

Florida State University Libraries

2020

An Exploration of Actionable Insights Regarding College Students with Autism: A Review of the Literature

Bradley E. Cox, Brett Ranon Nachman, Kerry Thompson, Steven Dawson, Jeffrey A. Edelstein and Chase Breeden

This is the pre-print version, and the versio of record can be found at <https://www.doi.org/10.1353/rhe.2020.0026>. Copyright © 2020 Association for the Study of Higher Education. This article first appeared in THE REVIEW OF HIGHER EDUCATION, Volume 43, Issue 4, Summer, 2020.



One in every 40 children is diagnosed with Autism Spectrum Disorder (ASD; Kogan et al., 2018), and effective childhood interventions continue to increase the likelihood that these students will graduate high school and pursue higher education with reasonable expectations for success (Hart, Grigal, & Weir, 2010; VanBergeijk, Klin, & Volkmar, 2008). However, nationally representative statistics indicate that fewer than 39% of autistic college students¹ earn any postsecondary credential (i.e., certificate, Associate's degrees, or Bachelor's degrees) within six years of completing high school (Newman et al., 2011).

Yet, it appears that autistic college students have received remarkably little attention from scholars in higher education. The term “autism” did not appear in any of the field’s traditional “top-tier” journals (i.e., *Journal of College Student Development*, *Journal of Higher Education*, *Research in Higher Education*, *Review of Higher Education*; Bray & Major, 2011; Creamer, 1994) until February 2017 (Cox et al., 2017). Moreover, in 2014, Gelbar, Smith, and Reichow found that the current understanding of college students with autism was based on empirical evidence from just 20 articles and only 68 students. More recently, Anderson, Stephenson, and Carter (2017) examined 29 articles reporting on 23 studies, whereas Kuder and Accardo (2018) could find only eight relevant studies.

Moreover, several of the studies addressing the needs of autistic college students (e.g., Newman et al., 2011; Shattuck et al., 2012; Wei, Wagner, Hudson, Yu, & Javitz, 2016) draw from a single national dataset (National Longitudinal Transition Study – 2; NLTS2) that has not been updated since 2009, while many of the others (e.g., Gobbo & Shmulsky, 2014; Morrison, Sansosti, & Hadley, 2009) base their conclusions on information collected from parents,

¹ There is considerable disagreement about the appropriate use of language associated with autism. Some advocates prefer “identity-first” language (e.g., autistic student), while other organizations promote “person-first” language (e.g., individual with autism). We are consciously not picking a side regarding terminology. Rather, we use both person-first and identity-first language interchangeably throughout this manuscript.

instructors, and administrators – not the students themselves. Thus, it appears colleges and universities do not yet have an adequate scholarly foundation upon which they can develop effective initiatives to facilitate the success of autistic students. Likewise, the current literature base offers little guidance for researchers who wish to make substantive new contributions to that body of literature.

The current paper begins to address these problems by identifying, cataloguing, reviewing, and critiquing articles about autistic college students to address three research questions:

1. What topics, data, and methods have scholars used to shape early development of the emerging body of literature about autistic college students?
2. What limitations, biases, and gaps in the current literature may be addressed by future research on the topic?
3. What actions can researchers take in the future to make the literature base more robust, inclusive, and comprehensive?

To answer these questions, we used an explicit framework to examine more than 13,000 articles published in any of 16 journals between 2000 and 2015. This process allowed us to map the contours of the emerging body of literature on college students with autism, uncover problematic patterns within that literature, identify important questions that remain unanswered, and provide explicit guidance for future research on the topic.

Guiding Framework

The Framework for the Development of Actionable Insights (Author Redacted) guides our review of the literature. The framework was derived jointly by a group of higher education scholars and practitioners (Author Redacted) looking to support previously underserved student populations (i.e., atheists, formerly incarcerated students) with programs and policies grounded in the best available research evidence. When considering student populations that have yet to

come to the forefront of mainstream higher education researchers, the framework accommodates the inclusion of research from multiple fields of study, widely varying methodologies, and diverse topical foci. Thus, the Framework serves as a multi-functional tool for exploration, a mechanism for mapping an otherwise disjointed scholarly terrain.

The Framework for the Development of Actionable Insights is depicted in Figure 1 as two opposing funnels (one for Insight, the other for Action). Both the Insight and Action funnels are further divided into four categories that move from broad to narrow as they approach the intersection where actionable insights may become clear. We use this framework as a classification guide, with each of the reviewed articles given a primary and secondary classification based on the articles' topical focus and substantive contribution. The insight and action funnels, with their respective four categories each, are described in detail next.

Insight

Articles classified as having a primary focus within the insight funnel generally provide descriptive information which helps readers develop a contextualized understanding of the focal population. The Insight funnel distinguishes between articles answering four questions, moving from broad to narrow:

- 1) Who are these students?
- 2) How are they doing in college?
- 3) What's happening while they are in college?
- 4) Where is there room for improvement?

Articles addressing Insight Question 1 typically provide key definitions, statistical profiles, or descriptive narratives that situate the population within the broader context of history, society, and/or higher education. Insight Question 2 includes articles offering details about

various “outcomes” specific to postsecondary education (e.g., enrollment, major selection, graduation, development of specific skills). Articles addressing Insight Question 3 describe students’ in-college experiences, often in an effort to identify factors that drive student outcomes. Finally, articles classified under Insight Question 4 synthesize information available from the other three types of Insight articles to articulate specific challenges, needs, or opportunities that students encounter in pursuit of postsecondary success.

Action

Articles classified as having a primary focus within the action funnel provide specific guidance for the development of initiatives, programs, policies, or interventions that might advance the prospects of postsecondary success for students in the population under investigation. Again, moving from broad to narrow, these articles can be further classified as answering one of four questions:

- 1) What matters to/for this student population?
- 2) Which theories shape people’s thinking related to this population?
- 3) How effective are current efforts to support these students?
- 4) What could be done to improve these students’ experiences or outcomes?

Articles addressing Action Question 1 describe the domains of life (e.g., family, sexuality, academics, executive functioning) that are distinctive for this population, most central to their identity, or most salient in their college experiences. Action Question 2 articles identify theories or models that may be used to frame people’s thinking about the population, including population-specific or domain-specific theories of development. Articles classified under Action Question 3 explore the effectiveness of current activities through systematic literature reviews, evaluations of existing programs/services, and empirical analyses of relevant data. Finally,

articles falling under Action Question 4 propose ideas for new programs, policies, practices, or interventions that might improve experiences or outcomes for the focal population.

