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A Systematic Review of Barriers and Facilitators of Disability Disclosure and Accommodations for Youth in Post-Secondary Education

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ABSTRACT

This review critically appraised the literature on disability disclosure and accommodations for youth with disabilities in post-secondary education (PSE). Systematic searches of 8 databases identified 36 studies meeting our inclusion criteria. These studies were analysed with respect to the characteristics of the participants, methodology, results of the studies and quality of evidence. Five thousand, one hundred and seventy four participants (mean age 26.4) were represented across six countries. Barriers to disability disclosure and requests for accommodations in PSE included stigma, discrimination, lack of knowledge of supports and how to access them, type of course and instructor, coping styles, and nature of the disability. Facilitators included supports and resources, coping and self-advocacy skills, mentorship, and realising the benefits of disclosure. Factors affecting the process and timing of disability disclosure in PSE included the type of disability, and mode of disclosure. There was a lack of consensus on the timing of disclosure.

Introduction

Well-educated citizens are the foundation of social equity, cohesion and successful participation in the economy (International Association of Universities, 2008). Access to, and participation in post-secondary education (PSE) are particularly essential for empowering marginalised groups, such as youth with disabilities (International Association of Universities, 2008; Tuomi, Lehtomäki, & Matonya, 2015). Currently, there are nearly 43,000 Canadian young adults aged 15–25 who have a disability in the post-secondary system (McCloy & DeClou, 2013). Exploring this group is especially important because youth with disabilities are less likely to pursue PSE, to stay enrolled, and secure employment (Burgstahler & Moore, 2009; National Council on Disability, 2003). Such trends are often a result of the numerous barriers that they encounter. Common challenges to attending and completing PSE include financial challenges, disclosing a disability and asking for accommodations, inadequate transition

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supports in high school, finding suitable programmes that match interests and abilities, accessibility and transportation issues, and discriminatory attitudes (Dutta, Kundu Madan, & Schiro-Geist, 2009; Herbert, Hong, & Byun, 2014; Lindsay, Duncanson et al., 2017; Lindsay, McPherson, & Maxwell, 2017).

Despite disability discrimination legislation mandating supports to ensure equitable access to PSE, youth with disabilities continue to encounter numerous barriers, which reduce their likelihood of finishing their programme (Hartley, 2010; Redpath et al., 1999; Venville, Street, & Fossey, 2014). For example, although the majority of typically developing youth (some 72%) attend PSE, only 50% of those with a disability are enrolled (McCloy & DeClou, 2013). As a result, youth may have poor or disrupted educational trajectories that impact their future employment, career aspirations and earning potential (Lindsay, Duncanson et al., 2017; Lindsay, McPherson et al., 2017; Venville et al., 2014; Waghorn, Chant, Lloyd, & Harris, 2011). Further, transition services from high school to PSE are often lacking, unavailable or inadequate (Lindsay, Duncanson et al., 2017; Wagner, Newman, Cameto, Garza, & Levine, 2005), especially with self-advocacy skills and requests for accommodations. Participating in PSE is critical for people with disabilities because there is a strong link between having PSE credentials, employment outcomes and reduced risk of poverty (Dowrick, Anderson, Heyer, & Acosta, 2005; Lindsay, McDougall, Menna-Dack, Sanford, & Adams, 2015; Lindsay, Duncanson et al., 2017; Lindsay, McPherson et al., 2017; Lustig & Strauser, 2003; Stodden & Dowrick, 2000). Therefore, more efforts are needed to increase and retain youth with disabilities in PSE to enhance their full participation in society (Dowrick et al., 2005).

The needs and rights of students with disabilities in PSE are officially recognised in many countries. For example, Canada, the United States, the United Kingdom, and Australia have legislation regarding the integration of youth with disabilities in PSE (Fuller, Healey, Bradley, & Hall, 2004; Lindsay, Duncanson et al., 2017). Providing adequate supports and accommodations for students with disabilities is critical for retention and completion of PSE (Getzel & Thoma, 2008). Accommodations within PSE are supported by human rights and accessibility legislation and place a duty on educators to provide reasonable accommodations for students (Davis, 2005; Sanford & Milchus, 2006). Accommodations include things such as modified environments, tasks and adaptive technology, which can optimise students' engagement in PSE (Hutchinson, Versnel, Chin, & Munby, 2008; Tuomi et al., 2015). Specific examples of accommodations that students commonly receive in PSE include note takers, extra time on tests, assistive technology and physical accommodations (Lindsay, Duncanson et al., 2017). Providing accommodations can enhance physical (i.e. improved symptom management, reduced fatigue) and psychological health (i.e. improved self-efficacy, social support, and reduced stress) (Brohan et al., 2012; Dong, Oire, MacDonald-Wilson, & Fabian, 2012). Within Canadian and American high schools, staff are responsible for identifying and providing necessary services to youth with disabilities, whereas at the post-secondary level, students are required to self-identify and request accommodations on their own (Barnard-Brak, Schmidt, & Wei, 2013; Stodden & Dowrick, 2000).

Although accommodations have the potential to engage youth in PSE they are often underutilised, with less than one in four PSE students with disabilities self-disclosing their condition at college (U.S. Department of Education, 2006). The low disability disclosure rate is often a result of many young people with disabilities being poorly prepared to disclose their condition and negotiate accommodations and how to access campus supports (Bruyere, Erickson, & VanLooy, 2004; Davis, 2005; Lindsay, Hartman, & Fellin, 2016; Lindsay, Duncanson

et al., 2017). Many youth encounter difficulties accessing and obtaining accommodations and supports (Dowrick et al., 2005; Erten, 2011). Educators also struggle with accommodating youth with disabilities (Lindsay, Duncanson et al., 2017).

Lacking access to or having inappropriate accommodations can hinder quality of life and ability for youth to complete their degree (Charmaz, 2010; Lindsay, Duncanson et al., 2017). Given the complexity of disclosing and requesting accommodations (i.e. how, when, whom to disclose), there is a critical need to understand how educators and youth can work together to have effective disclosure discussions to facilitate the successful outcomes.

Although policies exist to help accommodate students, they may encounter attitudinal barriers in accessing them (Flaherty & Roussy, 2013). For example, people with disabilities often encounter significant social exclusion, negative attitudes, discrimination and stigma, which are substantial barriers for youth entering and completing PSE (Flaherty & Roussy, 2013; Gilbride, Stensrud, Vandergoot, & Golden, 2003; Lindsay, Duncanson et al., 2017; Pennington, 2010). Stigmas refer to individual attributes that are viewed as personal flaws within a social context (Goffman, 1963). Those who lack disability awareness and experience in working with people who have a disability tend to base their knowledge on stereotypes and misperceptions, which can lead to negative attitudes and stigma (Getzel & Thoma, 2008; Lindsay, Duncanson et al., 2017). Youth with disabilities often encounter feelings of marginalisation and exclusion by other people's awkwardness and discomfort in interacting with them (Flaherty & Roussy, 2013; Lindsay & Cancelliere, 2017).

Given that student's success is often affected by attitudes and willingness of academic staff to provide accommodations, students with disabilities are often reluctant to disclose their condition for fear of differential and discriminatory treatment from their professors and peers (Fuller et al., 2004; Lindsay, Duncanson et al., 2017). Thus, it is important to better understand the factors facilitating and preventing youth from disclosing their condition to access accommodations in PSE.

This review addresses an important gap in the literature on youth with disabilities and PSE. Although there is growing research on disclosure and accommodations, it has not yet been synthesised for disabled youth who attempt to enter or remain in PSE. It is critical to identify effective disclosure strategies and accommodation processes because they can improve quality of life and employment outcomes (Lindsay, McPherson et al., 2017). People with disabilities lack an equal opportunity to access PSE, which can have a lifelong effect on them (Flaherty & Roussy, 2013). Lacking access to PSE accommodations places youth with disabilities at risk of not completing their degree and living in poverty (Barnard-Brak et al., 2013). Developing and understanding effective processes to disclose and providing accommodations for youth with disabilities in PSE can help student experiences and outcomes while also informing the role of educators and employers.

