, medical professionals, educators, researchers, and others seeking to help disabled people sometimes do not listen to or include them in the process (Keating, 2021; Millar & Renzaglia, 2002; Rood et al., 2014; Sanderson & Goldman, 2022). Recognizing this could be the case, and making concerted efforts to understand their lived experiences, needs and wants related to research, and any obstacles to participation, is a start to respecting disabled participants. It is also important to recognize that many disabled people have been subjected to testing and assessment as children but were never told the outcomes. For some, research has long been associated with highlighting their deficiencies. As such, it becomes even more important to use clear, accessible communication, to be patient with participants who might take longer to participate, to explain terms (e.g., “What exactly is an IRB [institutional review board]?”), to describe the researcher and the importance of the research, and to share findings in accessible ways.

# REPORTING ON DISABLED POPULATIONS, AND DISSEMINATION OF RESULTS

IR professionals play a critical role in disseminating relevant data to appropriate audiences. What data are shared and to whom depends on a variety of factors related to the IR office such as institutional size, type of institution (e.g., college, university), institutional priorities, and state or provincial requirements. Interpretation also plays a role in how the results are used by decision-makers.

IR offices and IR professionals are in a position where they will share different kinds of information with various audiences. Consideration of who the audience is can help decide which data are collected, and then analyzed, reported, and interpreted. The audience might be a government body that has specific reporting requirements, departmental or institutional leadership, practitioners, or students, faculty, and staff. Once the audience has been identified, IR professionals can determine the best way to share information.

After the results are prepared for dissemination, IR professionals must consider how they are going to share the information. The methods for dissemination must also take accessibility into account because, if the information is not accessible, it excludes potential audiences, and does not acknowledge the time and effort that disabled participants took to participate in the research. Accessibility at this dissemination stage can refer to different issues, such as making results available to different audiences so that they are easy to find and understand (Aidley & Fearon, 2021). Results could be shared using reports, presentations, infographics,

social media, journal articles, magazine articles, blogs, or podcasts. Like our earlier suggestion that there should be multiple ways for disabled people to participate in research, there should also be multiple ways of sharing information. For this reason, we recommend using a combination of methods to reach different audiences with varied abilities.

## Making Information Accessible

Some resources can guide IR professionals on how to consider the accessibility of their chosen means for dissemination. For example, the ICT for Information Accessibility in Learning project (ICT4IAL, n.d.) has a set of guidelines for making different types of information accessible. They categorize these information types as (1) text accessibility, (2) image accessibility, (3) audio accessibility, and (4) video accessibility.

### TEXT ACCESSIBILITY

The guidelines describe how important it is to have the ability to easily navigate the information using an effective structure. Doing this allows for readers to easily navigate the information and it makes it easier for someone to transfer the text to a different format. Questions that IR professionals might consider when writing reports are the following:

- Are headings, tables, and figures clearly labeled?
- Is there a description of the organization of the information?
- Is there a table of contents? (This would depend on length of the document.)
- Are there styles embedded within some software programs?



## IMAGE ACCESSIBILITY

The guidelines highlight that images convey meaning to readers and that a written description should also be included for this information to be accessible to everyone. This form of accessibility may be particularly relevant to IR professionals who are typically sharing tables and figures with various audiences. To illustrate the detrimental effect this can have on certain disabled people, Daddow (2021) shares their experience of color blindness:

After being on Twitter for 24 months, at the time of writing, I estimate that I can process “normally” around half the images I see on the platform. I can spend time deciphering what is going on in a few of the remainder if I concentrate hard. The rest remain an impenetrable morass of shapes and numbers, the content of which is meaningless if not invisible. Even if I can distinguish colours in, say, a line graph, it is usually impossible to translate from legend to graph. (p. 102)

Some ways of communicating information are going to include a combination of text, image, audio, and video. For example, infographics are a common way to clearly summarize information in a visual way. A key part of infographics is that they are trying to convey a story to the audience in a way that is easy to comprehend. Some questions to consider if you are using infographics include the following:

- Have you examined the use of colors and ensured there is accessible color contrast?
- Have you provided an alternative format for the infographic such as alternative text, audio, or video narrating the storyline?