[INSERT FIGURE 1 HERE]

Method

This review of the literature began following a meeting of six faculty members who had united to discuss their shared interest in studying autistic college students. The interdisciplinary team represented five distinct academic programs from the university's College of Education, the College of Communication and Information, and the College of Medicine. This group identified a total of 16 journals when asked where they would first go to find literature on the topic of college students with autism (see Table 1). Among the journals included were four journals historically considered "top-tier" journals in higher education (i.e., *Journal of College Student Development*, *Journal of Higher Education*, *Research in Higher Education*, *Review of Higher Education*; Bray & Major, 2011; Creamer, 1994) and that remain among the top journals in the field based on the SCImago Journal Rank Indicator (Tight, 2018).

[INSERT TABLE 1 HERE]

Over the next two years, we underwent an extensive article search and review process (see Figure 2), beginning with the retrieval of over 13,000 electronic records produced by these 16 journals – including "online first" publications – from 2000 to September 2015. With the aid of campus librarians and bibliographic software, we searched these records (i.e., titles, abstracts and other meta-data) to identify articles that included derivatives of terms related to autism (e.g., "auti*," "Asperger," "ASD") and higher education (e.g., "higher education," "colleg*," "postsecondary," "post-secondary"). This search yielded a total of 94 abstracts. Subsequent

review of those abstracts by this paper's authors filtered out 37 abstracts that included some variants of the search terms but did not appear to relate to autistic college students.

Full-text versions of the remaining 57 articles were independently reviewed by at least two co-authors using a structured annotation guide in which key elements of each article (e.g., purpose statements, samples, methods, findings) were extracted and critiqued. Reviewers subsequently met to discuss the articles, reconcile any disagreements, and merge their annotated reviews. An additional 36 articles were removed because the detailed review of the full text revealed that the articles did not substantially address the topic of college students with autism (detailed inclusion and exclusion criteria are presented in the next section). The majority of the articles omitted at this point in the filtering process were removed because, although they may have included autistic individuals as participants, the topical focus was not about college experiences or outcomes. For example, Stodden, Yamamoto, Folk, Kong, and Otsuji (2013) made it through our initial review of abstracts, but was excluded at this point because it focused on students with intellectual disabilities, never specifically addressing autistic college students. Other articles were omitted because the discussion of autistic students was indistinguishable from discussions of other student populations.

The resulting 21 articles were then reexamined by two of this paper's authors to determine each article's placement among the categories presented within the Framework for the Development of Actionable Insights. If the initial two reviewers disagreed, a third member of the research team examined the article and discussed it with the other reviewers until they reached consensus regarding the article's placement within the framework. Each article was assigned a single primary placement within the framework. There was no limit to the number of secondary

foci within the framework to which an article could be assigned; some articles contained no secondary foci.

Inclusion and Exclusion Criteria

To be considered for our review, a potential article needed to meet all of our inclusion criteria. First, articles had to have been published between 2000 and 2015 (inclusive of "online first" articles published digitally before print distribution) in one of the 16 specified journals (see Table 1). Second, articles had to present empirical studies, scholarly arguments, legal analyses, or reviews of literature. Third, articles needed to explicitly address topics related to college access, experiences, or outcomes. Fourth, the paper must have allowed, in either the data or the discussion, for differentiation of ASD or autism-related-characteristics from other conditions/characteristics.

We explicitly excluded from our review articles for which any of the following exclusion criteria applied. First, we excluded book reviews, letters to the editor, and introductions to special issues. Second, we excluded articles in which the data or discussion did not differentiate between autistic college students and students with other disabilities (e.g., ADHD, intellectual disabilities). Third, we excluded articles focused on courses, programs, or degrees designed to prepare professionals to work with autistic individuals (e.g., ABA therapist or social worker preparation).

Limitations

This study is subject to several limitations, primarily related to the manner in which we identified manuscripts to review. Although grounded in the collective suggestions of an interdisciplinary team from five distinct programs in three different colleges who described these 16 journals as the places they would first look for scholarship related to college students with

autism, our decision to examine only peer-reviewed articles published in these specific journals delimits the scope of our review and introduces a potential source of bias. For example, the selection of these 16 specific journals was dependent on the composition of the original group of researchers; if a computer scientist or anthropologist had been in the room, we likely would have identified a different set of journals.

In choosing to review exclusively those manuscripts which had been published in peer-reviewed journals, we consciously excluded several other potential sources of information about autistic college students. We did not review books, reports, dissertations, or conference papers/presentations. This choice meant we would be excluding from our analyses some of the pragmatic wisdom often found in books and reports, as well as some emerging evidence that may show up in dissertations or at conferences before reaching journal publication. The exclusion of these sources also means we cannot claim our review to be an exhaustive search for every potential source of information on the topic.

Nonetheless, we chose to constrain our review to peer-reviewed articles in these 16 journals for several reasons. First, we privileged journals over books because decisions to publish journal articles are made by editors whose primary (and explicit) purpose is not to generate a profit but to advance knowledge. Second, we privileged journals over conference papers and dissertations because of the added layer of quality control introduced by a peer-review process that typically is more critical than the review process for books, more independent than occurs with dissertations, and more selective than occurs at most conferences. Third, we focus on journals because they serve as the primary source of evidence used by scholars who subsequently decide which questions and methods will drive the next generation of research on the topic. Finally, although journal publication is subject to its own set of biases

(Dwan et al., 2008; Hopwell, Loudon, Clarke, Oxman, & Dickersin, 2009), we privilege journal publications – where biases have been well-documented and authors’ conflicts of interest are often reported explicitly – over other sources (especially non-refereed reports) where biases are less well documented and/or undisclosed. Although we did not formally adopt the 27-step process outlined by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009) as a rigid methodological mandate, we conducted our review in a manner consistent with PRISMA’s underlying principles related to transparency when identifying, selecting, screening, and reviewing articles.

Even within the limitations outlined above, the application of our inclusion/exclusion criteria required subjective judgments by this paper’s authors. Determinations regarding the inclusion/exclusion of specific articles were conducted via consensus following discussion with three of this paper’s authors. A similar approach was used to determine each article’s placement within the Framework for the Development of Actionable Insights. Although final decisions were made on the basis of consensus, many of the articles were “near misses” about which a different group of researchers might have reached a different conclusion. Indeed, if other researchers were to repeat our systematic search, we would expect to see minor deviations both with regard to the articles determined to meet the inclusion/exclusion criteria and the classification of those articles within the framework.