Methods

We conducted a systematic review to understand: (1) the barriers and facilitators to disability disclosure and accommodation requests in PSE among youth with disabilities; and (2) the processes involved regarding how and when disabled youth disclose their condition and request accommodations in PSE.

Search Strategy

We developed our search in consultation with a research librarian, youth with disabilities, clinicians and educators. We conducted a series of electronic searches for peer-reviewed literature using the following databases: MEDLINE, HealthStar, EMBASE, ERIC, JSTOR, Sociological abstracts, PsycInfo, and Scopus. Our search used subject headings and search terms related to PSE (e.g. college, higher education, university, skill development, training), disability manage*, disclosure and accommodations (e.g. disclosure, non-disclosure, conceal, discrimination, stigma, attitudes) youth (adolescent, young adult, teen), and disability (disab* and a broad list of disabilities). We used search terms reflecting varied methodological designs because we recognised the challenges in retrieving studies focusing on disability disclosure and accommodations among youth (Petticrew & Roberts, 2005). We also searched reference lists of the articles that met our inclusion criteria.

Article Selection

We applied the following inclusion criteria to select studies for this review: (1) at least 50% of the sample has a disability, defined as an impairment in body structure and function; (2) includes participants who are between 15 and 30 years of age, or an average age within this range, or they delineate their findings by age; (3) an empirical study reporting on disability disclosure and/or accommodations in PSE; (4) published in English in a peer-reviewed journal between 1996 and September 2016. We excluded: (1) descriptive or opinion articles, dissertations and conference proceedings; (2) studies that did not discuss disclosure/accommodations for disabled youth; (3) grey literature; and (4) studies focusing on mental health or autism because this is synthesised (Brohan et al., 2012; Jacob, Scott, Falkmer, & Falkmer, 2015; Venville et al., 2014, 2016).

Data Abstraction

We identified 3300 articles for potential inclusion in our review (see Figure 1). We imported articles meeting the inclusion criteria into *Endnotes* and removed duplicates (*n* = 1888). Two researchers independently applied the inclusion criteria to screen abstracts for relevance (*n* = 1412). We read the remaining 198 articles while independently applying the inclusion criteria. We resolved any discrepancies about which articles to include through discussion amongst the team and re-reading the article. Thirty-six articles met our inclusion criteria for this review (see Figure 1). We kept a journal of inclusion decisions as part of an audit trail.

The first author extracted relevant data from the articles, which was independently verified by the second author. We used a structured abstraction form, developed by a team member with expertise in synthesis methodology and pilot tested prior to applying to all of the articles (see Tables 1 and 2). Data included information about each study (country, recruitment setting, design and aims), participants (sample size, disability type, socio-demographics), results (barriers, facilitators, disclosure processes, timing, how disclosed and reasons for non-disclosure), accommodations (expectations and experiences, processes, timing, barriers/facilitators), limitations and risk of bias. We followed the PRISMA statement, a method of transparent reporting (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group,
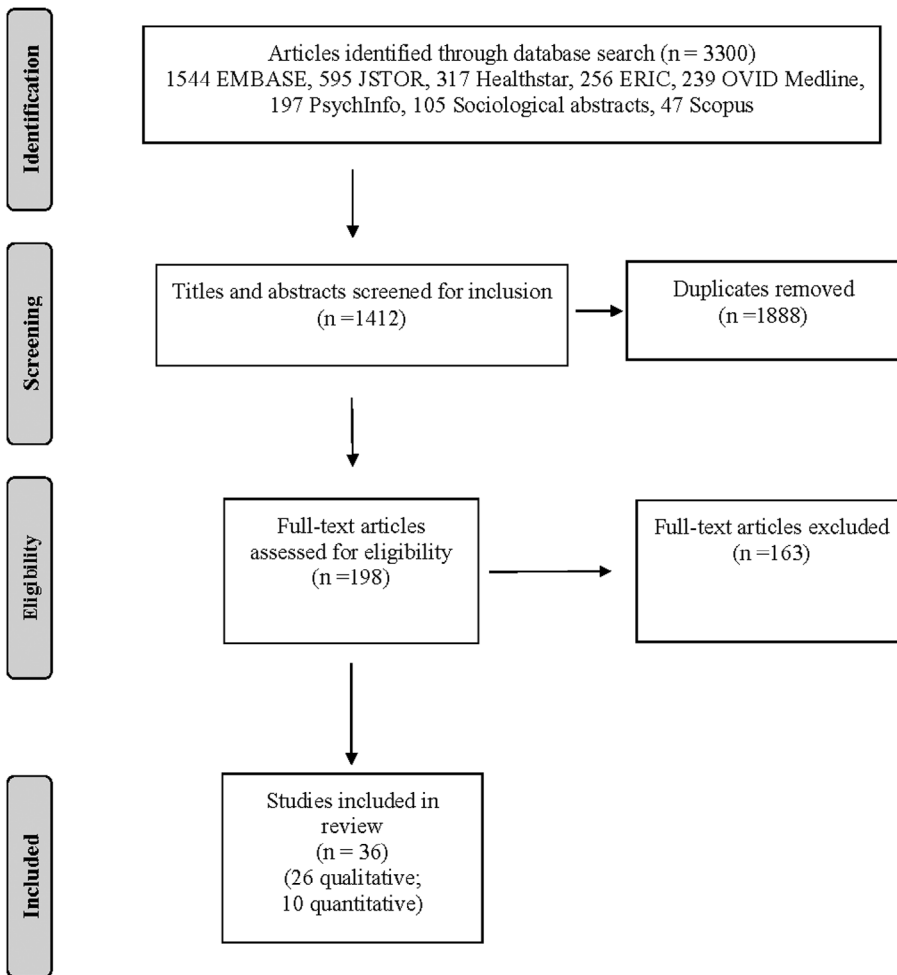
Figure 1. Search process flow diagram illustrating inclusion and exclusion of articles for systematic review.

2009) and the Cochrane guidelines for qualitative reviews (Noyes, Popay, Pearson, Hannes, & Booth, 2008) to guide us in reporting a rigorous review.

Data Synthesis and Analysis

Due to the heterogeneity across the study populations (i.e. clinical differences, ages, settings) and outcome measures, along with the lack of effect sizes reported, it was neither feasible nor appropriate to conduct a meta-analysis (Borenstein, Hedges, Higgins, & Rothstein, 2009; Loannidis, Patsopoulos, & Rothstein, 2008). In fact, some research has shown that pooling such heterogeneous data can be misleading (Letzel, 1995; Smeeth et al., 1999). Therefore, for our systematic review, we followed the guidelines for narrative synthesis outlined by Petticrew and Roberts (2005) which are relevant for reviews with diverse methodologies. To synthesise all of the articles that met our inclusion criteria, we first organised all of the included studies into categories (e.g. barriers, facilitators, how and when disclosed) to guide our analysis. Second, we grouped the studies by findings (outcomes and methodology)

Table 1. Overview of studies (mixed methods and quantitative).

