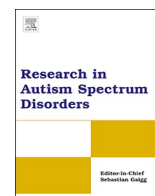


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Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others



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ABSTRACT

Background: Deciding to disclose a diagnosis of autism to others can be a major decision for people with autism and their families. This scoping review summarizes existing literature related to perceptions and outcomes of disclosing an autism diagnosis to others (e.g., teachers, peers, employers).

Methods: We conducted a scoping review of scientific literature using [Arksey and O'Malley's \(2005\)](#) methodological framework. Relevant English language databases and reference lists were searched using terms related to autism, disclosure, and perspective (e.g., attitude, accept*). Studies that focused on disclosure to the person with autism and/or their parents were excluded. **Results:** A total of 37 articles met inclusion criteria, including 14 that presented the perspective of people with ASD, four that presented the perspective of parents/family members, and 20 that presented the perspective of others. Our findings highlight disconnect in perspectives between others (primarily evaluated through vignettes) and persons with autism (primarily elicited through qualitative interviews). Others perceive that disclosure has positive effects on social acceptance and perceptions of disability for people with autism, especially when explanatory information about autism was provided with the autism label. Adolescents and adults with autism indicated reluctance to disclose their diagnosis due to perceived negative outcomes and stigma. Existing research also reflected an assumption that diagnosis should be disclosed.

Conclusions: Professionals and the general public should be aware of their assumptions related to autism and disclosure. More research on the processes and outcomes of diagnostic disclosure in autism, across the lifespan and in real life social contexts, is warranted.

1. Introduction

1.1. Background

Choosing to disclose a diagnosis of autism to others, such as teachers, peers, employers, or recreation program leaders can be a dilemma for people with autism and their caregivers ([Davidson & Henderson, 2010](#)). There is substantial evidence that people with autism are at particularly high risk of experiencing stigma, even when compared to other disability groups ([Cappadocia, Weiss, & Pepler, 2012](#); [Gray, 1993](#); [Kinneer, Link, Ballan, & Fashbach, 2016](#)). Autism is diagnosed based on pervasive impairment in social interactions, social communication, and the presence of socially atypical behaviors ([American Psychiatric Association, 2013](#)). These characteristics of autism have been described as the perfect storm for stigma ([Farrugia, 2009](#); [Link & Phelan, 2001](#)). As noted by [Gray](#)

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(1993), “it is this combination of pervasive disability and apparent physical normality that gives the stigma experienced by families with autistic children its unique quality” (p. 114).

1.2. Stigma and disclosure

Perceptions of stigma may contribute to decisions of whether to disclose one’s own or child’s diagnosis of autism to others. Children with autism are at high risk of experiencing social exclusion and bullying at school, even with the increased emphasis on inclusive education (Humphrey & Symes, 2010). In fact, some research indicates that children with autism may be increasingly isolated and bullied when integrated into mainstream education settings (Humphrey, 2008). Adolescents with autism are more socially isolated than adolescents without disabilities and other disability groups (Shattuck, Orsmond, Wagner, & Cooper, 2011), and post-secondary education and employment outcomes for persons with autism are also poor relative to persons who do not experience disability and most other disability groups (Nicholas, Attridge, Zwaigenbaum, & Clarke, 2015; Shattuck et al., 2012). As such, adolescents and adults with autism and their caregivers may wonder if, and/or how, disclosing their diagnosis of autism may influence social, educational and/or vocational opportunities. Parents of children with autism may struggle with whether disclosure will increase understanding, compassion and inclusion, or result in increased exclusion, stigma, and bullying for their children.

1.3. Disclosure and invisible conditions

Autism is considered an “invisible” condition, referring to conditions that are not apparent based on physical markers or symptoms. For example, conditions such as depression and diabetes may be considered invisible. Literature related to disclosure of other “invisible” conditions, including those with associated stigmatized identities, may have relevance to the disclosure of an autism diagnosis. People with a variety of invisible diagnoses often report positive outcomes related to emotional support and personal wellbeing following disclosure to a trusted confidant (Chadoir & Quinn, 2010). However, disclosure decisions do not always relate to personal support. Rather, they are commonly related to a desire for accommodations, professional services and supports, social inclusion, or education and advocacy (Eaton, Ohan, Stritzke, Courtauld, & Corrigan, 2017). A systematic review of stigma in mental illness, such as depression, anxiety, attention deficit hyperactivity disorder, and schizophrenia, for children and youth concluded that stigma is “significant, universal, and multifaceted”, making decisions around disclosure difficult (Kaushik, Kostaki, & Kyriakopoulos, 2016, p. 491). Mothers’ decisions related to disclosure of their child’s mental health diagnosis often relate to negative stigma about mental illness, and a desire to protect their child from stigma and negative reactions from others, although mothers do often feel supported following disclosure (Eaton et al., 2017). In a qualitative study based on lived experiences, parents of children with epilepsy reported challenges with disclosure decisions due to a desire to seek ‘normalcy’ for their child, a lack of public knowledge and poor public conceptions of epilepsy, and negative reactions to the diagnosis including stigma, prejudice, and discrimination (Benson, Lambert, Gallagher, Shahwan, & Austin, 2017). These parents reported concealing their child’s diagnosis for fear that they would be treated differently post-disclosure (Benson et al., 2015). These lived experiences are contrary to findings from analogue research, commonly used when representing people with disabilities and medical conditions, in which written vignettes or videos are used to represent the construct of interest (Cook & Rumrill, 2005). For example, adults (primarily university students) who read hypothetical vignettes reported that they would have more positive perceptions of, and be more likely to socially include, individuals with Tourette syndrome following disclosure of their diagnosis (Marcks, Berlin, Woods, & Davies, 2007). Similar findings of improvements of a variety of outcomes have been found following disclosure for perceptions of diabetes (Berlin, Sass, Davies, & Hains, 2002), attention deficit hyperactivity disorder (Jastrowski, Berlin, Sato, & Davies, 2007), and cystic fibrosis (Berlin, Sass, Davies, Jandrisevits, & Hains, 2005).

Disclosure can be a central issue in how one navigates daily routines, activities and relationships. . Autism is unique to other “invisible” conditions in its diagnostic criteria specific to social characteristics, which may uniquely influence decisions and outcomes of disclosure. No synthesis of research exists to help guide persons with autism and their families in making decisions related to disclosure, or to guide professionals to whom people with autism and their families turn for advice. Therefore, the purpose of this study was to identify, describe, and summarize existing literature on perspectives and outcomes of disclosure of an autism diagnosis to others, such as teachers, peers, coaches, employers, or the general public.

2. Method

Scoping reviews examine the extent, range, and nature of research in an area, with a focus on synthesizing existing knowledge and identifying research gaps in existing literature (Arksey & O’Malley, 2005). These are in contrast to systematic reviews, which generally identify a more focused research question and evaluate the rigor of research in an area. A scoping review was determined to be appropriate for this study given the complexity and nuance of the topic, lack of uniformity in measurement, and a lack of an existing review in this area. Arksey and O’Malley’s (2005) five-step methodological framework for conducting scoping reviews guided the review process.

2.1. Step 1: identifying the research question(s)

One key research question guided this review: (1) What is known about perceptions and/or outcomes of disclosure of an autism diagnosis to others (e.g., teachers, peers, employers)?

2.2. Step 2: systematic search to identify relevant studies

Academics and professionals from a variety of professional backgrounds (occupational therapy, speech language pathology, social work, education, psychology) with a variety of methodological expertise, and a research librarian with expertise in synthesis reviews, helped identify initial search terms. Three team members conducted the searches. Electronic searches of the following databases were conducted: PsycINFO, ERIC, CINAHL, Medline, and SocINDEX. The searches included English-language papers up to December 2019 when the final database search was conducted. We used broad and inclusive keywords related to autism (autis*, Asperger, ASD, pervasive develop* dis*), disclosure (disclos*, reveal*, expos*, divulge*), and perspective (perspective*, attitude*, accept*, inclus*). Reference lists of selected articles were also reviewed for potentially eligible studies.

2.3. Step 3: selection of studies

Studies were screened using a checklist that identified the following inclusion criteria: (1) the study population consisted of people with a diagnosis of autism, (2) the study looked at disclosure of the autism diagnosis, (3) the study focused on disclosure to others (e.g., peers, teachers, employers), and (4) the study included original research published in a peer-reviewed journal. Studies were excluded that focused on disclosure to the individual with autism, such as when a person with autism receives their diagnosis from a health care professional or health care team, or when a parent informs a child of their diagnosis. Of note, a recent review on parents' informing their children with autism about their diagnosis was recently published (Smith, Edelstein, Cox, & White, 2018). Three reviewers initially performed a title (n = 1671), and then abstract (n = 347), screen based on the inclusion/exclusion criteria. Two reviewers independently screened the full text of all remaining articles (n = 68), plus an additional seven articles identified through manual reference checks. A third reviewer resolved disagreements (n = 3 studies for which the primary reviewers disagreed).