Finally, our literature review is necessarily time bound. We restricted our search to articles published since 2000, compiling the 13,000+ resulting records in September 2015. Although autism-specific journals have seen an increase in articles about ASD in higher education over the last few years, the numbers remain small; in fact, Kuder and Accardo’s (2018) review of related literature found only four relevant articles per year published in 2016

and 2017. Indeed, the conclusions from Kuder and Accardo (2018), as well as Anderson et al. (2017), are consistent with ours: research on autistic college students remains sparse, key questions remain unanswered (e.g., “how many college students have autism?”), evidence is mixed and scattershot, and conclusions are tentative.

Our literature review, however, provides specific guidance for how to address these issues moving forward. Moreover, as outlined throughout our methods section, this review of the literature incorporates several efforts to minimize bias, ensure reliability, protect against threats to validity, and maximize the utility of our conclusions. Thus, while we acknowledge that our literature review cannot be exhaustive, it is nonetheless a comprehensive analysis of 16 years’ worth of peer-reviewed literature related to college students with autism.

Findings

Results from each step of the article screening process are presented in the PRISMA diagram (Figure 2). Although our review of the literature involved more than 13,000 records published by 16 journals over a 16 year period, we were able to identify only 21 articles (presented in Table 2) that met our inclusion/exclusion criteria. We open the results section by describing the distribution of articles in terms of topical focus using the Framework for the Development of Actionable Insights. Next, we discuss the methodological approaches in each article with a particular emphasis on sample size and composition. Subsequently, we note the distribution of journals in which the articles were published, and follow with a brief discussion of common limitations across the reviewed studies.

[INSERT FIGURE 2 HERE]

[INSERT TABLE 2 HERE]

Topical Foci of Journal Articles about Autistic College Students

Our categorization of articles within the Framework for the Development of Actionable Insights revealed some of the holes and biases currently present in the topical foci of the published literature on autistic college students. As Tables 2 and 3 illustrate, this body of literature tended to be action-oriented, with 57% (12/21) of the articles classified with a primary focus on “action.” Of these, just under half (5/12) explicitly evaluated a current service, policy or intervention; only one article’s (Gobbo & Shmulsky, 2014) primary purpose was to generate or evaluate a specific theory to guide such actions.

Fewer than half (9/21) of the reviewed articles had a primary focus on the development of insights related to the population of college students with autism. Describing the population was the primary focus of only two articles (Kanne et al., 2009; Wei et al., 2013). Only a single article addressed indications of college success as its primary theme (Chiang, Cheung, Hickson, Xiang, & Tsai, 2012). Similarly, only one article analyzed students’ college experiences as its primary theme (Nevill & White, 2011).

Table 4 demonstrates that the distribution of secondary themes differed from the classification of primary themes in important ways. Secondary theme distribution was somewhat more even across all eight parts of the Framework for the Development of Actionable Insights, though secondary themes were distributed to the “insight” side of the framework more than twice as often as they were to the “action” side. Together, these results suggest that the literature to date has emphasized action over insight, with the development of insight about this population generally serving as only a secondary consideration.

[INSERT TABLE 3 HERE]

[INSERT TABLE 4 HERE]

Approaches to the Study of Autistic College Students

In this section, we outline the wide range of approaches used to study issues affecting autistic college students. Of the 21 articles included in our analyses, three were qualitative studies, nine were quantitative, five were scholarly (essays or reviews), and four used mixed-methods; 16 of 21 explicitly presented empirical findings. We begin our description of these approaches with an overview of the context in which these studies are situated. Next, we describe their recruitment processes and participants. Next, we highlight the types of data examined in the studies. We close this section with a brief note about the publication outlets most frequently used to disseminate scholarship about autistic college students.

National and institutional context. Of the 16 empirical articles we reviewed, 11 were based in the USA, two from the UK, plus one each from Australia, Belgium, and Canada. Although the USA-heavy national context is likely reflective of the fact that the journals we reviewed were selected by scholars located in the USA, it is worth noting that *all* of the empirical articles in our analyses were from post-industrial, English-speaking nations in North America and Western Europe.

Of the two articles that report on data collected exclusively from autistic students, the one based in Belgium (Van Hees, Moyson, & Roeyers, 2014) included students from multiple institutions, while the one in the United States (Ames et al., 2015) involved only a single school. Likewise, single-institution samples were used in the article about faculty perceptions (Gobbo & Shmulsky, 2014), as were all three studies about stigma (Butler & Gillis, 2011; Gillespie-Lynch et al., 2015; Nevill & White, 2011). The college-specific sample from Baron-Cohen et al., (2001) was also from a single institution. All of the single-institution samples were collected from four-year colleges and universities. Although other studies based on samples derived from pre-

existing datasets or professional networks may have included students from 2-year institutions, only the articles using NLTS-2 data (Chiang et al., 2012; Wei et al., 2013) explicitly reported on the distribution of its sample across institutional type.

Recruitment. Participants were recruited via a variety of means, largely depending on the context of the study and the methodological approach. All of the qualitative studies sought participants through some form of convenience sampling: enlisting faculty who taught at a college that caters to students with disabilities (Gobbo & Shmulsky, 2014), relying on the authors' professional networks (Camarena & Sarigiani, 2009; Trembath et al., 2012), or soliciting participation through community organizations, clinical offices, or nearby institutions of postsecondary education (Van Hees, Moyson, & Roeyers, 2014). Convenience samples were also common among quantitative studies, with several drawing from some form of pre-existing participant pool (Butler & Gillis, 2010; Gillespie-Lynch et al., 2015; Nevill & White, 2011; Taylor & Seltzer, 2012) or recruiting through autism-focused organizations (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). The three qualitative studies (Gobbo & Shmulsky, 2014; Trembath, Germano, Johanson, & Dissanayake, 2012; Van Hees, Moyson, & Roeyers, 2014) each had fewer than 25 participants. Quantitative studies had samples ranging from 66 (Taylor & Seltzer, 2011) to 660 (Wei, Yu, Shattuck, McCracken & Blackorby, 2013).

Participants. Perhaps the most important - and startling - finding related to these articles' methodological approaches relates to *who* participated in the studies. Of the 16 empirical articles, five studies do not make use of *any* data drawn directly from autistic individuals themselves. Instead, two of those studies describe findings of surveys completed by staff at colleges that offered support for college students with autism and/or related disabilities (Barnhill, 2016²; Papay & Bambara, 2011). The two studies from Taylor and Seltzer (2011, 2012) draw from

² Barnhill (2016) was published "online-first" in 2014, and was thus included in our analyses.

interview data collected exclusively from parents of autistic individuals. Finally, Gobbo and Shmulsky (2013) present findings from focus groups conducted with faculty at a college distinctive for its emphasis on serving students with disabilities.