Authors, year (country)	Sample characteristics	Objective	Design and analysis (theory)	Key findings*	Limitations and future research
Barnard-Brak et al. (2010) (US)	276 college students (mean age 26.87; 65.5% female; 43.8% learning disability; 21.2% emotional disorder; 18.5% physical disability)	To develop and test the factor structure of a measure of attitudes towards requesting accommodations among college students with disabilities	Survey; attitudes towards requesting accommodations (ATRA scale) (theory: n/a)	• Students who have higher scores on ATRA appear less likely to request accommodations, thus attaining lower academic achievement • The utilisation of ATRA could help decrease the attribution of this increasing, non-traditional population of students by determining attitudes towards requesting accommodations among students with disabilities	• The sample may not be representative of college students with disabilities across the nation • Sample consisted of students registered with their office of disability accommodations, which excludes college students with disabilities who are not registered • We do not know the necessity of accommodations for these students with disabilities
Barnard-Brak and Sulak (2010) (US)	83 students with a disability (65% female; 23 academic degree programmemes represented)	To examine attitudes towards requesting accommodations in online learning among college students with disabilities compared to requesting accommodations face-to-face	Survey (ATRA scale) (theory: n/a)	• Students with disabilities did not have significantly different attitudes towards requesting accommodations face-to-face vs. online • Students with visible disabilities have more positive attitudes towards requesting accommodations online vs. face-to-face compared to students who have hidden disabilities	• Ages not reported • Somewhat of a convenience sample • Heterogeneous disability types; over-representation of females
Barnard-Brak et al. (2013) (US)	43 high school students with disabilities (48% female; 76% invisible disability); mean age not provided	To understand transition services for high school seniors with disabilities via one-on-one mentoring	Survey (ATRA) (theory: n/a)	• The transition service significantly improved attitudes towards requesting accommodations (large effect) • Positive outcomes linked with the programme included increased applications and enrolment in PSE	• Possibility of self-selection bias • Many demographic characteristics not reported

Study	Sample	Aim	Method	Findings	Limitations
Cawthon and Cole (2010) (US)	110 undergraduate students with learning disabilities (SLD)	To gather SLD perspectives on accommodations use and obstacles they faced in gaining access to services	Survey (theory: n/a)	• Student population might not have used the university resources to the extent available • There was an increase in accommodations from high school to college • Students lack knowledge of their IEP plans • Students generally knew the implications of their disability	• Not a representative sample • Convenience sample • Data is drawn from a single university • Future research through a longitudinal study design
Cole and Cawthon (2015) (US)	31 university students with learning disabilities (48% male; 45% were in their senior year)	Investigate differences in psychological attitudes and factors between SLD who disclose and who do not disclose; what factors SLDs consider when deciding if they will self-disclose their disability to university personnel	Survey (ATRA, self-determination and revised self-disclosure scale) (self-determination theory)	• ATRA, self-determination and self-disclosure scores were significantly different between those who disclosed and those who did not • Those who did not disclose had negative views of accommodations • Those who disclosed had more negative experiences with classmates than those who didn't • Those who had professors with positive demeanours disclosed through personal conversation rather than giving them a letter • Their view of their disability affected their choice to disclose	• Low number of participants in the quantitative study • Use of chosen self-determination and self-disclosure scales which are mostly unpublished and therefore unavailable for use of psychometric properties • Results are not likely to be generalisable • The presence and severity of learning disability was not reported • Sample characteristics were lacking
Cook et al. (2012) (UK)	31 medical students (17 females, 14 males)	To ascertain the effectiveness of the Student Support Card from the user's perspective in both institutions	Survey; semi-structured interviews (social model of disability)	• The student support card was well received by students and useful way of increasing confidence and reducing social barriers • The card helped them to disclose to their teacher • The card helped to validate their request • More knowledge about the card is needed	• Non-representative sample • Only 6 of the 31 participants completed an interview • Heterogeneous sample (various disabilities; ages not given)

Table 1. (Continued).

Authors, year (country)	Sample characteristics	Objective	Design and analysis (theory)	Key findings*	Limitations and future research
Fuller et al. (2004) (UK)	173 students (60% non-visible disabilities); age and gender not provided	To identify and evaluate disabled students' experience of teaching, learning and assessment in higher education	Survey (theory: n/a)	• More flexibility is needed for staff to make reasonable accommodations • Two-thirds of students with dyslexia consulted the disability co-ordinator compared to those with visible disabilities • Some teachers did not accommodate student's disability	• Lack of demographic characteristics reported • Lack of details in methods and analysis
Glover-Graf and Janikowski (2001) (US)	186 rehabilitation students (78% women; 20% men; mean age of 27; 16.1% had a disability)	To determine whether students disclosed their disability to others within a rehabilitation programme	Survey (theory: n/a)	• Identifying students with disabilities who have accommodation needs is essential for effective PSE • Having a disability influenced the majority of students to begin a career in rehabilitation • Those who requested accommodations asked instructors for learning modifications; and classmates for help with note taking, personal care and transportation	• Various disabilities • Relatively low response rate
Hill, 1996 (Canada)	264 students with disabilities (62% female; 22% with physical disabilities; 21% multiple disabilities, 19% learning and 15% auditory) mean age not reported	To examine the perceptions of students with disabilities attending universities in Canada regarding the adequacy of services from the Office of Students with Disabilities (OSD)	Survey (theory: n/a)	• The majority of students rated services as good or excellent; 35% indicated their needs were not being adequately met, with nearly one quarter of students lacking services • More than 20% of students reported that delays in obtaining services/lack of services impacted their education	• Limited to students attending universities in Canada

Author	Sample	Objective	Methods	Findings	Limitations
Kurth and Mellard (2006) (US)*	108 students with disabilities (mean age of 30; 51% female; 39% had learning disabilities, 23% orthopaedic or mobility, 13% deaf, 9% blind, 4% TBI, 12% other); at community and college	To determine student perceptions of the accommodation process	Surveys (theory: n/a)	• Five issues that students experienced: a sense of belonging, access to academic information, supports for independence, and labelling disabilities as they relate to discrimination and self-determination, or students' expressions of their willingness to work through difficulties they encounter	• Heterogeneous sample
Miller et al. (2009) (UK)	328 (age and gender not reported)	To explore rates and types of disability in medical students, whether they disclose and reasons for non-disclosure	Survey (theory: n/a)	• 4% disclosed disability on medical school application • Disability-related challenges to their studies were reported by half of participants but two-thirds did not seek support • 12% experienced discrimination • Non-disclosure may be a result of narrow definitions of disability and negative attitudes • Having supports helped with coursework	• Lack of description of demographic characteristics of sample • Only included one site • Possible selection bias
Newman and Madaus (2015) (US)	3190 students with disabilities (69% learning disabilities; 9% emotional disturbances, 6% intellectual disabilities, 6% other health impairments, 5% speech) mean age not reported	To understand the accommodations and supports provided to secondary and post-secondary students with disabilities	Secondary analysis of longitudinal survey (theory: n/a)	• Only 35% of youth with disabilities informed their college of their disability, while 95% received disability accommodations at high school, only 23% did so at the post-secondary level • Students with disabilities at post-secondary were more likely to be male than female (62% vs. 38%)	• Post-secondary supports may be under-reported • Frequency of each type of accommodation is unknown

Note: This table only reports findings related to our objective to understand best practices on how and when disabled youth disclose their condition and request accommodations; and what are the barriers/facilitators to disclosure and accommodations and implementation of filling these needs.

Table 2. Overview of studies (qualitative).

Authors, year (country)	Sample characteristics	Objective	Design and analysis (theory)	Key findings*	Limitations and future research
Baron et al. (1996) (UK)	23 social work students with various disabilities (specific ages and genders not reported)	To examine policy and practice within social work training	Interviews (social construction of disability)	• Barriers to training included disabling physical environment, stereotyping, lack of equal opportunities policy, discrimination and self-censorship • Students were reluctant to disclose their condition on their application • Issues of disclosure persisted once in the programme (especially for those with less visible impairments)	• Lack of description of demographic characteristics of sample • Description of analysis was lacking
Blockmans, 2015 (Belgium)	22 students with physical impairments (17 females; 5 males); mean age 23.1; 9 had visible disabilities, 4 had alternating and 9 were non-visible or easily concealable	To explore whether students with mobility or sensory impairments manage disability-disclosure and topic restraint in higher education	Survey and interviews (Communication accommodation theory; and CARE for inter-ability communication model)	• Disability disclosure is a balance between fulfilling physical needs and maintaining a normal positive identity • Visibility of impairments played a minor role in disclosing • Disclose to get practical assistance and maintain well-being and physical functioning • Those with undiagnosed, rare or alternating visible conditions needed to disclose to legitimise their request • Disclosed to those they were closest to • Concern about the negative implications of disclosing	• Small sample size precluded reliable statistical analyses to address the research goals • Study was likely to recruit people who were willing to talk about their disabilities and thus disability-disclosure was not an issue for any respondents • Heterogeneous sample
Burgstahler and Moore (2009) (US)	53 post-secondary students with various disabilities (43% female, 32% male, 25% did not specify) mean age not specified	To understand the challenges that students with disabilities face in using student services	13 focus groups (theory: n/a)	• Students reported that educators did not know how to deal with them and they felt disrespected • There is a need to increase staff knowledge of disability and comfort level • Better communication and accommodation strategies, rights and resources	• Heterogeneous sample • Sizes of focus groups varied greatly • They tried to quantify qualitative data