2.4. Step 4: charting the data

The following data were extracted from each selected article, and entered into a structured data charting spreadsheet: authors, year of publication, location (country) of research, study objective(s), participant information, research design/method, outcome measures/interpretation approach used, and main findings related to disclosure/non-disclosure.

2.5. Step 5: collate, summarize and report findings

Descriptive statistics were compiled to characterize the research literature (e.g., method, age of person with autism). A thematic analysis of the main findings was conducted. All team members had experience in qualitative data analysis. Our research team discussed and compared the charted data using an iterative process whereby we: (1) reviewed and coded the charted data independently, (2) discussed the data as a research team, including the identification of preliminary potential themes, (3) independently reflected on the discussion, (4) met to create mind maps of the data to assist in the refinement of themes, and (5) independently reviewed and reflected on the mind maps and related discussion. Mind mapping is a process that uses diagrams to explore and understand relationships between ideas (Davies, 2011). We continued the iterative process of revising mind maps over a series of seven research team analysis meetings until all team members were comfortable and confident that our thematic analysis adequately and comprehensively integrated and represented the existing literature in this area.

3. Results

3.1. Search results

Fig. 1 summarizes the results of our data searches. A total of 37 articles met inclusion criteria. Primary reasons for articles being excluded were a clear lack of fit to the research questions (e.g., did not include people diagnosed with autism, did not evaluate or discuss diagnostic disclosure). Six articles were excluded because they focused on disclosure of the autism diagnosis to the individual with autism or their parents (i.e., did not fit our criteria of 'others'). Three articles were excluded that provided commentary, but not original research, on diagnostic disclosure. Publication dates ranged from 2001 to 2019 with a trend towards increased publication related to this topic over time. We found between zero to two publications per year from 2001 to 2013, and four to seven publications per year in 2014–2016 and 2018–2019, although no papers published in 2017 were found.

Data were collected in seven, primarily English-speaking, countries, with over half (n = 22) of the studies completed in the United States. Approximately one-third (n = 15) of the studies presented the perspective of persons diagnosed with autism, most of which used qualitative methods (i.e., individual or group interviews). Persons with autism across the lifespan were represented in the papers; the youngest was 4-years old (Austin, Zinke, & Davies, 2016) and three studies included at least one participant over 50-years old (Crane, Maras, Hawken, Mulcahy, & Memon, 2016; Johnson & Joshi, 2016; Lum, Garnett, & O'Connor, 2014). All studies that presented the perspective of people unfamiliar or not personally connected with someone with autism (other; n = 24) used analogue methods, including written vignettes or video. Most videos used actors, but one research team used a child with a diagnosis of autism in their videos (Chambres, Auxiette, Vansingle, & Gil, 2008), and four research teams used adults with autism (n = 20 in each study) in their videos (Alkhaldi, Sheppard, & Mitchell, 2019; DeBrabander et al., 2019; Morrison, DeBrabander, Faso, & Sasson, 2019; Sasson

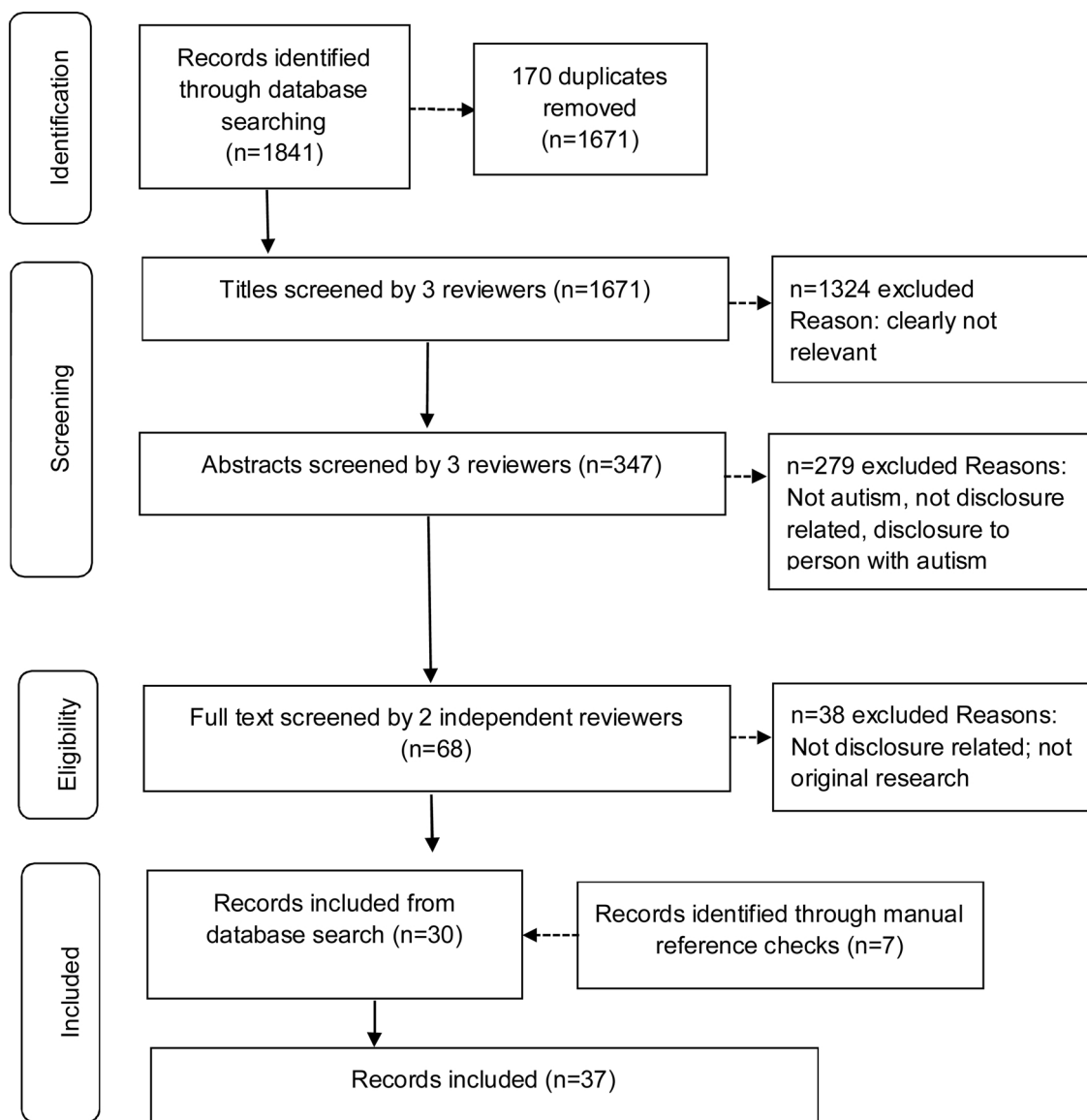


Fig. 1. Study retrieval and selection process.

& Morrison, 2019). DeBrabander et al. (2019) were unique in their inclusion of autistic adults as raters to evaluate how autistic adults viewed other autistic adults. Table 1 summarizes key demographic data related to the included studies. Table 2 provides a descriptive summary of each paper included in the scoping review.

3.2. Thematic analysis

Two main themes related to perspectives on disclosure or non-disclosure of an autism diagnosis to others emerged from the mind-mapping process: (1) altered view of the person with autism, and (2) onus to disclose. Fig. 2 summarizes these themes, including the divergent perspectives often portrayed by the different stakeholder groups represented in the papers.

3.3. Theme 1 –altered view of the person with autism

The first theme, altered view of the person with autism, refers to how others change their perceptions of the person with autism once they know their diagnosis. However, perspectives of how views were altered differed between people diagnosed with autism, their immediate family members, and others. People with autism often felt that others’ perceive their new primary identity as an ‘autistic person’ (which may or may not be how people choose to self-identify), and experienced judgment, discrimination, and stigma based on their diagnosis. The change in perception for others often related to positive changes in behavioral attribution, and

Table 1
Demographics of identified studies (n = 37).

	# of included papers (rounded %)
Country of data collection	
United States (USA)	22 (59)
United Kingdom	6 (16)
Australia	4 (11)
Canada	2 (5)
Belgium	1 (3)
France	1 (3)
Sweden	1 (3)
Perspective of participants*	
Other	
Peer, general public	20 (54)
Health care provider	1 (3)
University staff	1 (3)
Police	1 (3)
Jurors	1 (3)
Self (lived experience)	15 (41)
Parent/family member	4 (11)
Ages of persons with autism represented	
Children (up to 12 years)	12 (32)
Adolescents (13–18 years)	5 (14)
Post-secondary students (college/university)	13 (35)
Other adults (19+ years)	9 (24)

* five studies presented multiple perspectives.