Moreover, of the 11 empirical papers that employ at least some data from autistic individuals, only two (Ames et al., 2015; Van Hees, Moyson, & Roeyers, 2015) analyze data explicitly and exclusively draw from current and/or recent college students with autism. Of the remaining nine articles using student data, one analyzes data from students who scored high on an assessment used to screen for autism-related characteristics (Kanne, Christ, & Riersen, 2009)³, while three others that focused on the stigma associated with autism in college draw their data from a broader population of students taking undergraduate psychology courses (Butler & Gillis, 2011; Gillespie-Lynch et al., 2015; Nevill & White 2011). The Baron-Cohen et al. (2001) article includes four distinct samples used for comparative analyses, one of which was a cross-section of college students at a single university and another included autistic adults more broadly (only some of whom were in college). Two other studies considered data from individuals alongside data from these individuals' families or caregivers (Camarena & Sarigiani, 2009; Trembath et al., 2012), although all the autistic participants in Camarena and Sarigiani's (2009) study about postsecondary aspirations were students in K-12 settings. Two more studies conducted using the NLTS-2 dataset integrated data from students and parents in ways indistinguishable to readers (Chiang et al., 2012; Wei et al., 2013).

The 11 reviewed articles that include student data, and both which draw data exclusively from parents, used widely varying inclusion criteria when identifying participants. Three studies (Camarena & Sarigiani, 2009; Chiang et al., 2012; Wei et al., 2013) required the students being

³ Kanne, Christ, & Reiersen (2009) screened 1,847 students, but only 120 of those students were included in the analyses presented in their publication.

studied to have been eligible for K-12 special education services. One study (Kanne, Christ, & Reiersen, 2009) used an ASD screening instrument to identify students with relatively high levels of self-reported autism-related characteristics, while all other studies with autistic individuals as an analytical focus required some type of formal diagnosis. But even among those studies, the samples ranged from including *only* programs broadly serving individuals with intellectual or other developmental disabilities (Papay & Bambara, 2011) to those including *only* individuals described as having “high functioning” autism (Camarena & Sarigiani, 2009).

These studies’ varied samples, units of analyses, recruitment methods, and reporting practices prevent our reporting of precise and consistent data regarding the demographic composition of the participants. Nonetheless, we make note here of a few observations about these studies’ participants. First, all the empirical studies make at least some mention of gender. The autistic individuals included in all of these studies were predominately male, largely reflecting the gender distribution of autism diagnoses (Loomes, Hull, & Mandy, 2017); however, gender distribution was more balanced among the samples drawn from a cross-section of an institution's general population. The articles we reviewed were inconsistent in reporting participants’ racial or ethnic identities. None of the four articles based outside the United States made any mention of race, while at least some data about race or ethnicity was provided in all of the articles drawn from samples in the USA with students as the unit of analysis. Samples from the two NLTS-2 studies (Chiang et al., 2012; Wei et al., 2013) were between 65% and 70% White, and the cross-sectional sample of the general student population in Gillespie-Lynch et al. (2015) was 50% White. Samples from the other five studies reporting participant race were overwhelmingly White, ranging from 83% (Butler & Gillis, 2011) to 94% White (Taylor & Seltzer, 2012).

Data and measures. Beyond demographics like gender and race, studies also varied widely in the type of data collected and reported in the resulting publications. Perhaps reflective of the fact that autism has largely been studied as a medical or psychological phenomenon, many studies incorporated clinical assessments for autism (Taylor & Seltzer, 2011), instruments evaluating the severity of autism-related characteristics (Baron-Cohen et al., 2001; Kanne, Christ, & Reiersen, 2009; Nevill & White, 2011), and/or indicators of co-occurring psychological conditions (Kanne et al., 2009; Taylor & Seltzer, 2011). Others adapted previously published measures of social stigma (Butler & Gillis, 2011; Gillespie-Lynch et al., 2015) or attitudes toward peers (Nevill & White, 2011). Qualitative and mixed-method studies relied heavily on semi-structured interviews (e.g., Camarena & Sarigiani, 2009; Van Hees, Moyson, & Roeyers, 2014). Both studies for which institution-level programs were the unit of analysis developed their own questionnaires about the types of services provided to autistic college students (Barnhill, 2016; Papay & Bambara, 2011).

Dissemination. Although our search examined 13,000+ articles published in 16 different journals identified by an interdisciplinary group of scholars, only 21 articles from four of those journals met our inclusion/exclusion criteria. As Table 1 presents, the vast majority of the 21 articles were published in autism-specific journals, with 90% published in just two journals: *Focus on Autism and Other Developmental Disabilities* and *Journal of Autism and Developmental Disorders*. None of the five journals focused on higher education or student affairs had published a single article about the experiences of college students with autism. The placement of these articles in autism-specific journals rather than in journals directly focused on higher education suggests that researchers in this area are effectively “preaching to the choir.” Instead of bringing this population to the attention of a broad higher education audience,

researchers have thus far published their work in places that would only come to the attention of other researchers whose interests explicitly include autism or related disabilities. Likewise, these findings suggest that researchers within the field of higher education and student affairs have not yet expanded our core body of literature to include college students with autism.

Synthesis of Substantive Content

Since the mainstream higher education journals have largely ignored the topic of autistic college students, multiple stakeholders (e.g., faculty, student affairs practitioners, institutional administrators) are likely unsure where to turn for evidence-driven guidance as students with autism increasingly come to college. For these audiences, we use this section to synthesize the substantive content of the reviewed literature, with specific emphasis on stigmatization, parental expectations, and the need for self-advocacy. Nonetheless, we must begin our presentation of substantive conclusions with an important word of caution. The studies reviewed for this manuscript reflect a nascent body of literature that has only recently emerged as a point of emphasis among researchers. The conclusions to be drawn from such a body of research must be considered far more tentative than certain.

Throughout the collected literature, the most consistent findings relate to the various challenges confronting college students with autism. College students must navigate an environment in which community involvement is widely encouraged, but is often filled with unstructured social situations that can contribute to considerable stress for autistic students (Hendricks & Wehman, 2009). Moreover, since other students' acceptance of their autistic peers vary across fields of study (Nevill & White, 2011) and level of familiarity with autism (Butler & Gillis, 2011; Gillespie-Lynch et al., 2015; Nevill & White, 2011), autistic college students regularly face an unpredictable threat of stigmatization. These challenges can be magnified for

autistic college students when combined with other psychological complications including anxiety, depression, and Attention Deficit Hyperactivity Disorder (ADHD; Hendricks & Wehman, 2009; Taylor & Seltzer, 2011; Trembath et al., 2012; VanBergeijk et al., 2008), which commonly affect autistic individuals (Soke, Maenner, Christensen, Kurzius-Spencer, & Schieve, 2018; Vohra, Madhavan, & Sambamoorthi, 2017).