Study	Sample	Aim	Method (theory)	Findings	Limitations
Cole and Cawthon (2015) (US)	15 university students with learning disabilities (age/gender not specified)	Investigate differences in psychological attitudes and factors between SLD who disclose and who do not disclose	Semi-structured interviews (self-determination theory)	• Those who did not disclose had negative views of accommodations and their disability • Those who disclosed had more negative experiences with classmates and with disability services than those who didn't disclose • Those who had professors with positive demeanours disclosed in-person than giving them a letter • Their view of their disability affected their choice to disclose	• Convenience sample • The presence and severity of learning disability was not reported • Sample characteristics were lacking
Dowrick et al. (2005) (US)	Post-secondary students with various disabilities (sample size and characteristics not reported)	To explore student identified barriers to the access and utilisation of educational supports and employment	Focus groups (theory: n/a)	• Students have difficulty obtaining accommodations • Discriminatory attitudes about their ability also negatively impact students in PSE • Programmes need better co-ordination • A need for faculty mentoring, internships, job training and knowledge of accommodations	• Did not have the recommended sample size for focus groups • Did not provide the demographic characteristics of the participants or the types of disabilities
Erten, 2011 (Canada)	7 females (5 learning disabilities, 2 mobility disability; mean age 25 years)	To explore the perspectives of students with disabilities studying at PSE	Focus group (social model of disability)	• Barriers: attitudes from faculty and peers • Office for students with disabilities was an important source of support in providing accommodations • More support is needed to address attitudinal barriers	• Small and heterogeneous sample (likely did not achieve saturation) • Female-only sample
Fox et al. (2011) (UK)	8 (5 females, 3 males; aged 22–35; various disabilities and chronic conditions)	To explore how junior doctors' perceive the illness experience during their training	Interviews (theory: n/a)	• Ineffective communication results in difficulties experienced by trainees • Coping style plays a key role in their experience • Stigma and fears about other people's perceptions prevented disclosure • Willingness to disclose was affected by the extent of supervisor support • Those who had disclosed felt relieved	• Small, heterogeneous sample

(Continued)

Table 2. (*Continued*).

Authors, year (country)	Sample characteristics	Objective	Design and analysis (theory)	Key findings*	Limitations and future research
Goode, 2007 (UK)	20 (14 females, 6 males) university students (age not provided), with various disabilities	To understand the experiences of students with disabilities at university	Interviews (theory: n/a)	• Accessing learning accommodations at PSE was challenging • Disclosure and needs assessment is often shocking to some who have been in denial about their disability • Lack of awareness of the supports available • Students with visible disabilities often draw unwanted attention	• Heterogeneous sample • Demographic characteristics not provided
Graves et al. (2011) (US)	11 (2 females, 9 males) students with learning disabilities in STEM; mean age not provided	To explore whether online access to course readings was beneficial to students with disabilities	Interviews (theory of universal design)	• Online asynchronous access enhanced their learning experience (clarity, organisation, access, convenience, achievement and a disability coping mechanism)	• Small, heterogeneous sample
Holloway, 2001 (UK)	6 university students with disabilities (age, gender and disability type not specified)	To explore the experiences of PSE from the perspective of students with disabilities	Interviews (theory: n/a)	• Those who had positive experiences had supports and accommodations from disability office and external agencies • Accessibility issues (stressful and time consuming)	• Sample size is too small to reach saturation • Insufficient demographic characteristics
Hong, 2015 (US)	16 (4 males, 12 females; various disabilities) college students with disabilities	To explore the experiences of students with disabilities	Reflective journaling for 10-weeks (integration/ involvement theories)	• Barriers: faculty had lower expectations; advisors lacked knowledge of disability and were unresponsive • Stressors included physical, mental and emotional demands, stigma; quality of support received	• Heterogeneous sample • Ages and duration of disability not provided
Jung et al. (2014) (Canada)	14 student OTs with various disabilities (age not reported)	To explore the lived experience of student occupational therapists with disabilities	Interviews (theory: n/a)	• Most participants were self-reliant and took action when they required accommodations • Some felt accepted while others were excluded and needed to conceal their disability • Most reported that disability disclosure is a complex and personal issue • Most were fearful of disclosing • Those who disclosed recognised the benefits • Misalignment between inclusionary PSE polices and support they received • Educators often unsure of how to accommodate youth	• Heterogeneous sample • Demographic characteristics not reported (age, gender etc.)

Source	Sample	Purpose	Method	Findings	Limitations
Kurth and Mellard (2006) (US)	104 students with disabilities (mean age of 30; 49% male, 51% female), 39% had learning disabilities, 23% orthopaedic or mobility, 13% deaf, 9% blind, 4% TBI, 12% other; community and college	To determine student perceptions of the accommodation process	Focus groups (ecology of human performance)	• Five issues that students experienced: a sense of belonging, access to academic information, supports for independence, and discrimination and self-determination, or students' expressions of their willingness to work through difficulties they encounter	• Heterogeneous sample
Lewis and Arber (2015) (UK)	35 (11 females; 24 males; mean age 26.7 years with end stage renal failure)	To explore how youth with end-stage renal failure experience education and employment	Interviews (biographical disruption, fateful movements and critical moments)	• Unpredictable nature of renal therapy, side effects of treatments often coincided with critical moments for education • Difficulties with fatigue • 20 youth were working; 8 were in school; remainder were too ill to work • All youth thought about how, when and whether to disclose • Disclosure was perceived as risky and timing was difficult to manage • Many youth avoided disclosure	• Different modes of interview • Don't know how the interviewees were selected from a larger survey • Different stages of illness and age of onset
Magnus and Tossebro (2014) (Norway)	19 university students, various disabilities; mean age and gender not provided	To explore how disabled youth negotiate accessibility in higher education	Diaries, interviews, focus groups (theory of stigma)	• Students with invisible disability can hide it but still need supports; they reflected on what to disclose, to whom, and when • Fear of isolation and stigma • Those who disclosed received support	• Heterogeneous sample • Sample only from one site • Lack of information on the demographics of the students
Marshack et al. (2010) (US)	16 (3 males, 13 females, mean age 24.3 years) college students with various disabilities	To understand the barriers to college use of disability services and accommodations	Interviews (theory: n/a)	• Barriers to using accommodations included: identity issues, desires to avoid negative reactions, insufficient knowledge, perceived quality and usefulness of services and negative experiences with faculty	• Convenience sample • Mostly female sample • Heterogeneous sample
Meeks et al. (2015) (US)	1 (student with hearing loss); Age and gender not provided	To explore the barriers to clinical education among deaf students	Case study (theory: n/a)	• Clinical student placements pose obstacles to deaf students • Disability services provided accommodations	• Sample size wasn't sufficient to reach saturation

(*Continued*)

Table 2. (*Continued*).