[†] Bottema-Beutel et al. (2016) included youth between 14–24 years; Alkhalidi et al. (2019) included youth between 13–21 years.

improved confidence of knowing how to assist or accommodate someone with autism. Findings related to intentions of social engagement were more variable across analogue studies.

3.3.1. Lived experience and connected family members

Across the sample, adolescents and adults with autism were described as reluctant and cautious in disclosing their diagnosis to others due to experiences with and/or fears of negative outcomes. Parents of children with autism expressed similar fears. Some adult females with autism declined to disclose to health care providers as the adult females believed that most health care providers were uninformed about autism (Lum et al., 2014). Parents of children with autism also expressed concerns about disclosing their child's diagnosis in an emergency room, due to potential diagnostic overshadowing and negative labeling by health care providers (Muskat et al., 2016). Adults with autism grappled with whether to disclose to police because they felt that the police officer would then devalue their evidence because of their diagnosis (Crane et al., 2016). In one study, first-generation Iranian-American mothers described feeling socially rejected when they disclosed their child's autism diagnosis to others within their cultural community (Tarian, 2014).

Indeed, persons with autism, including post-secondary students (Altman, 2010; Anderson, Carter, & Stephenson, 2018; Bottema-Beutel, Mullins, Harvey, Gustafson, & Carter, 2016; Cai & Richdale, 2016; Knott & Taylor, 2014; Van Hees, Moyson, & Roeyers, 2015) and adults (Davidson & Henderson, 2010; Johnson & Joshi, 2016), often reported concerns about negative judgment, discrimination, and stigma. Diagnostic disclosure was a requirement to receive disability support services at some post-secondary institutions (Cai & Richdale, 2016; Knott & Taylor, 2014; MacLeod, Allan, Lewis, & Robertson, 2018; Van Hees et al., 2015). Some college students with multiple disabilities disclosed their physical disabilities, but not autism (Briel & Getzel, 2014). However, students often limited their disclosure to the support services personnel or professors, and rarely disclosed to peers based on fears of exclusion and stigma (Altman, 2010; Knott & Taylor, 2014). Some people with autism who reported reluctance to disclose due to their fear of judgment, discrimination, and stigma, did find acceptance and support when they disclosed to people they felt were trustworthy (Altman, 2010; Johnson & Joshi, 2016; Van Hees et al., 2015). Persons with autism also rarely disclosed their diagnosis to employers due to stigma (Briel & Getzel, 2014; Johnson & Joshi, 2016), although many post-secondary students with autism did indicate interest in creating a 'disclosure plan' for employers should they choose to disclose (Briel & Getzel, 2014). Unfortunately, Briel and Getzel (2014) found that the one student in their study who did disclose to her employer did not receive what she perceived to be adequate workplace accommodations.

In addition to concerns about experiencing stigma, some persons with autism had mixed feelings about disclosure based on experiences with, or fears that, others would then treat them differently even if they were still accepted (Bottema-Beutel et al., 2016; Davidson & Henderson, 2010; Johnson & Joshi, 2016; Mogensen & Mason, 2015). MacLeod et al. (2018) found that one's diagnosis became the focus once disclosed, rather than the person. One college student with autism, who disclosed his diagnosis on his application package, perceived that his autism 'identity' was the rationale for being assigned a roommate also diagnosed with autism (Reid, 2015). Many persons with autism have written about exercising caution around disclosing their diagnosis to help manage their identity (Davidson & Henderson, 2010). Although well-intentioned, the authors of one study investigating higher education

Table 2
Description of included studies categorized by perspectives.

Authors; Location	Objective(s)	Participant Info	Method	Outcome Measures/ Interpretation of Data	Main Findings Related to Disclosure/ Non-Disclosure
Perspective: Lived					
Altman (2010); USA	To examine the social experiences of college students with autism, and the impact of self-disclosure on those social experiences	13 college students diagnosed with autism (18–23 years old)	Individual semi-structured interviews Phenomenology	Content analysis	7/13 never disclosed to peers for fear of negative reactions or judgment, or prior negative experiences with disclosure; 6/13 disclosed to close peers, perceived to be trustworthy, 5 of whom felt the disclosure elicited understanding and support
Anderson et al. (2018) Australia	To explore experiences of university students with autism in 8 universities, including a focus on whether students delay their disclosure to disabilities services, and if so, their reasons and identified consequences	48 university students diagnosed with autism (17 years + old)	32-item anonymous, online questionnaire (13 demographic items, 5 open-ended questions, 6 Likert-style scales, 8 multiple choice questions)	Descriptive statistics of responses	25 % of participants delayed disclosure. Reasons: try university on their own (n = 5), diagnosis after enrollment (n = 3), belief disclosure was unnecessary (n = 2), fear of being stigmatized (n = 2), not knowing how to disclose (n = 2), condition deteriorated after enrollment (n = 2), disclosure difficult (n = 1), disagreed with diagnosis (n = 1), not initially aware of disability services (n = 1). Similar academic and non-academic concerns between delayed and non-delayed disclosure. Those who delayed used fewer supports and services, and were less satisfied with overall supports than those who did not delay.
Bottema-Beutel et al. (2016); USA	To explore and understand how youth with autism view key components of school-based, social focused interventions	33 youth with autism between the ages of 14–24	Individual interviews with open ended questions	Content analysis	Participants had mixed feelings about disclosure; Positive outcomes: educational support, opportunity for social success, and positive interactions; Negative outcomes: stigma and lack of understanding from peers

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Table 2 (continued)

Perspective: Lived		Objective(s)	Participant Info	Method	Outcome Measures/ Interpretation of Data	Main Findings Related to Disclosure/ Non-Disclosure
Briel and Getzel (2014); USA	To describe the experiences of college students with autism related to their status in career planning and preparation, use of campus services/ supports, and their satisfaction with these services/supports	18 post-secondary students with autism	Individual interviews based on 7 structured questions	Content analysis	Only one student disclosed diagnosis to workplace. Minimal accommodations received; Students with multiple disabilities disclosed physical disabilities but not autism; Many participants expressed interest in developing a disclosure plan for employers	
Davidson and Henderson (2010); Canada	To explore key issues surrounding the management of autism disclosure and the process of “coming out”	45 autobiographical works and edited collections of first-hand accounts of autism	A text based qualitative approach to autism narratives (secondary analysis)	Discourse analysis	Disclosure and coming out are part of a contextualized process that takes into account protective strategies (e.g., methodically choosing when and whom to disclose to), the use of deception (or deliberate withholding of information) to manage their identities and situations in ways that can diffuse threatening acts, and education that increases mutual understanding among those with autism and society.	
Johnson and Joshi (2016); USA	Comprised two studies: (1) inductive study to understand how ‘others’ respond to an autism diagnosis in the workplace, and whether the diagnosis has implications for their attitudes regarding work; (2) to examine the implications of an autism diagnosis for workplace well-being	Study 1: 30 adults diagnosed with autism or AD Study 2: 193 employed adults diagnosed with autism or AD	Study 1: Individual semi-structured telephone interviews Study 2: Survey developed based on data from study 1 and stigma-induced identity threat theory	Study 1: Thematic analysis Study 2: Regression analysis: age of diagnosis and disclosure as predictor variables for outcomes related to workplace well-being (based on indices of perceived discrimination, state anxiety, organization-based self-esteem)	Study 1: Decisions related to disclosure were very careful and purposeful; most often chose nondisclosure for fear of stigma and discrimination within the workplace; only disclosed to those they considered close friends. Study 2: People diagnosed at a younger age reported lower perceived discrimination when they disclosed	
Lum et al. (2014); Australia	Pilot study to explore how characteristics of autism influence health care experiences for women as compared to women without autism	32 adult females diagnosed with autism	Exploratory questionnaire	Women with autism rated 7-items related to outcomes of disclosure in healthcare settings using a phrase completion scale (e.g., never...always). Descriptive statistics (e.g., mean responses, # responses per descriptor) provided for each item.	Overall, high levels of negative responses to their autism diagnosis by health care providers reported; 75 % reported non-disclosure at least once because they believed that disclosure would affect treatment or communication; 100 % experienced frustration with healthcare professionals uninformed about autism	

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Table 2 (continued)