These challenges appear to be prominent in the minds of students' parents, many of whom expressed concern about their children's readiness to navigate the transition from high school to college. Camarena and Sarigiani (2009) noted that parents were unsure whether their children had (or would develop) the skills necessary for living independently or interacting socially with peers in college. Such parental worries seemed exacerbated by the fact that postsecondary institutional infrastructures necessary to support such a smooth transition are often lacking or nonexistent (Barnhill, 2016; Hendricks & Wehman, 2009; Papay & Bambara, 2011; Roberts, 2010; Van Hees et al., 2014). Moreover, the literature provided little evidence of wide-scale adaptation of institutional efforts to serve college students with autism more effectively, with faculty education programs often limited to discussion groups, one-on-one conversations, or one-time workshops (Barnhill, 2016). With so few services, little training, and an incomplete literature on the topic, it is doubtful that many institutions of higher education are currently able to adequately address the needs and interests of this population.

It is perhaps no surprise, then, that among the most consistent suggestions from the literature was that autistic college students would be served best by coming to terms with their diagnoses and developing the self-advocacy skills necessary for obtaining support and resources (e.g., Roberts, 2010, Wehman et al., 2014). Specifically, these articles often suggested that self-disclosure, particularly to institutions' disability services offices, was an important step for

autistic college students to take while pursuing a postsecondary degree (e.g., Roux et al., 2015; Van Hees et al., 2014). We make note of this suggestion from the literature, however, with one major caveat; none of the 21 studies we reviewed explicitly assessed the manner or extent to which such disclosure - or the formal accommodations which typically necessitate disclosure - actually contribute to student outcomes.

Discussion

Although we began our review of the literature with a clear purpose and great optimism, we have since come to realize that the current literature on autistic college students remains underdeveloped in critical ways. First, the literature base is remarkably small (only 21 articles published between 2000 and 2015), with relevant articles published almost exclusively in autism-specific journals (i.e., *Focus on Autism and Other Developmental Disabilities*; *Journal of Autism and Developmental Disorders*). None had been published in any of the higher education journals included in our examination. Second, the distribution of topical foci across the Framework for the Development of Actionable Insights indicates the current literature tends to place more of an emphasis on taking actions to support this population than on developing insights about this population's needs, desires, experiences, and outcomes. Third, methodological limitations related to participant recruitment, data collection, and institutional contexts restrict the generalizability or transferability of findings from most of the studies we reviewed. As a result, we are able to draw few firm conclusions from the literature. Likewise, we are able to offer only tentative suggestions regarding evidence-supported policies and practices that might support college success for students with autism.

Thus, our findings are largely consistent with those from other recent efforts to summarize and synthesize what is known about autistic college students (Anderson et al., 2017;

Gelbar, Smith, and Reichow, 2014; Kuder & Accardo, 2018). The overarching conclusion from all these efforts is that the literature on autistic college students is sparse, evidence is inconsistent, and conclusions to be drawn from the literature must be considered cautiously. Thus, it remains difficult to know what college practices work, in part, because our scholarly community still lacks a thorough understanding of how autistic college students access, select, experience, and persist through college.

Nonetheless, our study brings about an important contribution to the literature as it addresses the gaps and builds upon the foundations of other reviews in several notable ways. First, our study involves a high degree of rigor in the ultimate selection of articles. As we examined more than 13,000 articles for potential inclusion in our analysis, this is the largest study of its kind, encompassing a wider breadth than the Gelbar, Smith, and Reichow (2014) review. Meanwhile, because Anderson et al. (2017) developed their initial pool of potential articles by searching three article indexing databases (*A Plus*, *ERIC*, and *Educational Research Complete* [formerly *EBSCOhost*]), their final review included several items that had not undergone external peer review (i.e., dissertations and reports). We reviewed only articles published in peer-reviewed journals. Second, because fewer than half of college students with disabilities disclose that status to their institutions (Wagner, Newman, Cameto, Garza, & Levine, 2005) and in contrast to the three prior reviews (Anderson et al., 2017; Gelbar, Smith, & Reichow, 2014; Kuder & Accardo, 2018), our selection criteria did not predicate inclusion on participants' formal disclosure of an autism diagnosis. Instead, our review includes scholarly essays from multiple stakeholders, as well as articles drawing data from a variety of sources where the unit of analysis could be at the level of whole programs or individual students. Third, unlike the Anderson et al. (2017) study, our analysis has been guided by an explicit framework

meant to enable a holistic evaluation of the extent to which the current literature yields actionable insights related to an emerging or overlooked student population. We use this framework to map the contours of the current research landscape, identify critical gaps and imbalances, and offer explicit directions for future research and practice.

The remainder of this discussion section is divided into four parts. The first part addresses the first and second research questions, as well as the relationships between them (i.e., how topics, data, and methods connect to current biases, limitations, and gaps in the literature). The final three parts of the section address the third research question by offering explicit guidance to scholars on how to contribute to a more robust, inclusive, and comprehensive body of literature in the future.

Bias, Imbalance, and Holes in the Current Literature

Our systematic review of a broad and diverse set of sources over an extended period of time allows us to draw conclusions about biases, imbalances, and holes in the current literature on autistic college students. The most obvious of these conclusions relates to the distribution of articles across the topics identified in our framework. As highlighted in Table 2, the primary foci of the articles we reviewed were disproportionately action-oriented. The heavy focus on intervention research may be reflective of the good intentions of those seeking to serve this growing population of college students. Researchers, practitioners, and policymakers are belatedly recognizing the accuracy of White, Ollendick, and Bray's (2011) conclusions that the influx of college students with autism creates "a considerable challenge for which [colleges] may be ill-prepared" (p. 697), and these educational leaders understandably want to address that challenge. Thus, it is not surprising, nor inherently inappropriate, that the field is inclined to do

something immediately, while using assessment data from these interventions to figure out what works along the way.