Authors, year (country)	Sample characteristics	Objective	Design and analysis (theory)	Key findings*	Limitations and future research
Morris and Turnbull (2007) (UK)	18 student nurses with dyslexia (mean age and genders not provided)	To explore the experiences of disclosing dyslexia among student nurses	Interviews (theory: n/a)	• The decision to disclose was related to the attitudes of co-workers, concerns for patient safety, expectations for support, confidentiality issues and stigma • 6 disclosed in clinical practice • Most experienced difficulty disclosing • Having a trusting and supportive relationship with mentors helped • Experience with students who have dyslexia may enhance disability comfort	• Results section was short and did not provide rich descriptions of all themes • Did not provide demographic characteristics of the students
O'Shea and Meyer (2016) (US)	11 college students (6 females, 5 male) with nonvisible disabilities; mean age not provided	To explore the motivation of college students with disabilities to disclose and utilise supports	Interviews (self-determination theory)	• Interactions with adults helped or hindered their decision-making to disclose • It is important to understand the subjective experience of students' perceived needs and their motivation to utilise supports • Student's experiences of disability support in high school is important for their motivation and self-advocacy to disclose in college	• Small sample size from one centre
Onley and Brockelman (2003) (US)	25 university students (median age 25; 15 females, 10 males), various disabilities	To explore how university students with hidden disabilities manage the perceptions of others	Focus groups (social identity theory)	• Students were aware of others attitudes towards them • Some denied or hid their disability to avoid disclosure • Process of accessing supports and accommodations was complicated • People endeavour to control the timing and setting of disclosure regardless of whether the disability is visible • People engage in an intricate decision-making process to disclose their disability	• Possible selection bias • Heterogeneous sample • Composition of the focus groups was not reported
Patrick and Wessel (2013) (US)	12 first-year college students (6 with physical disabilities, 6 with cognitive or learning disabilities); 10 females, 2 males (ages not reported)	To understand the transition experiences of youth with disabilities who had a faculty mentor	Interviews (Tinto's theory of individual departure)	• Having a faculty mentor helped them transition to college • Most youth were unprepared for the disclosure process in college • Some needed to arrange for attendant care in PSE	• Small, heterogeneous sample • Ages not reported

Study	Sample	Objective	Method (theory)	Findings	Limitations
Shelvin, Kenny, & McNeela (2004) (Ireland)	16 (7 males, 9 females; mean age 24.5), various disabilities	To explore the quality of access and participation for students with disability in higher education	Interviews (theory: n/a)	• Lack of awareness of student needs • Positive attitudes and knowledgeable staff are critical to equitable treatment • Barriers include physical access barriers, transportation • Despite support from disability office, accommodations were inconsistent, incomplete, delivered inappropriately	• Heterogeneous sample
Terras, Leggio, & Phillips (2015) (US)	11 graduate students (all females; mean age not reported); various disabilities	To explore the experiences of disability accommodations in online courses among graduate students	Interviews (theory: n/a)	• Disabilities presented concentration and scheduling challenges • The flexibility of online learning, instructor's willingness to provide accommodations, and self-advocacy helped students' success • Students felt it was their responsibility to be knowledge about their needs and to initiate communication about obtaining accommodations	• Small, female-only sample • Sample were graduate students who may have already been familiar with requesting accommodations
Thompson-Ebanks, 2014 (US)	5 (2 females, 3 male), various invisible disabilities, undergraduate students (mean age 27.8)	To explore personal factors that students with invisible disabilities associate with their voluntary withdraw from university	Interviews (theory: n/a)	• Feelings of inadequacy to advocate for disability-related needs • Fear of disclosing due to stigma	• Sample size insufficient to reach saturation
Timmerman and Mulvihill (2015) (US)	2 college students (1 with cerebral palsy, 1 learning disability); mean age 22.5 years)	To explore students' experiences concerning accommodations, modifications and adaptations	Multiple interviews and observations (theory: n/a)	• Important to have a strong relationship with a faculty mentor who can help them with accommodations • Accommodations were helpful but some faculty did not understand their need for accommodations	• Insufficient sample size to achieve saturation • Heterogeneous sample
Tinklin and Hall (1999) (UK)	12 students with various disabilities (ages not provided)	To explore the experiences of disabled students in higher education	Case studies (surveys and interviews) (theory: n/a)	• Challenges in the physical environment, access to information, discrimination • Students did not realise they were eligible for support • Need to declare disability on admissions form to receive support (but many did not want to)	• Small, heterogeneous sample • Demographic characteristics of participants not provided

Note: This table only reports findings related to our objective to understand best practices on how and when disabled youth disclose their condition and request accommodations; and what are the barriers/facilitators to disclosure and accommodations and implementation of filling these needs.

where we compared and contrasted key trends. Then, we conducted a within-study analysis where we examined the findings of each study and its quality (Petticrew & Roberts). In the final step, we produced an across-study synthesis to summarise the findings while also considering the various methodological designs, samples and quality of the studies (Petticrew & Roberts).

Methodological Quality Assessment

Recommendations for disability disclosure and requests for accommodations for youth in PSE are based on the overall strength and quality of the evidence we reviewed. As an overall measure of bias, we used Kmet, Lee, and Cook (2004), a standard quality assessment criteria. We applied this appraisal tool because it allows for a common approach to assessing the quality of each study (see supplemental table) while capturing the range in methodological quality and risk of bias across both qualitative and quantitative studies (Kmet). Two authors independently reviewed each article and assigned a score while using this tool for each item and an overall score for each study (see supplemental table). We derived a total score for each study, which indicates the strength of the evidence (Kmet) while also noting any significant issues concerning bias. We did not exclude any studies based on quality. Any discrepancies in the scores were resolved through discussion and a re-examination of the article.

Results

Study and Participant Characteristics

Thirty-six articles met our inclusion criteria (see Figure 1). Twenty of the studies were conducted in the US, 10 in the UK, 3 in Canada and 1 each in Belgium, Norway and Ireland. They involved a range of methods including 26 qualitative (e.g. interviews, focus groups, reflective journaling, diaries, case studies and observations) and 10 quantitative (e.g. surveys and secondary analysis of longitudinal data) and 2 mixed methods. Sample sizes ranged from 1 to 3190, representing a total of 5174 participants (mean age 26.4 years). Most studies included a wide variety of disability types while a few studies focused on specific conditions including learning disability, dyslexia, end stage renal failure, and hearing loss. Of the studies that reported the gender composition of their sample, the majority were female for the qualitative studies, while the quantitative studies had an equitable gender distribution. Three studies had female-only samples.

Less than half of the studies applied a theoretical framework. Among those that did use a theory, they included a wide variety of theories including those commonly used in disability studies such as social model of disability (Baron, Phillips, & Stalker, 1996; Cook, Griffin, Hayden, Hinson, & Raven, 2012; Erten, 2011), stigma (Magnus & Tossebro, 2014), theory of universal design (Graves, Asunda, Plant, & Goad, 2011), social identity theory (Onley & Brockelman, 2003), self-determination theory (Cole & Cawthon, 2015; O'Shea & Meyer, 2016), biographical disruption (Lewis & Arber, 2015) and model of integration (Hong, 2015; Tinto, 1975). Other theories focused more specifically on areas related to disclosure such as the communication predicament of disability model and communication accommodation theory (Blockmans, 2015). This model is driven by social psychological theories on stereotyping

and communication accommodation theory (Blockmans, 2015; Giles, 2008). The communi-cation accommodation theory maintains that individuals adjust their communicative behav-iour to create and maintain either closeness or distance (Blockmans, 2015; Giles, 2008). The communication predicament model of disability attributes non-accommodation to able-bod-ied person's reliance on stereotypical rather than individual features of people with disabil-ities (Blockmans, 2015). Further the 'Contact, Ask, Respect, Empathy (CARE) for inter-ability communication model' (Blockmans, 2015; Ryan, Bajorek, Beaman, & Anas, 2005) recommends that able-bodied people ask people with disabilities about their needs instead of making assumptions and thereby showing respect and empathy for their strengths, needs and pref-erences (Blockmans, 2015). Another model, the ecology of human performance theory, (Dunn, Brown, & McGuigan, 1994; Kurth & Mellard, 2006) also contributes to our thinking about accommodations by encouraging us to consider how the interaction between person and environment affects human behaviour and performance.

Barriers to Disability Disclosure and Accommodations

Thirty-one studies outlined various barriers to disability disclosure and requests for accom-modations among youth with disabilities in PSE (see Table 3 for overview) including stigma and discrimination, lack of knowledge of supports and how to access them, type of course and instructor, coping and type of disability.