Perspective: Lived		Objective(s)	Participant Info	Method	Outcome Measures/ Interpretation of Data	Main Findings Related to Disclosure/ Non-Disclosure
MacLeod et al. (2018); United Kingdom	To explore experiences with success in higher education for students with autism	16 higher education students with autism	Individual semi-structured interviews	Interpretive phenomenology analysis	One subtheme: Having the diagnosis put this barrier there as they looked at the label instead of me; Acknowledge that additional supports are contingent on disclosing diagnosis, yet have the choice as autism can be hidden.	
Mogensen & Mason (2015); Australia	To learn about the lived experiences of teenagers diagnosed with autism and the meaning of a label for negotiating identity	5 teenagers diagnosed with autism	Participatory Action Research informed by Phenomenology and Ethnography	Thematic analysis of interview transcripts, e-mails, and photos of a communication board	Participants were reluctant to disclose diagnosis due to stereotypes and negative public attitudes attached to the diagnosis in society; 2 participants feared sharing diagnosis with friends would result in being treated differently; 1 participant comfortable with sharing diagnosis, and being different helped him socially	
Reid (2015); USA	To chronicle key incidents through the educational journey of a college student with AD enrolled in a Christian university	1, male university student (21 years old) diagnosed with Asperger Disorder	Individual semi-structured interview; researcher field notes, research reflective journal, personal poem provided by participant; informed by phenomenological lens	Recursive analysis of data	Participant disclosed his diagnosis on his application package, but subsequently chose not to disclose for the purpose of receiving accommodations. He reported one negative outcome of disclosing on his application: being assigned a roommate with autism. Otherwise, he reported a very positive university experience, including feeling accepted by friends and professors without disclosure.	
Van Hees et al. (2015); Belgium	To gain a thorough understanding of how universities and colleges can optimally support students with autism	23 students with autism in higher education (18 – 23 years old)	Individual semi-structured interviews	Thematic analysis followed principles of Grounded Theory	Disclosure was a challenge for participants; Students often disclosed their diagnosis to Disability Services to become eligible for academic accommodations; Students reluctant to disclose to peers and instructors due to perceived ignorance, stigma, prejudice and rejection. However, some participants reported positive outcomes related to disclosing their diagnosis to professors; “Hiding” their diagnosis was often stressful for participants.	

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Table 2 (continued)

Authors; Location	Objective(s)	Participant Info	Method	Outcome Measures/ Interpretation of Data	Main Findings Related to Disclosure/Non-Disclosure
Cai and Richdale (2016); Australia	To examine the experiences and support needs of students with autism and experiences of their families	Lived: n = 23 post-secondary students with autism Parent/family: n = 15 family members	Semi-structured student focus groups and family focus groups	Thematic analysis	Disclosure required to access support services; Only one student disclosed at enrolment, with encouragement from parents. Inferred that non-disclosure due to past negative experiences; Parents often disclosed to the institution, either with or without the student present; Most students disclosed due to crisis – to access assistance; Positive academic outcomes were reported by students who had accessed disclosed their diagnosis to, and accessed disability support services
Crane et al. (2016); United Kingdom	To understand and interpret police officers: (1) experiences of working with victims, witnesses and suspects with autism, (2) their awareness and use of mandatory provisions and adjustments, (3) how satisfied they are with their professional dealings with the autism community, and (4) police training needs	Other: n = 394 police officers Lived: n = 31 adults with autism Parent/family: n = 49 parents of individuals with autism	Surveys with opportunity to elaborate and provide additional comments in open-ended text boxes	Descriptive summary of survey responses Thematic analysis of additional comments	Police officers reported that a person's autism diagnosis was 'always' or 'sometimes' made known to them prior to or upon first contact. The disclosure came from the person with autism or their parent; Disclosure : (1) helped with support and adjustments when being questioned, (2) helped police understand behaviours for safety, (3) led to victimization, devaluing of the person with autism's evidence, or discrimination (4) could be helpful to explain why the individual was targeted/ involved in an offence
DeBrabander et al. (2019); USA	To examine views of autistic adults for autistic and TD raters with and without diagnostic disclosure	Lived: n = 32 autistic adults Other: n = 32 neurotypical adults	Videos of adults with (n = 20) and without (n = 20) autism. 15 videos of autistic adults from Sasson et al. (2017) ; 5 new videos created. Half of the videos were presented with an accurate diagnosis (autism or no diagnosis) and half were presented with no label.	First Impression Scale	TD raters evaluated autistic adults less favourably than non-autistic adults across conditions. Disclosure improved ratings for TD raters (awkwardness, likeability, interest living near and having a conversation with); Autistic raters evaluated autistic adults less favourably than TD adults, but higher than TD raters. Disclosure did not influence ratings for autistic raters. Trait judgements did not influence desire for social interaction of autistic raters with autistic adults, which was consistent regardless of disclosure or not.

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Table 2 (continued)

Perspective: Parents/Family and Multiple Perspectives					
Authors; Location	Objective(s)	Participant Info	Method	Outcome Measures/ Interpretation of Data	Main Findings Related to Disclosure/Non-Disclosure
Knott and Taylor (2014); United Kingdom	To examine and identify the achievements, challenges, barriers, and supports for successful progress through university for students with autism	Lived: n = 4 male post-secondary students with autism Other: n = 9 staff who worked with individuals with autism	Focus groups: 2 with staff, 1 with students	Thematic analysis	Staff believed students should disclose their diagnosis so that teachers would know how to interpret and react to odd behaviours and poor progress; students were hesitant to disclose, and those willing to were more inclined to disclose to staff than to peers
Muskat et al. (2016); Canada	To understand the experiences of parents and health care providers related to the disclosure of a child's diagnosis of autism in emergency departments (ED)	Parent/family n = 28 parents of children with autism Other: n = 16 health care providers (HCP)	Secondary analysis of interview transcripts	Thematic analysis informed by Grounded Theory	Parents described a process of considering benefits and risks of disclosing; benefits for parents include helping HCP's to understand and accommodate child's needs and possibly expedite services; risks for parents include the potential for negative labeling associated with autism and their reluctance to disclose in front of child; HCP's believe disclosure assists in understanding and for effectively caring for child in ED, and helps them prepare prior to interacting with the family
Tarant (2014); USA	To explore the experiences and coping strategies of Iranian American mothers raising children with autism, including how cultural factors affect experience	Parent/family: n = 6 first-generation Iranian American mothers of children (ages 8 – 12 years) with autism	Individual semi-structured interviews	Thematic analysis of interview data	Disclosure emerged as a theme: Mothers conflicted about disclosing due to fear of stigma in their cultural community; Half of the mothers delayed disclosure due to feelings of shame and embarrassment, and of not wanting to be judged by their Iranian community; 5/6 mothers felt judged or rejected when disclosing their child's autism diagnosis. Two of these mothers also reported relief following disclosure to others; Mothers often disclosed to reduce judgment from others and feelings of shame when their children displayed challenging behaviours in public

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Table 2 (continued)

Authors; Location	Objective(s)	Participant Info	Method	Outcome Measures/ Interpretation of Data	Main Findings Related to Disclosure/Non-Disclosure
Alkhalidi et al. (2019); UK	To evaluate perceptions of social favorability of people with autism by neurotypical perceivers:	Study 1: 31 young adults (20–28 years) Study 2: 30 young adults (18–25 years)	Videos of 40 youth (20 with autism, 20 TD) responding to one of four scenarios (compliment, joke, story, waiting) Neurotypical perceivers scored social favourability across the 40 videos. Study 1: perceivers were not aware of whether the target (in the video) was or was not diagnosed with autism Study 2: perceivers (different than study 1) were aware of autism diagnosis	Perceivers rated each video on 9 questions related to social favourability. Scores for 9 items averaged to create a global social favourability score.	Non-autistic perceivers rated non-autistic targets more socially favourably across scenarios than autistic targets in both non-disclosure and disclosure conditions with one exception. In waiting scenario, autism/no autism ratings were equally poor with nondisclosure. However, autistic targets were rated more poorly than non-autistic targets with disclosure for this scenario
Austin et al. (2016); USA	To investigate the use of an autism disclosure card on perceptions of a mother-child interaction in public when the child is misbehaving	160 community parents	2 × 2 between-subjects design using written vignettes: card/no card, child age (4 or 8 years old)	14 item online survey developed for this study	Disclosure card = lower scores for maternal skill deficit and negative reaction to the dyad, no influence on sympathy for the mother.
Austin et al. (2018); USA	To evaluate relative effects of different disclosure methods (disclosure card, disclosure bracelet, no disclosure) on perceptions of a mother-child dyad	383 community parents of 6–12 year old children	3 × 2 between-subjects design using written vignettes: card/bracelet/no disclosure, child age (4 or 8 years old)	18 item online survey developed for this study; some questions from Austin et al. (2016)	Disclosure card and bracelet both = less critical of mother/child than non-disclosure condition Disclosure card less critical than bracelet Disclosure card and bracelet = less need to protect their own (non-autistic) child than non-disclosure; no difference between card and bracelet Non-disclosure = more embarrassment for mother; no difference between card and bracelet
Brosnan and Mills (2016) United Kingdom	To evaluate the impact of clinical labels on affective experience of college students	120 college students	Online questionnaire, with demographics and two written vignettes depicting social interactions typical of a person with autism. Informed that (1) typical college student, (2) clinical disorder (either autism, Asperger's syndrome, or schizophrenia) with above average intelligence	Affective responses. Measured using Positive and Negative Affect Scale	Affective responses more positive and less negative towards behaviours associated with clinical groups compared to typical college students. No difference between clinical groups.
Butler and Ghills (2011); USA	To investigate whether the label Asperger's Disorder (AD), the behavioural characteristics common to AD, or both impact stigmatization of adults with AD by undergraduate students enrolled in a psychology class	195 college students	2 × 3 between-subjects design: Written vignettes with AD label/no label, and behavioural description related to no, mild, or more notable social deficits characteristic of AD	Modified Social Distance Scale: Evaluates stigma Level of knowledge and experience with AD (0–10 scale)	Social impairment, but not AD label, led to increased stigmatization