However, this rush to action appears to have had several unintended consequences. First, in part because the literature to date has rarely focused explicitly on theory development or evaluation, interventions are likely to be entirely atheoretical or dependent on tenuous adaptation of theories originally developed for other populations (e.g., young autistic children, college students with other disabilities). Second, the unique structures, resources, and contexts surrounding novel campus-specific initiatives make interventions difficult to replicate in other settings. Studies describing these initiatives rarely anticipate potential challenges to implementation, replication, or evaluation; nor do they typically provide evidence that their initiative would be effective in other contexts. Third, most of the reviewed studies draw from small samples built using recruitment methods driven largely by convenience, thus undermining most claims of generalizability or transferability. Collectively, these issues lead to inconsistencies in measurement, analytic approach, and interpretation of findings that severely limit the field's ability to make comparisons across studies or draw substantive conclusions from the collective body of literature.

Thus, it appears the field may be putting the cart before the proverbial horse, seeking to define “best” practices for interventions before generating the empirical and theoretical insights that would lead to identification of potentially effective practices. Without a clear understanding of these students' characteristics, interests, activities, needs, and aspirations, even the most well-intended interventions are going to be based as much on implicit assumptions as they are on appropriate theories or empirical evidence. Indeed, this disproportionate emphasis on action before insight indirectly validates the untested assumptions of intervention researchers whose

perspectives on the population are largely reflective of the pervasive deficit-based medical model that paints autism as a detrimental condition that would ideally be eliminated (Bagatell, 2010). In addition, institutional leaders who see these students' arrival on campus as a problem may tend to think that this issue may be best solved by discrete programs or individual offices.

The limited data surrounding college student experiences and outcomes for this population are particularly problematic for policymakers and educational administrators. The relative dearth of literature addressing even the most basic questions regarding autistic college students (e.g., How large is this population?; What are they doing in college?; Are they being successful in college?) undermines efforts to develop, assess, and implement interventions to facilitate this population's college success. Without answers to these most basic questions, even if researchers were able to draw firm conclusions about what types of interventions work, the educational leaders who direct policy and allocate resources are not likely to take significant interest until they are presented clear evidence that this population is large, growing, and likely to succeed when adequately supported.

Leveraging Large Datasets

Large-scale quantitative studies are necessary to address these basic issues of population size and outcomes, and researchers currently have only one real option for such data (i.e., NLTS2). Yet the NLTS2 has its own sampling limitations, and includes minimal data regarding even basic college outcomes. The dataset almost entirely ignores the subtleties of students' experiences, with relatively few variables to address student involvement, engagement, integration, sense of belonging, or use of disability accommodations. Moreover, the NLTS2 already has been heavily mined for relevant data (e.g., Chiang et al., 2012; Wei et al., 2013). A new iteration of the NLTS began in 2012 (i.e., NLTS2012) but has been delayed in its collection

of postsecondary enrollment or completion data (Y. Sekino, personal communication, August 23, 2017). If patterns from the NLTS2 hold for this new iteration of the project, initial reports get published roughly two years after completion of data collection for a particular phase. Thus, it may be 2022 before the field can rely on this federally sponsored project for the next substantive update to basic questions.

Beyond the NLTS datasets, the federal government collects very little data about students with autism in higher education. The Institutional Postsecondary Data System (IPEDS) does not collect any data regarding students' disability status. The National Postsecondary Student Aid Study (NPSAS) incorporates four questions addressing student disabilities, but it does not specifically mention autism or provide sufficient categorical differentiation to infer autism's inclusion in any particular disability type reported. The same is true for the Baccalaureate and Beyond (B&B) and Beginning Postsecondary Students (BPS) projects.

The first wave (in 9th grade) of the 2009 High School Longitudinal Study (HSLs) includes a variable indicative of autism diagnosis, while the 2016 follow-up survey includes indicators of students' college enrollment three years after completion of high school. Theoretically, such data might allow analyses to determine the proportion and volume of autistic students entering higher education; however, we have been unable to find any reports of such analyses, perhaps in part because the base-year HSLs dataset includes only 157 students with autism, and student participation in the surveys drops with every wave of data collection (Ingels et al., 2011).

This lack of data suggests that federal education surveys have been slow to respond to this increasingly prominent population. It also severely limits scholars' ability to develop nationally representative studies addressing topics on the insight side of our Framework for the

Development of Actionable Insights and thereby impedes the ability of administrators, faculty, staff, students, and advocates to shape policies and/or practices in ways that would advance widespread postsecondary success for this population. Considering the size of the samples and the volume of questions typically included as part of these national surveys, it seems future iterations of these surveys could rectify the problem either by adding a new question about autism or reframing the existing disability questions to allow for disability-specific differentiation that includes autism.

With little federal data currently available, researchers interested in answers to critical questions about autism in higher education would be wise to look for other sources. Major national studies are beginning to address this population, but only tangentially and periodically. For example, the Cooperative Institutional Research Program's (CIRP) freshman survey recently began including biannual questions related to disability, allowing students to offer at least one indication of their identity on the autism spectrum. However, those data are not yet publicly available, nor have results using that data yet been published in peer-reviewed journals.

Collecting Original Data

Rather than wait for the federal government or major national surveys to collect data and disseminate their work, we suggest researchers interested in this population establish multi-institutional research teams that can draw participants from their respective institutions. These multi-institution collaborations might facilitate the development of more consistent instrumentation and analyses, as researchers at multiple sites could employ the same assessment instruments, examine the same outcomes, and use the same analytic techniques. Doing so would also allow researchers to pool their data to create larger samples, which may increase the clarity

of statistical results. McLeod, Meanwell, and Amelia (2019) have done just that, drawing samples from 14 campuses in Indiana to yield an analytic sample of 95 students with autism.

There are a growing number of mechanisms through which such collaborative projects may be developed. At its 2019 conference, the International Society for Autism Research (INSAR) is hosting a Special Interest Group (SIG) called “Adapting and Advancing Postsecondary Education for Autistic Students,” explicitly created to facilitate multi-national collaborations; ideas developed in-person at INSAR will continue digitally through the College Autism Network’s Virtual Association of Scholars (CANVAS), a group of 70+ scholars from around the world who host monthly meetings to present emerging research and advance collaborative research projects. The National Science Foundation has recently begun supporting these types of initiatives through their Research Collaboration Networks (program announcement #17594), a grant worth up to \$500,000 over five years.

Admittedly, gathering data about college students with autism can be difficult even when working with a single institution. Using campus disability service offices to identify potential participants is a common practice, but is limited by the fact that more than half of the students who come to college with disabilities do not disclose the disability to their institution (Wagner et al., 2005). Federal laws (e.g., FERPA, HIPPA, IDEA) further complicate the collection, storage, and sharing of student records. Moreover, efforts to circumvent these challenges by resorting to creative recruitment processes (e.g., Van Hees et al., 2014) likely introduces new biases, precludes generalization, and limits transferability.