## AUDIO ACCESSIBILITY

The guidelines explain how audio should be shared in combination with other types of information so that the audience can access the information in different ways. For example, it is common to use a PowerPoint presentation to convey information, which sometimes includes audio. The combination of the PowerPoint slides with the audio makes this approach to sharing information more accessible.

## VIDEO ACCESSIBILITY

Some of the barriers with videos are similar to those with images. When video is not accessible to an individual, they might need audio description in which there is dialogue explaining what is occurring. You can also include closed captioning for those who cannot access audio within a video so they can still access the material.

## Interpretation of Data

Coburn and Turner (2011) point out, “Data does not speak for itself. Rather, people must actively make meaning of data and construct implications for action” (p. 177). IR professionals are in critical positions to inform audiences across their institutions and beyond about what the data mean—what the story is that can be taken away from the analysis. One of the AIR (2019) ethical principles is, “We provide accurate and contextualized information. We do not knowingly or intentionally mislead the consumers of our information.” In terms of interpreting data, IR professionals might consider these questions:

- Have you situated the research questions and results within various contexts such as the higher education landscape, the institution, or the department?

- Have results been translated into concrete advice for all audiences, both internal and external to the institution?
- Have you taken the results and interpretation to disabled people to do member-checking?
- Have you discussed the limitations of the work?

## Protecting Privacy and Confidentiality

The task of dissemination also addresses this AIR (2019) ethical principle: “We protect privacy and maintain confidentiality when collecting, compiling, analyzing, and disseminating information.” We connect dissemination to this principle because confidentiality is a significant area of concern for disabled participants. If IR professionals are not cautious with certain information, there is a risk that participants’ identities could be revealed. This is of particular concern when a sample size is small or when qualitative methods are being used and participant quotations are included in reports.

## LIMITATIONS AND FEASIBILITY

Limitations exist related to the recommendations offered in this article. As mentioned in the introduction, because the literature is scarce on the topic of disabled populations on campus, it is not possible to conduct a scoping review that includes only articles published within a specific timeframe. Thus, recommendations offered are a synthesis of findings from the limited disability and IR research, known literature from non-IR sources that the authors believe might be helpful to the field of IR, and the authors’ combined experience over several decades researching disabled populations in higher education. As this topic garners increased attention on campus and within the IR profession, this

will likely be a campus population that continues to be discussed. Future work may, therefore, include a more systematic approach to reviewing the applicable literature. Another limitation of this work is the small sample size of the five student surveys reviewed. A more comprehensive examination of higher education surveys would provide a greater understanding of the landscape for whether and how disability and impairments are included or excluded. Finally, student surveys were reviewed but, despite advocating for the use of multiple modes of data collection, the disability-related content of non-survey techniques were not explored. Future work should use interviews or focus groups to consider how disability-related questions are raised, and what information might be gleaned from posing such questions.

Beyond the limitations of this article are feasibility considerations. How realistic is it that IR professionals can develop knowledge and understanding of disability and the skill at developing universally accessible methods and measures, and that they include disabled people in ways that go beyond simply serving as participants? This is a reasonable question. Although equitable, accessible, inclusive research should be a goal, it is not always achievable in every instance, especially when researching diverse people. Competing access needs of participants, turnaround time, and knowledge and skill related to accessibility prevent universal access from being achievable. For this very reason, disability experts (e.g., disability resource professionals, ADA coordinators, access technologists) can be an important resource to the IR professional. Even so, implementing all the recommendations may seem daunting. It is important to recognize that, in the absence of 100% accessibility, taking steps to move toward that goal is still an important accomplishment. For this reason, we suggest that IR professionals use a Plus-One

approach, which is typically used to help educators embed UD-IL principles into their teaching and course development. Tobin and Behling (2018) suggest that a sustainable method of incorporating those principles into a course is by finding just one more way to support their students' learning. This concept can be applied to IR, where IR professionals can gradually incorporate more-inclusive practices for disabled campus populations by finding just one more way to make their practices more inclusive. To support IR professionals with identifying one specific thing they would like to change in their practices, we have provided a supplementary resource to this article called Starting Points for Disability-Related Access, Equity, and Inclusion for Research (see appendix). In this appendix, we offer a series of questions that are intended as a guide to improve the accessibility, equity, inclusion, and quality of IR. In line with a Plus-One approach, we invite IR professionals to identify a question that may be achievable as an action item, and focus on that question prior to implementing further changes.