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Table 2 (continued)

Authors; Location	Objective(s)	Participant Info	Method	Outcome Measures/ Interpretation of Data	Main Findings Related to Disclosure/Non-Disclosure
Campbell et al. (2004); USA	To examine the effect of descriptive and explanatory information on peers' perceptions and behavioural intentions toward an unfamiliar child with autism (replication of Swain & Morgan, 2001)	576 neurotypical grade 3–5 students	Video vignettes of a 12-year-old male actor portraying a child who does/does not exhibit symptoms of autism. Participants randomly assigned to one of three conditions: (1) No autism with descriptive information about similarities between the actor and participant; (2) autism with similar descriptive information; (3) autism with descriptive + explanatory information	Adjective Checklist: cognitive attitudes; Shared Activities Questionnaire: willingness to engage in activities; Similarity Rating Form: recognition of presence of autism	Less positive attitudes and behavioural intentions towards child showing autism characteristics; More positive outcomes noted when explanatory information provided
Campbell et al. (2005); USA	To examine the influence of sociometric status, and interactive effects of sociometric status and explanatory information on peers' perceptions of an unfamiliar child with autism	*Same study as Campbell et al. (2004)	*Same study as Campbell et al. (2004)	*Same as Campbell et al. (2004) + Peer nominations of sociometric status: who they like to play with the most and least	Attitudes and behavioural intentions towards children with autism varied based on the sociometric status of the neurotypical peer: "neglected" children reported most negative outcomes, "rejected" children reported most positive outcomes when explanatory information provided
Campbell (2007); USA	To examine the effects of educational messages provided by a student with autism on middle school students' attitudes toward an unfamiliar student with autism	233 neurotypical middle school students	Video vignette of a 14-year-old male actor portraying a child with symptoms indicative of autism. Participants randomly assigned to receive 1 of 4 first-person narratives presented in a pamphlet that reflect varying types of information about autism: (1) none, (2) descriptive, (3) explanatory, (4) descriptive + explanatory	*Same as Campbell et al. (2004)	More positive outcomes noted: (1) when explanatory information was provided, (2) for female participants, (3) for students with prior awareness of autism
Chambres et al. (2008); France	To explore adult attitudes towards problematic and non-problematic behaviours of a 6-year-old child with autism in disclosure or non-disclosure conditions	88 adults unfamiliar with autism	Four videos of a 6-year-old with autism (not actor): two videos displayed a problematic behavior not related to autism symptoms (moaning; temper tantrum), two videos displayed non-problematic behavior (using the computer; talking while seated at a table). Participants randomly assigned to condition that did/did not inform them of autism diagnosis	Participants rated child's behavior on 10 continuous scales reflecting social (e.g., well-raised, aggressive), cognitive (e.g., intelligent, alert) and emotional (e.g., anxious) dimensions	Disclosure led to more positive outcomes for: social dimension across behaviours; cognitive dimensions for non-problematic behaviours (no effect for problematic), and emotional dimension for non-problematic behaviours; Disclosure led to more severe ratings of problematic behaviours (being more "disturbed")

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Table 2 (continued)

Authors; Location	Objective(s)	Participant Info	Method	Outcome Measures/ Interpretation of Data	Main Findings Related to Disclosure/Non-Disclosure
<p>Perspective: Other</p> <p>Dowjat (2009); USA</p>	<p>To investigate effects of disclosure and severity of autism symptoms on neurotypical students attitudes towards adolescents with autism</p>	<p>61 neurotypical middle school students</p>	<p>Three written, computer-based vignettes. 2 × 3 mixed experimental design:</p> <p>Between-subjects: random assignment to disclosure/non-disclosure condition; Within-subjects: 3 levels of autism severity</p>	<p>Chekote-McMaster Attitudes Towards Children with Handicaps (CATCH) – abbreviated;</p> <p>Social Anxiety Scale: to evaluate social anxiety as potential confound</p> <p>Ranked items developed for this study to evaluate participants desire to provide socially appropriate responses; Developmental Disabilities Background: to evaluate prior knowledge of autism</p>	<p>Main effect for severity: peer attitudes decreased with increased autism symptom severity; Disclosing diagnosis led to more positive outcomes for adolescents with moderate and severe, but not mild, autism characteristics</p>
<p>Iobst et al. (2009); USA</p>	<p>To evaluate the influence of different types of information on college students' attitudes about a child with autism</p>	<p>288 college students</p>	<p>Video vignettes from Campbell et al. (2004); 2 × 4 between-subjects design with random assignment to autism/typical behaviours condition, and 1 of 4 written vignettes reflecting varying types of information about autism: (1) none, (2) explanatory, (3) neuropsychological (brain-behaviour relationships), (4) explanatory + neuropsychological</p>	<p>Ratings of the Child Questionnaire: attitudes about and acceptance of the boy in the video</p>	<p>Main effects for autism symptoms, type of information, and participant gender: ratings were more favourable for the boy displaying "typical" behaviours, for the explanatory or neuropsychological information as compared to the combined or no information, and for women</p>
<p>Lainpelto et al. (2016); Sweden</p>	<p>To evaluate if attitudes toward children with neuropsychiatric disorders influence evaluations concerning allegations of child sexual abuse</p>	<p>107 law students (university level)</p>	<p>Written transcript of a mock police interview with an 11-year-old girl. Participants randomly assigned to two conditions: no diagnostic background or disclosure of co-morbid AD/ADHD diagnosis</p>	<p>Participants rated 5-items: (1) credibility of child, (2) degree to which she talked about self-experienced events, (3) degree to which her narration was rich and detailed, (4) truthfulness, and (5) competence.</p>	<p>Lower scores across all 5 items for the child with the AD/ADHD diagnosis</p>
<p>Maras et al. (2019); UK</p>	<p>To examine mock juror perceptions of credibility and culpability of a defendant who is described as displaying autistic-like characteristics and behaviours, and whether disclosure alters these perceptions</p>	<p>160 adults eligible for jury service (ages 18 – 68 years)</p>	<p>Written vignette depicting a 27-year-old man who was agitated and aggressive in the community, and charged with assault and battery of a police officer. Part one described the scene in the community, part two provided an excerpt of questioning in court. Participants randomly assigned to non-labelled or labelled (autism + information about how autism may influence behaviour) conditions</p>	<p>Credibility items (1 – 7 scale): cognitive functioning, honesty, likability; blame for the incident; guilty/not guilty recommended (yes/no). If yes, sentencing leniency (1 – 7 scale). Participants provided qualitative responses to explain their rating for each question.</p> <p>One-way MANOVA (label x credibility variables); t-tests (blame; leniency); Chi square (guilt). Inductive thematic analysis</p>	<p>Improved ratings for honesty and likability, less blameworthy for actions, less guilty verdict with disclosure. If indicated guilty verdict, more lenient sentencing with disclosure. No influence on perceived cognitive functioning;</p> <p>Behaviour attributed to autism diagnosis in disclosure condition.</p>