Stigma and Discrimination

The most common barrier, noted in 19 studies, included stigma, discrimination and the related concerns about the negative effects of disclosing a disability. For example, Miller, Ross, and Cleland (2009) found that 12% of medical students with various conditions (includ-ing learning difficulties, sensory impairment, chronic illness and mobility problems) expe-rienced disability-related discrimination. Meanwhile, Erten (2011) highlighted that negative attitudes from faculty and other students presented a challenge to youth who disclosed their condition. Many studies (e.g. Fox et al., 2011; Kurth & Mellard, 2006; Magnus & Tossebro, 2014; Morris & Turnbull, 2007; Thompson-Ebanks, 2014) reported that youth with various types of disabilities and chronic conditions worried about experiencing stigma, discrimina-tion and/or isolation, which often prevented them from disclosing their condition. One study focused on the related elements of jealousy or rejection that are often linked to disclosing (Magnus & Tossebro). For example, some youth worried they would be labelled by their disability while at college (Magnus & Tossebro). Kurth & Mellard (p. 81), whose sample involved youth with learning disabilities, mobility and sensory impairments provided an example from a student, 'I don't want to walk through a door and have someone say, "you're disabled." I just want to be included as a normal student'.

　　In other studies, students experienced feelings of discomfort, unequal treatment and feelings of inadequacy (Magnus & Tossebro, 2014; Thompson-Ebanks, 2014). For example, Dowrick et al. (2005) found that discriminatory attitudes and assumptions about youth's abilities and accommodations negatively impacted students. Meanwhile, others (Hong, 2015) reported that faculty had lower expectations of youth with disabilities which often contrib-uted to discriminatory attitudes. Further, Fox et al. (2011) reported that among medical students the diagnosis and the duration of their illness influenced the extent to which they experienced stigma and also affected their decision to disclose. Erten (2011), who explored

Table 3. Overview of themes.

Barriers	Facilitators	How disclosed	When Disclosed
• Stigma/discrimination of disclosing • Lack of knowledge of accommodations available and how to access them • Lack of awareness of needs & discrimination by school staff • Accommodations and supports not provided • Ineffective communication • Coping style and disability identity (sense of self) • Nature of the disability (visible vs. non-visible) • More difficulty disclosing for non-visible disabilities	• Supports and resources enabling access to accommodations • Peer mentoring • Coping style • Online access to learning materials • Self-advocacy • Realising the benefits of disclosing • Students with visible disabilities have positive attitudes about accommodations • Transition service improved attitudes towards requesting accommodations • Disability identity, self-awareness, advocacy • Student support card helped disclose and increased confidence	• Disclosure is a complex and personal issue • Many avoided disclosing • Decision to disclose influenced by experiences of disability support in high school • Disclose disability to people you are closest to and those who need to know • Disclosed in person when they had a good rapport with teacher otherwise handed in a letter • No difference in disclosure between face-to-face vs. online accommodation requests • Student support card (accommodations outlined on card – no need to disclose) • Type of accommodation requested varied by person asked (teacher vs. classmate)	• Need to disclose on college application to receive support • Fewer students disclose in post-secondary compared to high school • Need for ongoing disclosure • Those with undiagnosed, rare or altering visible conditions disclosed to legitimise their accommodation request • Disclose condition only when accommodations are needed • Timing of disclosure difficult to manage

youth with learning disabilities, highlighted that more support is needed to address the hidden attitudinal barriers towards youth with disabilities to prevent discrimination.

Lack of Knowledge of Supports

A second barrier for youth (noted in 14 studies) included lacking knowledge of potential supports and accommodations (e.g. note takers, tutors, extra time, physical access, assistive technology) and how to access them. For example, Cawthon and Cole (2010) found that undergraduate students with learning disabilities were not using the university resources to the extent that they were available, which may be a result of students not needing accommodations, or that they found them inadequate or difficult to access. Students also lacked knowledge of their individualised education plans from high school and the details of what supports they would need at PSE, which indicates that students may be unprepared to access and advocate for services in PSE (Cawthon & Cole).

Other studies similarly mentioned that some youth did not understand their need for accommodations (Tinklin & Hall, 1999), their eligibility for support, and the requirement to disclose their disability to access accommodations. For example, Miller et al. (2009) found that disability-related challenges among medical students were reported by half of the participants, and yet two-thirds did not seek support. Newman and Madaus (2015) similarly reported that although 95% of the youth in their sample received disability accommodations in high school only 23% received them in college.

Type of Course and Instructor

Barriers to disclosure and accommodations were also noted by the type of course and instructor. For instance, Hill (1996) highlighted some differences between disability disclosure and the type of course students took where lab instructors were very unaccommodating and viewed students with disabilities as an inconvenience. Meanwhile, graduate students mentioned that faculty were more willing to make accommodations than those in undergraduate programmes (Hill, 1996).

Five studies found that faculty lacked knowledge about youth's disability-related needs and were often unresponsive to accommodation requests (Burgstahler & Moore, 2009; Erten, 2011; Hong, 2015; Marshack, Van Wieren, Ferrel, Swiss, & Dugan, 2010; Shelvin, Kenny, & McNeela, 2004) or had ineffective communication that prevented youth from disclosing (Fox et al., 2011). For example, in Shelvin et al.'s (2004) study, youth reported that PSE accommodations provided were often inconsistent, incomplete or delivered inappropriately. Some other studies noted that accommodations and related supports were not provided or were difficult to access (Baron et al., 1996; Dowrick et al., 2005; Goode, 2007; Holloway, 2001; Shelvin et al., 2004). For example, Holloway (2001) described that students found it stressful and time consuming to arrange their accommodations. Some youth had negative experiences with faculty who often had insufficient knowledge about disabilities. Burgstahler and Moore (2009) reported that there is a strong need to increase staff knowledge and comfort level in working with students who have a disability.

Coping Style and Disability Type

Other challenges to disability disclosure and requests for accommodations occurred at the individual level and included things such as coping style, disability identity (e.g. sense of self) and the nature of the disability (Barnard-Brak, Sulak, Tate, & Lechtenberger, 2010;

Blockmans, 2015; Fox et al., 2011; Goode, 2007; Holloway, 2001; Lewis & Arber, 2015; Magnus & Tossebro, 2014; Marshack et al., 2010; Onley & Brockelman, 2003; Patrick & Wessel, 2013; Thompson-Ebanks, 2014; Terras, Leggio, & Phillips, 2015). For example, in Onley & Brockelman (2003) study some youth reported that they denied or hid their disability to avoid having to disclose. Meanwhile, two studies reported that youth had negative views about accommodations (Barnard-Brak et al., 2010; Cole & Cawthon, 2015) and therefore, were reluctant to disclose. Other youth mentioned they lacked the self-confidence to disclose and advocate for their disability-related needs (Thompson-Ebanks). Youth with invisible disabilities (e.g. learning disability) specifically noted feelings of inadequacy and fear of disclosing due to stigma related to society's limited tolerance to learning and mental health disabilities (Thompson-Ebanks).

In regard to the nature of the disability, Goode (2007) highlighted that disability disclosure and needs assessments in college were often shocking to some youth who denied their disability and how it impacted them. In contrast, some students with visible disabilities often drew unwanted attention regarding the accommodations they received (Goode). Youth also found it exhausting making disability specific adjustments while adapting to university life. For example, Lewis and Arber (2015) highlighted that the unpredictable nature of renal therapy, and side effects of the treatments often coincided with critical moments in education. They also found that those with an earlier disability onset often had more difficulties with fatigue, along with frequent and prolonged absences from school (Lewis & Arber). Some youth had difficulties arranging attendant care to assist with personal needs and their tasks of daily living while at college (Patrick & Wessel, 2013). Others found that the physical, mental and emotional demands of disclosing presented challenges to receiving accommodations (Hong, 2015; Shelvin et al., 2004).

Facilitators to Disability Disclosure and Accommodations

Twenty-six studies reported on facilitators that helped enable youth to disclose their disability and request PSE accommodations including supports and resources, mentorship, realising the benefits of disclosure, and coping and self-advocacy skills.

Supports and Resources

One of the most common facilitators in the studies we reviewed included students with disabilities having supports and resources that enabled their access to accommodations. For example, Erten (2011) reported that the office for students with disabilities provided an important source of support in providing accommodations. Holloway (2001) and Meeks et al. (2015) likewise uncovered that students who had positive experiences also had supports and accommodations from their disability office and other external agencies. Supports for students with disabilities were provided in a variety of ways. For example, Terras et al. (2015) explored requests for accommodations within an online course amongst students with various types of disabilities and found that the flexibility of online learning, instructor's willingness to provide accommodations, combined with student's self-advocacy skills enhanced their academic success. Two other studies reported that online access to learning materials helped to facilitate their accommodations (Graves et al., 2011; Terras et al., 2015). For instance, Graves et al. found that online asynchronous access enhanced the clarity, access and achievement of their experience.