Perhaps these data challenges explain why the qualitative studies we reviewed featured so few students themselves and often supplemented those voices with data from parents or affiliated professionals (e.g., Trembath et al., 2012). Questions about postsecondary aspirations, access,

experiences, and outcomes for autistic students were frequently answered by soliciting information from people other than the autistic students themselves. Such questions were commonly directed toward parents (e.g., Taylor & Seltzer, 2011), instructors (e.g., Gobbo & Shmulsky, 2014), college peers (Gillespie-Lynch et al., 2015; Nevill & White 2011), and support service providers (e.g., Barnhill, 2016; Papay & Bambara, 2011). Thus, researchers bold enough to generate their own original data must be careful to not inadvertently marginalize the very population they seek to serve.

Thankfully, the challenges associated with identifying and studying autistic college students may have eased somewhat over the last few years, as the substantial growth in the rates of autism diagnoses means there are likely a greater number of students with autism on college campuses now than at any time in the past. Partnerships with major self-advocacy groups like the Autistic Self Advocacy Network (ASAN) or the Autism Women's Network (AWN) might also enable large-scale participatory action research.

Making Research More Inclusive

The common lack of student voice in the literature reinforces a power structure where researchers set the agenda and determine whose perspectives are being shared in what ways. The phenomenon may also be reflective of the field's slow evolution in its understanding of autism. Early depictions of autism, in both research (e.g., Kanner, 1943) and popular culture (e.g., the 1988 movie *Rain Man*), emphasized autistic individuals' cognitive and communication limitations. With the current generation of autism researchers socialized into the field amid such depictions of autism, there may be an unconscious presumption that these students lack the cognitive maturity to know what is really important to their lives and/or lack the ability to effectively communicate their ideas to researchers. Having been surrounded by such

presumptions much of their lives, many self-aware, articulate, and insightful autistic students may be reluctant to engage in research during college due to the fear of stigmatization that accompanies any requirement for self-disclosure.

The next generation of scholarship on the topic can disrupt this pattern if researchers make it a priority to actively seek, engage with, and include individuals with autism themselves as key informants and research partners. Inquiries built around direct communication with students with autism would help researchers recognize subtleties in experiences not always obvious to parents, instructors, or institutions. In particular, qualitative approaches like interviews with students, focus groups, or photo ethnography provide opportunities for students themselves to be powerful sources of insight. Hotez et al. (2018) provides evidence that participatory action research is both possible and productive, while Nicolaidis et al. (2019) offers explicit guidance for researchers looking to adopt this approach to research. Such participatory methods would help ensure scholars do not undermine students' agency by speaking for or about autistic students, but instead use their scholarly privilege to validate and amplify the voices of the students themselves. These approaches would also allow researchers to check their own assumptions about these students, their needs, and their interests.

The need to recognize and address researcher assumptions and biases is particularly important when scholars lack appropriate theories or frameworks to guide their inquiries. Our analyses revealed only a single study with a primary focus on theory building/testing (Gobbo & Shmulsky, 2014) and only three more with theory as a secondary focus. Grounded theory approaches that center on students' experiences and perspectives would help build a more robust theoretical foundation upon which subsequent studies and interventions could be based. In the meantime, scholars might consider using existing theories about disability identity development.

Johnstone's (2004) distillation of the literature yielded several distinct identity profiles that might be useful. Davidson and Henderson's (2010) model, ostensibly focused on the "coming out" process, draws from 45 first-hand accounts exclusively written by autistic individuals.

More broadly, scholars can situate their approaches within one of the several paradigms about disability that have evolved over the last several decades. These paradigms have moved from the early medical/deficit model to more recent social justice driven approaches (Evans, Broido, Brown, & Wilke, 2017; Kimball, Wells, Ostiguy, Manly, & Lauterbach, 2016). The concept of Neurodiversity (Blume, 1998) highlights the strengths of autistic individuals by reframing autism as a form of diversity because autistic individuals interpret, process, and respond to the world around them in novel ways. Each of these theoretical frameworks and paradigmatic perspectives have great potential to guide scholars' inquiries about autistic college students.

Conclusion

In some respects, the literature's current focus on actions, especially the evaluation of institutional initiatives designed to support autistic college students, is a promising sign. It suggests that some institutions are proactively taking the initiative to create novel support programs for this distinctive population of students. Just as importantly, our review of the literature suggests that many of these institutional initiatives are subject to empirically-driven review processes. These evaluations likely help to improve services at specific institutions and inch the field toward the collective understanding of effective on-the-ground practice.

However, without an equally robust literature populating the insight sections of the Framework for the Development of Actionable Insights, this inclination towards an "action first" approach may reinforce the propagation of inappropriate, inadequate, or idiosyncratic "solutions"

to poorly understood “problems” that have only recently garnered widespread attention from postsecondary scholars and practitioners. Insight-focused publications are necessary to comprehensively and contextually describe these students’ experiences and define the issues affecting college students with autism. With the current literature providing comparatively few insights regarding these students’ college pathways, experiences, and outcomes, even the best intended efforts are likely to be saddled with major limitations. For example, in part because there are few studies explicitly addressing the applicability of specific theories to this population, it is likely that newly developed interventions will be largely atheoretical or based on broad assumptions about the utility of theories originally developed for other populations or in other contexts (e.g., K-12 or clinical settings).

The most important sources of insight regarding this population are likely autistic college students themselves. Yet, their voices are largely absent from the literature we reviewed. With a few notable exceptions, the vast majority of studies on autistic college students have been written without the explicit involvement of the students themselves. Until researchers begin actively engaging *with* autistic individuals, more than simply reporting *about* them, autistic college students are likely to remain wary of educational institutions that purport to work in their best interests without having asked or adequately understood what those interests are.

We conclude by encouraging educators and researchers to capitalize on the recent momentum that has generated a fast-growing literature, by ensuring that efforts to support this population are framed by appropriate theories, embedded with comprehensive assessments, and developed in collaboration with the students themselves. Moreover, we implore researchers who want their work to inform postsecondary policy, influence educational practice, and improve experiences for autistic college students to submit future manuscripts not only to autism-specific

journals, but to widely read higher education journals as well. Finally, we encourage the gatekeepers at such publications (i.e., reviewers, editorial board members, and editors) to recognize the need for and value of research on autistic college students. Collectively acting on these three suggestions will enable ongoing dissemination of actionable insights that inform targeted initiatives addressing specific issues in ways that promote success for college students with autism.