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Authors; Location	Objective(s)	Participant Info	Method	Outcome Measures/ Interpretation of Data	Main Findings Related to Disclosure/Non-Disclosure
<p>Perspective: Other</p> <p>Matthews et al. (2015); USA</p>	To evaluate affective, behavioural, and cognitive peer attitudes toward college students with high functioning autism	224 undergraduate students	Three online, written vignettes that depict typical undergraduate experience (group work, living in dorm, joining club). Each vignette described a behaviour characteristic of autism. Vignette labelled: high functioning autism (HFA), typical college student, no label.	<p>Multidimensional Attitudes Scale toward Persons with Disabilities.</p> <p>Repeated measures 3 (condition) x 3 (vignette) ANOVA</p>	No effect on affective attitudes. HFA label condition reported more positive behavioural and cognitive attitudes toward vignette characters than no label. No difference between HFA and typical label. Conclude that knowing the HFA label may not lead college students to feel differently, but they may think and act more positively towards peers with autism.
Morrison et al. (2019); USA	To examine first impressions of autistic adults by neurotypical raters, including the influence of raters' knowledge and beliefs about autism	505 neurotypical undergraduate students	Videos of adults with autism (n = 20) from Sasson et al. (2017) . Participants viewed all videos, half of which were randomly assigned an autism descriptive label (autistic, autism, Asperger's, on the autism spectrum or disability) and half of which were labelled "no diagnosis". Participants completed a first impression scale after each video.	<p>First Impression Scale, Autism Awareness Scale, Social Distance Scale, Level of Contact Report</p>	<p>Diagnostic label worsened impressions for raters with high stigma towards autism</p> <p>Higher autism knowledge produced improved impressions, but only when diagnosis disclosed;</p> <p>Benefits of disclosure did not vary based on term used to describe autism;</p> <p>Conclusion: Characteristics of raters influence impressions more than characteristics of autistic adults</p>
Morton & Campbell (2008); USA	To examine the impact of information source and interactive effects of source and receiver characteristics on peers' attitudes towards autism	296 neurotypical elementary school students	Video vignette of a 12-year-old male actor portraying a child who exhibits symptoms of autism (from Campbell et al., 2004). Classrooms randomly assigned to receive information from one of five sources: (1) videotape, (2) classroom teacher, (3) actor portraying child's mother, (4) actor portraying child's father, (5) actor portraying a doctor who worked with children similar to the child in the video	<p>Adjective Checklist: cognitive attitudes;</p> <p>Shared Activities Questionnaire: willingness to engage in activities</p>	<p>Many interactive effects between source and grade noted. Advise that children learn about autism from multiple sources to influence behaviour across contexts; Fifth-graders reported more favourable cognitive and behavioural attitudes when information was provided by extra-familial sources (e.g., doctor, teacher) than parents.</p>

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Perspective: Other	Objective(s)	Participant Info	Method	Outcome Measures/ Interpretation of Data	Main Findings Related to Disclosure/Non-Disclosure
Sasson and Morrison (2019); USA	To evaluate first impressions of adults with autism versus 'typically developing' (TD) adults from the perspective of non-autistic undergraduate students	215 non-autistic undergraduate students	40 adults (20 with autism, 20 TD) recorded in video participating in High Risk Social Challenge Task (performance-based measure of social skill with mock 60 s audition for reality/game show).	Each video rated on 10 items using 4-point scale (strongly disagree to strongly agree): 6 trait items (awkwardness, attractiveness, likability, trustworthiness, intelligence, dominance/ submissiveness), 4 behavioural intention to socially engage items (likelihood of starting conversation, hanging out with in free time, willingness to live near, comfort sitting beside). 2 (autism/no) x 4 (label) x 10 (survey questions) mixed methods ANOVA	First impressions made by unfamiliar TD observers were markedly less positive for adults with autism compared to TD controls across a range of judgments, including greater hesitancy to socially interact with participants with autism. Interaction effect: people with more autism knowledge had more positive perceptions about people with autism, but only when the diagnosis was disclosed; First impressions were significantly more favourable for autism stimulus participants when they were labeled as having autism vs no label. Concluded: disclosure helps social evaluation of adults with autism; provides explanation for behaviour.
Silton and Fogel (2012); USA	To determine which types of information: descriptive, explanatory, peer strategy or strengths (e.g., savant abilities) information best promotes positive behavioural intentions and attitudes of neurotypical children towards children with autism	158 neurotypical grade 4 – 6 children	Students assigned to watch one of four 22 min videos that included male and female child actors portraying a boy and girl with autism: (1) descriptive (D) + explanatory (E) information, (2) D + E + Peer strategies (PS), (3) D + E + strengths, (4) D + E + PS + strengths	Autism Knowledge sheet; check for previous knowledge of autism Adjective Checklist: cognitive attitudes; Shared Activities Questionnaire: willingness to engage in activities	Videos that incorporated peer strategies more positively influenced behavioural intentions that videos that incorporated strengths information. Videos did not influence attitudes of participants.
Swaim and Morgan (2001); USA	To examine the effect of descriptive and explanatory information on peers' perceptions and behavioural intentions toward an unfamiliar child with autism	233 neurotypical grade 3 and 6 students	Video vignettes of a 12-year-old male actor portraying a child who does/does not exhibit symptoms of autism. Participants randomly assigned to one of three conditions: (1) no autism + descriptive info; (2) autism + descriptive info; (3) autism with descriptive + explanatory information	Adjective Checklist: cognitive attitudes; Shared Activities Questionnaire: willingness to engage in activities; Similarity Rating Form: recognition of presence of autism	Less positive attitudes and behavioural intentions towards child showing autism characteristics; No change in attitudes or behavioural intentions when explanatory information provided

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Perspective: Other						
Authors; Location	Objective(s)	Participant Info	Method	Outcome Measures/ Interpretation of Data	Main Findings Related to Disclosure/Non-Disclosure	
Underhill et al. (2019); USA	To evaluate how autism stigma may influence peers responses to students with autism in college communication classrooms	216 college students without autism (18–49 years)	Written vignette about a college student that described behaviours and communication deficits consistent with autism. Open-ended questions about participants' openness toward students like the person depicted in the vignette (with no diagnosis provided); questionnaires related to their knowledge of autism, attitudes towards inclusion students with autism in college, desired social distance from students with autism, and opinions on disclosure.	Openness Scale; Social Distance Scale; Autism Stigma and Knowledge Questionnaire; Attitudes on Postsecondary Education for Students with Intellectual Disabilities and Autism Survey Open-ended questions to expand on answers on scale items, and to ask their belief about whether or not students with autism should disclose their diagnosis to classmates	50 % of participants said students should not disclose, 41 % said 'maybe' disclose, and 5% said should disclose (4% no response); Students expressed various indicators of stigma: although they expressed kindness and understanding related to behaviour, they did not desire to interact and form relationships with the peer with autism; Qualitative data indicated that peers desired the student with autism to conceal their condition and mask as 'normal'	

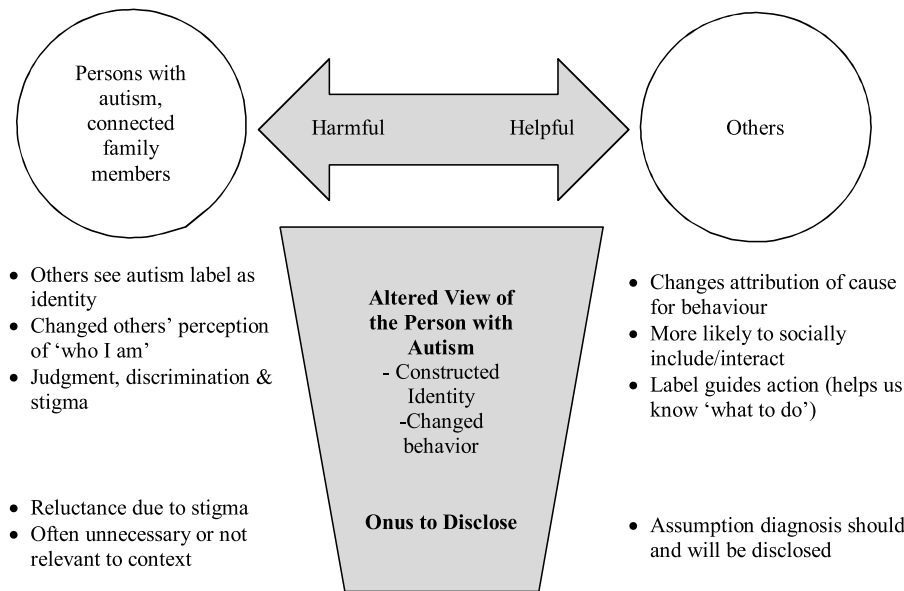


Fig. 2. Summary of emergent themes depicting the divergent considerations and perspectives of outcomes of disclosure portrayed by the different stakeholder groups represented in the included papers (n = 37).

experiences of students with autism reinforced this sentiment of ‘diagnosis becoming one’s identity’ (whether or not that is how students choose to identify) in their statement that academic environments should “nurture an atmosphere where students are given the opportunity to disclose to others who they are in a safe way, and encouraged to be themselves, instead of feeling the need to hide their identity” (Van Hees et al., 2015, p. 1685).

Interestingly, autistic raters did evaluate videos of autistic adults less favorably than typically developing adults, although their ratings of autistic adults were still more positive than those of typically developing raters. However, unlike typically developing raters, the ratings of autistic adults were not associated with less social interest in those adults, and were not influenced by disclosure or non-disclosure (DeBrabander et al., 2019).