Mentoring

Seven studies reported that mentoring helped youth to become aware of the helpful resources and accommodations available to them. For example, Patrick and Wessel (2013) reported that having a faculty mentor assisted youth with their transition to college by enhancing awareness of the resources, supports and accommodations available to them. Timmerman and Mulvihill (2015) highlighted the importance of having a strong relationship with a faculty mentor who could help find and acquire accommodations. Morris and Turnbull's study (2007) found that among student nurses with dyslexia, having a trusting and supportive relationship helped them to feel comfortable with disclosing their condition. Meanwhile, having interactions with adults (i.e. informal mentoring) sometimes helped with disclosure among youth with non-visible disabilities (O'Shea & Meyer, 2016). Further, one innovative pilot mentoring programme explored how they could help students access accommodations. They found that youth had significantly improved attitudes about disclosure along with increased confidence (Barnard-Brak et al., 2013). Other studies within our review found that having positive attitudes and knowledgeable educational staff are critical to ensuring access and equitable treatment (Shelvin et al., 2004). One study noted that attitudes rather than specific socio-demographic characteristics such as age or gender had the most important impact on addressing accommodation requests (Hill, 1996).

Realising the Benefits of Disclosure

Other facilitators for enabling disability disclosure and accommodations included realising the benefits of disclosing their disability such as getting practical assistance and support (e.g. different chair, extra time for tests, note-taking, etc.) (Blockmans, 2015; Hill, 1996; Jung et al., 2014; Kurth & Mellard, 2006; Magnus & Tossebro, 2014; Miller et al., 2009). Interestingly, Barnard-Brak and Sulak (2010) found that students with visible disabilities had more positive attitudes about requesting accommodations, yet they preferred making such requests in the online learning environment rather than in-person classes. Another facilitator of disability disclosure included youth's self-awareness and self-advocacy skills to disclose their condition and request accommodations (Cole & Cawthon, 2015; Jung et al., 2014; Onley & Brockelman, 2003; Terras et al., 2015). For example, Jung et al. found that among student occupational therapists, those who were self-reliant disclosed. Some youth needed help with self-advocacy and had a family member help to advocate for them to gain access to needed supports (Blockmans, 2015).

Coping and Self-advocacy Skills

Several individual-related facilitators helped empower youth to disclose their disability and seek PSE accommodations. For example, Fox et al. (2011) reported that youth's ability to cope with their disability played a key role in their experience. Specifically, individual coping styles affected student's willingness to disclose. For example, students who actively sought disability-related supports were often satisfied with the response they received (Fox et al., 2011).

Process and Timing of Disability Disclosure

Fewer studies within our review focused on the process or timing of disability disclosure and accommodation requests. Many studies conveyed that disclosing was a complex and

personal issue that depended on many factors such as disability type, extent of self-advocacy skills and availability of supports (Baron et al., 1996; Blockmans, 2015; Jung et al., 2014; Lewis & Arber, 2015; Onley & Brockelman, 2003; O'Shea & Meyer, 2016).

In regard to mode of disclosure, one study compared face-to-face disclosure with their professor/instructor vs. online accommodation requests and found no differences in disclosure rates (Barnard-Brak & Sulak, 2010). However, those with visible disabilities had more positive attitudes towards requesting accommodations in an online format vs. face-to-face compared to those with hidden disabilities (Barnard-Brak). Others (Glover-Graf & Janikowski, 2001) found that the types of accommodation requested varied by who asked (e.g. teacher vs. classmate). For example, youth asked their instructors for learning modifications while they asked their classmates for help with note taking, personal care and transportation (Glover-Graf & Janikowski). Some studies highlighted that youth disclosed their condition in person when they had a good rapport with their professor (Blockmans, 2015; Cole & Cawthon, 2015; Timmerman & Mulvihill, 2015). Cole and Cawthon's study demonstrated that professors with positive demeanours created an environment for youth with learning disabilities to disclose their condition more so than professors who had a negative or mixed demeanour. Those who disclosed did so because they needed accommodations and were aware of the supports available to them.

Meanwhile, Blockmans (2015) found that most youth with physical impairments reported disclosing to their close peers, which helped with the bonding process and also decreased social distance, and others discomfort with their disability (Blockmans, 2015). In contrast, some youth hesitated disclosing their condition with their professors whom they did not have a good rapport (Blockmans, 2015). Meanwhile, in Cook et al.'s (2012) study, disclosing specific details about their condition was unnecessary because any accommodations that students needed were outlined on their student card. This involved a unique method that helped students to avoid the discomfort that they often experience in disclosing.

Disclosure sometimes varied by disability type, the extent of the impairment and every day functioning (Blockmans, 2015; Lewis & Arber, 2015). For example, some youth disclosed because of the unpredictable or unstable nature of their condition (e.g. pain associated with a physical condition) (Blockmans, 2015). However, students reported that the visibility of their condition did not affect their initial orientation towards disclosure because they wanted to appear as 'normal' as possible to their peers (Blockmans, 2015). With respect to disability type, those with undiagnosed, rare, or altering visible conditions disclosed to help legitimise their accommodation requests and also to be understood and taken seriously by their professors (Blockmans, 2015).

The studies in our review regarding the timing of disability disclosure lacked consensus. For instance, Newman and Madaus (2015) found that fewer students disclosed their condition in PSE compared to high school, which was likely a result of their lack of knowledge of the supports available and how to access them. In two studies, youth reported they needed to disclose their condition on their college application to receive accommodations (Miller et al., 2009; Tinklin & Hall, 1999). Some felt ambivalent about this because they were unclear about who would see this information and whether it would affect their acceptance into college; however, at the same time did not want to risk going without supports. Meanwhile, other studies mentioned that youth with various types of disabilities only disclosed their condition to their professors when accommodations were needed (Jung et al., 2014). In some studies, students commented that disclosing their condition to their professor was

necessary so they could discuss potential areas of difficulty before problems arose, to justify behaviours (e.g. slow progress) and/or their need for extra time on tests and assignments (Blockmans, 2015; Hill, 1996). Meanwhile, others such as Baron et al. (1996) highlighted the how social work students needed ongoing disclosure (e.g. on their application, to their professors and during their placements) because their needs varied over the course of the programme. Blockmans found that students that required extensive and/or repeated disclosure struggled to gain access to accommodations because disclosing to every instructor can be emotionally taxing.

Quality Assessment and Risk of Bias within Studies

We noted several limitations within each of the studies that we included within this review. Two authors independently rated each study using Kmet's (2004) standard quality assessment, which included a 10-item checklist for qualitative studies and a 14-item checklist for quantitative studies (see Kmet for list of items and scoring). Articles received a score of 2 if they full-filled the criteria, a 1 if it was partially fulfilled and 0 if they did not.

Total overall scores for each study were derived (summed and converted into a percentage) indicating the strength of the evidence. Scores ranged from 0.40 to 0.80 (mean 0.65) for qualitative studies (inter-rater agreement 83%) and 0.50–0.75 (mean 0.55) for quantitative studies (inter-rater agreement 80%) (see supplemental table). For the remaining studies that did not have inter-rater agreement, discrepancies in the overall scores ranged from 0.05 to 0.35. Most of the discrepancies reflected the extent of the applicability of certain items (e.g. yes, vs. partial fulfilment). We re-read these articles and discussed any discrepancies until consensus was reached.

Using the Kmet et al. (2004) checklist helped us to examine the quality and risk of bias within each study. Areas of the Kmet quality assessment where the qualitative studies had lower scores included: sampling strategy, methods and analysis described appropriately, having a verification procedure to establish credibility and reflexivity of the account. Areas where the quantitative studies scored lower included: description of methods, participants, and analysis, estimate of variance for main results, and controlling for confounding factors. We did not exclude any studies based on the quality of the evidence.