## POTENTIAL IMPLICATIONS

The recommendations offered have the potential to improve the comprehensiveness of the data that IR professionals collect and the stories they can tell. Again, relatively little is known about the experiences, outcomes, and opinions of disabled students, faculty, and staff. With better data and a greater understanding of disabled people on campus, decision-makers are better equipped to make critical decisions on budget, staffing, retention, and decisions.

In addition to improved decision-making ability, the recommendations could increase collaboration with disability experts on campus such as disability

resources professionals, ADA coordinators, and accessible technology professionals. Disability resource scholars (e.g., Madaus et al., 2018) have called for more-comprehensive data and research on disabled people in higher education. As such, collaborators within disability-related departments might be highly interested in supporting and being a resource for IR professionals who are seeking to better understand disabled students, faculty, and staff.

Finally, IR may be positioned to request additional resources to facilitate data collection related to disabled people. New, more-accessible survey software could be an option, and additional staff with expertise in disability, accessibility, and research might be justifiable with increased research on disabled campus populations and the associated findings. Given the increasing number of students disclosing their disabilities on campus (Parsons et al., 2020; National Center for Education Statistics, 2023), the need for information about this student population will become only more critical and require more investment in personnel across departments, including IR.

## CONCLUSION

One of the AIR (2019) ethical principles is this:

We value lifelong learning and the enhancement of our field. We draw on and contribute to relevant and emerging scholarship and educate ourselves on developing trends. We utilize those methods and techniques for which we have, or can obtain, appropriate knowledge and capabilities.

As the demographic of people on college and university campuses continues to diversify, it becomes even more important for IR professionals

to continue learning about specific populations on campus. IR professionals must acknowledge their position as change agents on campus and recognize that, because they are in this position, they have a significant role to play in advancing social justice and equity-driven approaches and initiatives. Reflecting on their practice and the choices they make is critical to moving the IR field forward and potentially improving the experiences of marginalized groups on campus, such as disabled students, faculty, and staff. Without actively working toward more-inclusive IR practices, there is a risk that the marginalization of certain groups will continue. Peña (2014) points out, “When certain areas of inquiry are marginalized, they bring less attention to the education problems in need of change because those problems and areas of change are neither addressed nor discussed: they become invisible” (p. 31). In this article, we discussed ensuring the ethical and equitable treatment of disabled people, identifying and discussing or defining disabled people using accessible methods of data collection, and reporting about disabled people on campus. Throughout these discussions, we have recommended inclusive approaches and practices for IR that would support building a more inclusive IR system that takes disability into account.

## **APPENDIX: STARTING POINTS FOR DISABILITY-RELATED ACCESS, EQUITY, AND INCLUSION FOR RESEARCH**

This series of questions is intended as a guide to improve the accessibility, equity, inclusion, and quality of IR. These two lists are not exhaustive. We invite you to view them as a starting place with developing IR practices that are more inclusive. Try

to address one or more of these questions in your work, reflect on the process of making the relevant changes, and share your experiences in some way with the rest of the IR community.

### **Planning and Research Development**

- Have disabled people been considered as co-researchers?
- Have disabled people been considered in the development of the research purpose and research question?
- Does the research consider diversity in ability (e.g., cognitive, physical, sensory)?
- Has universal design been used to develop the procedures and data collection methods?
- Have extraneous elements (e.g., questions, language) been removed from recruitment materials, consent forms, and instruments or scripts?
- Have jargon, key constructs, and other complex terms been defined and/or simplified on recruitment materials, consent forms, and instruments or scripts?
- Have recruitment materials, consent forms, and instruments or scripts been developed in multiple formats (e.g., written, auditory)?
- Are all materials created in accessible formats (e.g., alternative text, formatted for text-to-speech and speech-to-text technology, reading level at or above a 7th-grade reading level)?
- Is the length of the survey or interview reasonable for students with difficulty processing information quickly, reading, and/or paying attention?
- Are disability demographics being collected? Has disaggregation of disability profiles been considered?

## Data Analysis and Dissemination

- Have disabled people reviewed the findings for cultural context?
- Have disabled people reviewed the reports for cultural context?
- Have disabled people given their feedback on implications?
- Have disabled people been asked about avenues for sharing the findings with the disabled community?
- Are the findings presented in multiple formats (e.g., written, auditory)?

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