3.3.2. Others

In contrast to perceptions garnered from lived experience that disclosure often led to negative outcomes for persons with autism, studies that elicited the perspective of others primarily reported positive perspectives/outcomes related to diagnostic disclosure, especially when explanatory information about autism was provided in addition to the label (Campbell, Ferguson, Herzinger, Jackson, & Marino, 2004; Austin et al., 2016; Austin, Galijot, & Davies, 2018; Brosnan & Mills, 2016; Campbell, Ferguson, Herzinger, Jackson, & Marino, 2005; Campbell, 2007; Chambres et al., 2008; Crane et al., 2016; Dowjotas, 2009; Iobst et al., 2009; Knott & Taylor, 2014; Sasson & Morrison, 2019). However, benefits of explanatory information varied based on sociometric status (Campbell et al., 2005) and who provided the information about autism to peers (Morton & Campbell, 2008). Findings generally indicated that disclosure would lead others to positively change their perception of the attribution of behaviors (Campbell et al., 2004; Campbell, 2007; DeBrabander et al., 2019; Iobst et al., 2009; Maras, Marshall, & Sands, 2019; Silton & Fogel, 2012; Tarian, 2014), especially for female ‘others’ (Campbell et al., 2004; Iobst et al., 2009). Unconnected children and adults suggested that they would be more likely to interact, or let their child interact, with someone with autism if a diagnosis was disclosed (2004, Austin et al., 2016; Campbell et al., 2005; Campbell, 2007; DeBrabander et al., 2019); especially if a child had more severe autistic characteristics (Dowjotas, 2009) and when strategies to support a peer with autism were provided with the diagnostic label (Silton & Fogel, 2012).

Sasson and Morrison (2019) and Morrison et al. (2019) used adults with and without autism engaged in a social task within a video vignette study with post-secondary students. In general, these students reported more negative impressions of someone with autism (the person who was autistic in real life) when a label was not provided, but a more positive social evaluation of this person when a diagnostic label was provided. However, these benefits did not extend to students with high levels of autism-related stigma, whose impressions of the adult with autism worsened with disclosure (Morrison et al., 2019). Additionally, greater autism knowledge of the rater predicted more positive perceptions of people with autism, but only when the diagnosis was disclosed (Morrison et al., 2019; Sasson & Morrison, 2019). Brosnan and Mills (2016) also found that diagnostic disclosure in persons who had above average intelligence led to more positive affective responses by college peers, with no difference in outcomes between the diagnoses of autism or schizophrenia. However, Matthews, Agnes, and Goldberg (2015) found that an autism label did not influence affective outcomes for post-secondary students. They did, however, find that diagnostic disclosure led to more positive behavioral and cognitive attitudes towards a vignette character than no label. They concluded that knowing a diagnosis of autism may not lead post-secondary students to feel differently about their peers, but may help them think and act more positively towards peers with autism. Willingness to interact was more positive when an extra-familiar source (e.g., doctor, teacher), rather than a parent, disclosed the diagnosis (Morton

& Campbell, 2008).

Maras et al. (2019) found that disclosure of an autism diagnosis improved potential jury members' perceptions of a hypothetical defendant who was charged with assault and battery of a police officer. The defendant was perceived as more honest and likable, and less blameworthy for his actions with disclosure. Furthermore, many participants did not indicate a guilty verdict with disclosure, and if they did, they became more lenient in their sentencing. These findings related to interactions with the criminal justice system are contrary to ratings of law students, who rated the credibility, truthfulness, and competence of an alleged child sexual assault victim lower when they learned that child had an autism diagnosis (Lainpelto, Isaksson, & Lindblad, 2016).

Others also reported some neutral or negative outcomes related to disclosure within studies involving analogue methods. For example, Chambres et al. (2008) found that adults rated problematic behaviors more severely when an autism diagnosis was disclosed. Alkhaldi et al. (2019) found that non-autistic raters rated social favorability of people with and without autism similarly in a scenario where they were kept waiting without explanation, yet perceptions of the autistic adults were more negative with disclosure. University students expressed increased kindness towards and improved understanding of atypical behaviors of a peer with autism with disclosure; however, the disclosure did not improve their desire to interact with and form a relationship with that peer (Underhill, Ledford, & Adams, 2019). Together, these findings support concerns related to judgments, discrimination, and stigma related to an autism diagnosis (Alkhaldi et al., 2019; Chambres et al., 2008; Lainpelto et al., 2016; Matthews et al., 2015; Swaim & Morgan, 2001; Underhill et al., 2019). However, Swaim and Morgan (2001) found no effect of disclosing diagnosis, on its own or with descriptive and/or explanatory information, for grade three and six students unfamiliar with autism, suggesting that negative attitudes and perceptions related to the behavioral characteristics of autism, but not the diagnosis. Similarly, Butler and Gillis (2011) found that college students reported increased stigmatization of observable social impairments, but not an Asperger's Disorder label, suggesting that the label did not lead to increased discrimination in that context.

Differences in perspectives were apparent in studies that included multiple stakeholder groups. For example, although parents of children with autism expressed concerns about disclosing their child's diagnosis in an emergency room, the health care providers in the same study believed that knowing the diagnosis helped them better care for the child and family (Muskat et al., 2016). Similarly, even though adults with autism were hesitant to disclose their diagnosis to police officers, these officers reported that diagnostic disclosure would help them know how to support someone with autism (Crane et al., 2016). University staff also felt that diagnostic disclosure would help them know how to support someone with autism (Knott & Taylor, 2014).

Outcomes of disclosure on perceptions of mothers of children with autism were also evaluated in two studies. Austin et al. (2016, 2018) used written vignettes to evaluate how community parents perceive mothers of children with autism. They found that both a disclosure card, which provided the label and explanatory information, and a disclosure bracelet, which provided the label and the statement 'be patient', improved perceptions of the mother. Both strategies decreased scores of others' perceptions of maternal skill deficit, with the card being more effective than the bracelet, and both strategies equally decreased feelings of negative social valorization and stigma for the mother (Austin et al., 2018).

3.4. Theme 2 – onus to disclose

The second theme, onus to disclose, relates to an overall assumption by others that one's diagnosis of autism should be disclosed, despite reluctance by people with autism due to stigma or a lack of necessity or relevance.

3.4.1. Lived experience and connected family members

Non-disclosure or selective disclosure was commonly advocated by people with autism, often based on the extent to which the person to whom they chose to disclose was perceived to be supportive and trustworthy (Altman, 2010; Johnson & Joshi, 2016; Knott & Taylor, 2014; Mogensen & Mason, 2015; Van Hees et al., 2015). Parents also advocated for selective disclosure; for example, to support academic success (Cai & Richdale, 2016), to explain disruptive behaviors (Muskat et al., 2016; Tarian, 2014), to support interaction with police (Crane et al., 2016), or to expedite medical care (Muskat et al., 2016). Some people with autism did not disclose their diagnosis because it was not relevant to the context (Altman, 2010; Anderson et al., 2018; Davidson & Henderson, 2010; Mogensen & Mason, 2015). However, some of these individuals stated that they would disclose without issue if asked (Altman, 2010).

3.4.2. Others

As indicated above, negative assumptions, discrimination, and stigma were significant barriers to people with autism disclosing their diagnosis to others (Altman, 2010; Bottema-Beutel et al., 2016; Briel & Getzel, 2014; Cai & Richdale, 2016; Davidson & Henderson, 2010; Johnson & Joshi, 2016; Knott & Taylor, 2014; Lainpelto et al., 2016; Reid, 2015; Van Hees et al., 2015). However, despite personal apprehension to disclose, some negative findings related to disclosure based on analogue studies, and one study which found that the majority of university students without autism do not think their peers with autism should disclose in that context (Underhill et al., 2019), no authors explicitly stated non-disclosure as an option.

Although not malicious, statements that explicitly indicated disclosure as the only option were noted. For example, in their discussion related to accessing supports following crises, Cai and Richdale (2016) stated, "it is essential that [disability support unit] are aware of these students. This cannot occur without disclosure of ASD diagnosis" (p. 39), and Lum et al. (2014) stated that patients with autism should be encouraged to disclose, even though 100 percent of the participants in their study had experienced frustration when they disclosed their diagnosis to health care providers. Other authors did suggest caution based on their findings (Chambres et al., 2008; Lainpelto et al., 2016), and some authors acknowledged the option of non-disclosure through specific use of language and wording. For example, Altman (2010) reflected this option by saying "if a client is interested in self-disclosing" (p. 86), and

Davidson and Henderson (2010) framed their discussion as, “how disclosure *may* be best accomplished” (p. 166). Underhill et al. acknowledged, “advocating for disclosure could remove ASD students’ autonomy” (p. 189). Rather, they, along with others, suggested that interventions to increase knowledge and decrease stigma directed at others might be the most beneficial approaches (Morrison et al., 2019; Underhill et al., 2019).