Risk of Bias Across Studies

We considered and noted the risk of bias across studies within our review. First, the sample demographics, ages and types of disabilities of the participants in the studies varied widely and caution should be taken in generalising the findings. Second, it is important to note that not all studies contributed equally to the overall summary of the findings. Some studies included in our review focused specifically on disability disclosure and accommodations, while for other studies it was only one aspect of what they explored. Third, several studies did not report their mean age and we could not calculate this in our overall average age for this review. Finally, it is important to consider that the studies in this review spanned across six countries, all of which have differences in policies for disclosing a disability and asking for accommodations in PSE institutions.

Limitations of the Review

First, we only included peer-reviewed articles that were published in English articles due to budgetary constraints. Thus, it is possible that other eligible studies may have been missed. Future reviews should consider including publications in other languages to explore how disclosure and accommodations may vary by culture. Second, the databases and search terms we selected may have missed some potentially relevant studies. Nevertheless, we did consult with a librarian who is experienced in this field to help design our search strategy. Third, the studies included in this review had heterogeneous samples, settings and outcome measures, which made it challenging to make comparisons across studies. Thus, caution should be used in generalising the findings.

Discussion

This review explored disability disclosure and PSE accommodations among youth and young adults over a 20-year period. Exploring this topic is salient because having a disability reduces the likelihood of completing PSE (Hartley, 2010; Schutz, Rivers, McNamara, Schutz, & Lobato, 2010). Many youth with various types of disabilities (visible and non-visible) are not disclosing their condition and are not receiving the needed supports that could enhance their academic outcomes (Lindsay, Duncanson et al., 2017; Venville et al., 2014).

Our review highlights that barriers to disability disclosure and requests for accommodations within PSE included: stigma, discrimination, lack of knowledge of supports and how to access them, type of course and instructor, coping styles, and type of disability. These findings are consistent with research on stigma and discrimination among working-age cancer survivors (Stergiou-Kita, Qie, Yau, & Lindsay, 2017), which is often due to a lack of knowledge, misperceptions and discomfort that people experience around those who have a disability (Lindsay, Duncanson et al., 2017; Lindsay & Edwards, 2013). Goffman's (1963) notion of stigma highlights that it can discredit a person's self-worth and produce a discrepancy between how society views them and their actual abilities. Indeed, the consequences of stigma and negative attitudes can have a detrimental impact on a person's identity and well-being (Blockmans, 2015; Duggan, Medway, & Bunke, 2004). There is a strong need to improve disability awareness, knowledge, and comfort for PSE educators to reduce discrimination, enhance retention, PSE outcomes and overall well-being for youth with disabilities. Research shows that people who have more knowledge and experience with people who have a disability often have more positive attitudes towards them (Hernandez, Keys, & Balcazar, 2000; Lindsay & Cancelliere, 2017; Lindsay & Edwards, 2013).

Further, lacking knowledge about PSE supports is a common trend among youth with disabilities (Lindsay, Duncanson et al., 2017). By increasing knowledge and awareness about disability and related supports, we can aim to enhance educator's disability comfort, while creating an atmosphere where youth could feel comfortable disclosing their condition and requesting accommodations (Lindsay et al., 2016).

Consistent with previous research, our review found that those with non-visible disabilities often encounter additional challenges with identifying their need for support (Blockmans, 2015; Salzer, Wick, & Rogers, 2008; Venville et al., 2014). Thus, students with hidden or less visible disabilities may receive fewer supports than their peers with physical disabilities because it is more difficult for them to identify their needs (Magnus & Tossebro, 2014; Venville

et al., 2014). Murphy, Scheer, Murphy, and Mack (1988) argues that the more visible the disability the more likely the 'spread phenomenon' is to occur where a person's characteristics are overshadowed by their disability label. Meanwhile, others argue that there is often a hierarchy of preference among PSE educators where they are more accepting of students with sensory and physical needs and less receptive of those with learning disabilities, mental illness, and social or emotional disabilities (Leyser, 1989). Some researchers have found that there is a similar 'hierarchy of accommodations' where some modifications are more readily provided than others, which might be related to the acceptance of certain disability types and/or the amount of effort to implement them (Leyser, 1989; Nelson, Dodd, & Smith, 1990). Future studies should explore this further.

Our review showed that facilitators for disability disclosure and accommodations included supports and resources, coping, self-advocacy, mentorship and realising the benefits of disclosure. Our findings are similar to Stergiou-Kita et al. (2017) who explored cancer survivors returning to work, and found that those who advocated for their needs and were aware of supports and anti-discrimination policies often had a better experience (Stergiou-Kita et al.). Having good coping and self-advocacy skills is essential for disability disclosure and self-management (Lindsay, McDougall, & Sanford, 2013). Others have found that components of having strong advocacy skills include: being knowledgeable about legal rights, awareness of specific medical issues and related supports, and effective communication skills (Pardeck, 2005; Stergiou-Kita et al., 2017). Our findings are also consistent with previous research showing that mentorship can help to enhance positive academic and employment outcomes for youth with disabilities (Lindsay et al., 2016).

Our review highlighted that factors affecting the process and timing of disability disclosure in PSE included the type of disability, and mode of disclosure (e.g. face-to-face vs. online). Blockmans (2015) recommends that educators should limit their questions and remarks about a student's impairments to what is relevant for their educational success and also respect their privacy.

In comparison to people with mental health conditions, reasons for non-disclosure included trying to conceal their (stigmatised) identity (Brohan et al., 2012). They similarly highlighted the personal and complex nature of the process and timing of disability disclosure. Research on students with mental illness shows that they may experience intermittent disruptions of varying intensity to their learning process throughout the school year (Venville et al., 2014). The challenges that they encounter may not be easily understood by educators (Venville et al., 2014). The findings in our review are somewhat consistent to research on students with mental health conditions which showed that they also encounter discrimination and lack knowledge about how and when to ask for accommodations as well as what supports are available. Students who have less visible or fluctuating conditions may be overlooked and there is a strong need for more inclusive approaches to teaching and learning for youth with disabilities in PSE (Goode, 2007; Magnus & Tossebro, 2014; Venville et al., 2014).

The findings of our review showed a lack of consensus on the best timing to disclose, which may be a result of the varying nature and need for disclosure amongst different types of visible and less visible disabilities. Our results are consistent with a review of disclosure and accommodations amongst adults with mental illness who found that the process and timing of disclosure was complex (Brohan et al., 2012). They reported that people with mental illness chose to selectively or partially disclose while others strategically timed it (Brohan et

al., 2012). Further work is needed to better understand the optimal processes and timing for disability disclosure among youth with disabilities in PSE.

Although disability PSE policy varies by region and country, disability legislation in the countries where the studies were conducted in this review (Canada, US, UK, Belgium, Norway, Ireland) encourages PSE institutions to take a strategic approach to identify reasonable adjustments to teaching, learning and assessment (Fuller et al., 2004). The context of the PSE environments where these studies took place is important to consider because perceptions of disability can vary by culture and region (Lindsay, Tetreault, King, Desmarais, & Pierart, 2014). None of the studies within this review compared differences in accommodation policies (e.g. by institution or country); however, this is an important area for future research. Enhancing research in a broader range of cultural and educational contexts could increase the applicability of the findings. For example, future studies should consider how policies differ and what components facilitate youth disclosing their disability.

Conclusions

This systematic review highlights the barriers and facilitators of disability disclosure for youth with disabilities in PSE. Barriers to disability disclosure and requests for accommodations in PSE included stigma, discrimination, lack of knowledge of supports and how to access them, type of course and instructor, coping styles and nature of the disability (e.g. visible vs. invisible). Facilitators included supports and resources, coping/self-advocacy, mentorship and realising the benefits of disclosure. Factors affecting the process and timing of how disability should be discussed in PSE among youth with disabilities included the type of disability, and mode of disclosure (in-person vs. online). There was a lack of consensus regarding the optimal timing to disclose among the studies in our review. There is a critical need for more disability awareness and anti-stigma training for educators and promotion of self-advocacy skills for youth.

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