4. Discussion

This scoping review revealed discrepant viewpoints between people with autism and others regarding perceptions and outcomes of diagnostic disclosure. In particular, two main themes emerged from existing research that reflect (1) an altered view of the person with autism following disclosure, and (2) an assumed onus to disclose one’s diagnosis to others. Others often reported positive outcomes from diagnostic disclosure, including changing the attribution of cause for behaviors from an undesirable personal characteristic to something related to autism beyond that person’s control, yet the lived experiences of people with autism do not support these findings. To our knowledge, this is the first review to focus on discrepant views between people with a diagnosis and others who do not have this lived experience. Consideration of both types of research - based on lived experience or vignettes - is important because people with autism, their caregivers, and professionals with whom they interact, may look to both types of research to inform their decisions and advice related to whether to disclose a diagnosis.

Related to how diagnostic disclosure alters views, people with autism report that disclosing their autism diagnosis often changes others’ perceptions of who they are, even if they knew each other prior to disclosing their diagnosis. People with autism experienced that the newly revealed autism label becomes their primary identity to other people. Indeed, identity management is one reason that people with autism may choose not to disclose their diagnosis, similar to other marginalized groups (Davidson & Henderson, 2010). Little has been written in the peer-reviewed scientific literature about autism and identity construction, although some literature suggests that identity construction is insignificant for people with autism due to the social impairments inherent in the diagnosis (Bagatell, 2007). However, Bagatell’s (2007) ethnographic study of one young man with autism disputes this notion and provides important commentary on potential discrepant positions between the autistic community and others. The person with autism in her study negotiated multiple identities and related tensions between his neurotypical world, which reinforced his marginalized position as a person with autism and the importance of fitting in, and his “Aspie” world, which reinforced his ability to live a meaningful life as a person with autism. There is increasing discourse within the autistic community of a preference for identity-first language, to reinforce that autism is of value and deserving of respect (Vivanti, 2020); however, different from our findings, this identity construction is controlled by people with autism, not others.

People with autism are marginalized, often experiencing judgment, discrimination, and stigma (Gillespie-Lynch, Kapp, Brooks, Pickens, & Schwartzman, 2017). Joachim and Acorn (2000) suggest that non-disclosure may lead to inclusion if one passes for normal, but passing can be stressful and result in stigma and exclusion when one can no longer pass, or if one chooses to pass as a response to internalized/self stigma. Alternatively, they propose that preventive disclosure, when others are purposefully told about one’s diagnosis, may counteract social stigma by preventing negative perceptions and ensuring help. Indeed, some autistic self-advocates also suggest that disclosure may be necessary to provide context for one’s needs and promote mutual understanding (Davidson & Henderson, 2010; Shore, 2004). The findings from some analogue research also support the theory that preventive disclosure may counteract social stigma. A strength of analogue research is the ability to control for threats to internal validity; however, one must be aware that social desirability bias, conscious or unconscious, may influence results, and generalizability to real life situations may be limited (Cook & Rumrill, 2005). In other words, it is possible that some research participants without an Autism diagnosis in the analogue studies may have demonstrated social desirability bias when they reported more positive feelings and intentions towards people with autism, which they may not enact in everyday life. Our findings from studies that explored lived experiences, which often refuted the positive findings from analogue research, may support social desirability bias, as people with autism often experienced judgment, discrimination, and stigma following disclosure of their autism diagnosis.

Why do people with autism report discrimination and stigma following disclosure? Stigma is often rooted in a conscious or unconscious ableist belief system, which sees persons with disabilities as being less worthy of respect and consideration, and less able to contribute and participate (Goffman, 1963). The need to fit in experienced by people with autism trying to pass reinforces this notion (Bagatell, 2007). The media, for example, often portrays autism narrowly as people who are anti-social or with savant capabilities (Belcher & Maich, 2014; Draaisma, 2009; Prochnow, 2014). These depictions of autism may also perpetuate inaccurate stereotypes, contributing to ongoing judgment, discrimination, and stigma. Underhill et al. (2019) suggest that university students without autism may prefer concealment to avoid potentially uncomfortable interactions based on disclosure. This concept, which Goffman (1963) called phantom normalcy, is rooted in stigma.

Existing research related to perspectives and outcomes of disclosure does not adequately represent the diversity of autism, nor does it consider co-occurring conditions that are common for people with autism. For example, there is a lack of research related to how disclosure may generalize across factors such as intellectual ability. Children, adolescents, and adults are represented in existing literature, yet no studies included the lived experience of children with autism, and their role in disclosure decisions. As such, we cannot conclude that the lived experiences reflected in our theme, altered view of the person with autism, generalizes to the lived experiences of children with autism. Negative attitudes and stigma about autism could reflect a developmental process of learning and socialization over time (DeBrabander et al., 2019). The lived experiences represented in the reviewed research were all based on experiences of adolescents and adults. Perhaps children do not experience negative attitudes and stigma to the same extent or it is experienced in a different way. Autism research under-represents the diversity of intellectual abilities, communication abilities, and adaptive function across the lifespan, with a bias towards including people with autism with less severe impairments (Russell et al.,

2019; Stedman, Taylor, Erard, Peura, & Siegel, 2019). As such, we also cannot conclude that the lived experiences reflected in our theme, altered view of the person with autism, generalizes to the lived experiences of people with autism who have co-occurring intellectual impairment or who communicate in ways not captured in current research.

Among other disability groups, disclosure is described as a personal, dynamic, and ongoing process of “self-negotiated decisions about why, how, when and to whom to disclose” (Valle, Solis, Volpitta, & Connor, 2004; p.4). Despite this recognition among other groups, the perception that others should know one’s autism diagnosis was pervasive in the existing literature, especially when the reader considers that what was not written is perhaps more important than what was written. Even if authors did not state that diagnosis should be disclosed, no authors of the papers included in the review explicitly stated that non-disclosure might be an option. Others, including scholars and clinicians, need to be aware of their assumptions and biases related to diagnostic disclosure to others. They should think carefully about who should know this information, why they should know this information, and how they will use this information. Others reported that knowing the autism diagnosis would provide knowledge of how to support someone with autism. However, the diagnosis alone does not provide a roadmap for supporting someone with autism. How this information would change their behavior was not articulated in the identified literature. Even for people who have a desire to disclose their diagnosis, the process of disclosure can be difficult given the social nuance and context (Johnson & Joshi, 2016). As such, engagement in critical reflexivity by scholars, clinicians, and others is necessary to best support diagnostic disclosure when it is desired.

4.1. Directions for future research

Findings from the analogue studies suggest that others perceive that disclosure will increase understanding, decrease stigma, and support social inclusion for people with autism. However, there is a gap in the literature evaluating how self-reported perceptions and behaviors align with actual outcomes (Heasman & Gillespie, 2019). Some studies (Alkhalidi et al., 2019; DeBrabander et al., 2019; Morrison et al., 2019; Sasson & Morrison, 2019) did use autistic children and adults in their videos, which does enhance ecological validity. However, no studies have observed whether disclosure leads to positive behavioral, affective, and cognitive changes in others in the natural contexts in which social interactions occur (e.g., schools, recreation experiences, workplaces). Future research across abilities, ages, and contexts is needed to explore real-life outcomes related to diagnostic disclosure. Ideally, these outcomes would be evaluated through direct observation of behavior of others to determine whether hypothetical findings generalize to everyday life experiences. These real-life evaluations are especially important given the discrepancies in findings between analogue studies and lived experience of people from the autism community, who are the real experts (Gillespie-Lynch et al., 2017). Future research should also explore optimal strategies and processes for disclosure should someone choose to disclose, and, conversely, explore strategies and processes should someone choose not to disclose. Children with autism’s perceptions of outcomes and preferences for disclosure are significant gaps that warrant research attention. Similarly, perceptions of outcomes and preferences for disclosure from the perspective of people with autism with intellectual impairment and communication abilities not represented in current accounts of lived experiences warrants research attention. Finally, one study that included Iranian-American mothers and their community’s acceptance suggests that outcomes of disclosure may vary across cultural groups; however, no generalizations should be drawn from the limited research that has explored cultural nuances related to this topic. Culturally sensitive research on perceptions and outcomes of disclosure across cultural diversity/differences would be beneficial.

5. Conclusion

This scoping review reveals that relatively little research has focused on processes and perceived outcomes of disclosure of an autism diagnosis to others, and the research that does exist presents discrepant views on perceived outcomes between people with autism and others. Although experiences related to disclosure will undoubtedly be unique based on individual circumstances, distinct patterns were found in the literature. More specifically, people with autism generally report negative outcomes from disclosure, whereas others generally report positive outcomes from disclosure, often based on vignettes that portrayed someone with autism but who was not labeled with autism in real life. Ultimately, little is known about outcomes of disclosure to others in everyday contexts such as school, community settings, and workplaces. Reflection on perceptions of disclosure from various viewpoints, and future research that systematically evaluates outcomes of disclosure in context, can have important implications in addressing assumptions and stigma in relation to autism, ultimately improving inclusion, participation, and quality of life for people with autism and their families.

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