References

- Ames, M. E., McMorris, C. A., Alli, L., N., & Bebko, J. M. (2016). Overview and evaluation of a mentorship program for university students with ASD, *Focus on Autism and Other Developmental Disabilities*, 31(1), 1-10, doi: 10.1177/1088357615583465.
- Anderson, A. H., Stephenson, J., & Carter, M. (2017). A systematic literature review of the experiences and supports of students with autism spectrum disorder in post-secondary education. *Research in Autism Spectrum Disorders*, 39, 33-53.
- Bagatell, N. (2010). From cure to community: Transforming notions of autism. *Ethos*, 38(1), 33-55.
- Barnhill, G. P. (2016). Supporting students with Asperger syndrome on college campuses current practices. *Focus on Autism and Other Developmental Disabilities*, 31(1), 3-15. doi: 10.1177/1088357615611880.
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-Spectrum Quotient (AQ): Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders*, 31(1), 5-17. doi: 10.1023/a:1005653411471.
- Blume, H. (1998, September 30). Neurodiversity: On the neurological underpinnings of geekdom. The Atlantic. Retrieved November 4, 2018.
<http://www.theatlantic.com/magazine/archive/1998/09/neurodiversity/305909/>
- Bray, N. J., & Major, C. H. (2011). Status of journals in the field of higher education. *The Journal of Higher Education*, 82(4), 479-503.

- Butler, R. C., & Gillis, J. M. (2011). The impact of labels and behaviors on the stigmatization of adults with Asperger's Disorder. *Journal of Autism and Developmental Disorders, 41*(6), 741-749. doi: 10.1007/s10803-010-1093-9.
- Camarena, P. M., & Sarigiani, P. A. (2009). Postsecondary educational aspirations of high-functioning adolescents with Autism Spectrum Disorders and their parents. *Focus on Autism and Other Developmental Disabilities, 24*(2), 115–128. doi: 10.1177/1088357609332675.
- Centers for Disease Control and Prevention. (2014). *Community Report from the Autism and Developmental Disabilities Monitoring Network: Prevalence of Autism Spectrum Disorders Among Multiple Areas of the United States in 2010*. Retrieved from <http://www.cdc.gov/ncbddd/autism/data.html> .
- Chiang, H. M., Cheung, Y. K., Hickson, L., Xiang, R., & Tsai, L. Y. (2012). Predictive factors of participation in postsecondary education for high school leavers with autism. *Journal of Autism and Developmental Disorders, 42*(5), 685-696.
- Christensen, D. L., Bilder, D. A., Zahorodny, W., Pettygrove, S., Durkin, M. S., Fitzgerald, R. T., ... & Yeargin-Allsopp, M. (2016). Prevalence and characteristics of autism spectrum disorder among 4-year-old children in the autism and developmental disabilities monitoring network. *Journal of Developmental & Behavioral Pediatrics, 37*(1), 1-8.
- Cox, B. E., Thompson, K., Anderson, A., Mintz, A., Locks, T., Morgan, L., ... & Wolz, A. (2017). College experiences for students with Autism Spectrum Disorder: Personal identity, public disclosure, and institutional support. *Journal of College Student Development, 58*(1), 71-87.

- Creamer, E. G. (1994). Gender and publications in core higher education journals. *Journal of College Student Development*, 35(1), 35-39.
- Davidson, J. & Henderson, V. L. (2010) 'Coming out' on the spectrum: Autism, identity and disclosure. *Social & Cultural Geography*, 11(2), 155-170, DOI: 10.1080/14649360903525240.
- Dwan, K., Altman, D. G., Arnaiz, J. A., Bloom, J., Chan, A.-W., Cronin, E., . . . Williamson, P. R. (2008). Systematic review of the empirical evidence of study publication bias and outcome reporting bias. *PLoS One*, 3(8), e3081. doi:10.1371/journal.pone.0003081
- Evans, N. J., Broido, E. M., Brown, K. R., & Wilke, A. K. (2017). *Disability in higher education: A social justice approach*. San Francisco, John Wiley & Sons.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2(3), 217-250.
- Gelbar, N. W., Smith, I., & Reichow, B. (2014). Systematic review of articles describing experience and supports of individuals with autism enrolled in college and university programs. *Journal of Autism and Developmental Disorders*, 44(10), 2593-2601.
- Gillespie-Lynch, K., Brooks, P., Someki, F., Obeid, R., Shane Simpson, C., Kapp, S., Daou, N., Smith, D. (2015). Changing college students' conceptions of autism: An online training to increase knowledge and decrease stigma. *Journal of Autism Developmental Disorders*, 45(8), 2553-25566. doi: 10.007/s10803-015-2422-9.
- Gobbo, K., & Shmulsky, S. (2014). Faculty experience with college students with autism spectrum disorders: A qualitative study of challenges and solutions. *Focus on Autism and Other Developmental Disabilities*, 29(1), 13-22.

- Gernsbacher, M. A. (2017). Editorial perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry*, 58(7), 859-861.
- Hart, D., Grigal, M., & Weir, C. (2010). Expanding the paradigm: Postsecondary education options for individuals with autism spectrum disorder and intellectual disabilities. *Focus on Autism and Other Developmental Disabilities*, 25(3), 134-150.
- Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, 24(2), 77-88.
- Hewitt, L. E. (2011). Perspectives on support needs of individuals with Autism Spectrum Disorders: Transition to college. *Topics in Language Disorders*, 31 (3), 273-285.
- Hopewell, S., Loudon, K., Clarke, M. J., Oxman, A. D., & Dickersin, K. (2009). Publication bias in clinical trials due to statistical significance or direction of trial results. *Cochrane Database of Systematic Reviews*(1). doi:10.1002/14651858.MR000006.pub3
- Hosking, D. L. (2008, Sept). *Critical disability theory*. Paper presented at the 4th Biennial Disability Studies Conference at Lancaster University, UK. Retrieved from http://www.lancs.ac.uk/fass/events/disabilityconference_archive/2008/abstracts/hosking.htm
- Hotez, E., Shane-Simpson, C., Obeid, R., DeNigris, D., Siller, M., Costikas, C., ... & Gillespie-Lynch, K. (2018). Designing a summer transition program for incoming and current college students on the Autism Spectrum: A participatory approach. *Frontiers in Psychology*, 9: 46.

- Ingels, S.J., Pratt, D.J., Herget, D.R., Burns, L.J., Dever, J. A., Ottem, R., Rogers, J.E., Jin, Y., and Leinwand, S. (2011). High School Longitudinal Study of 2009 (HSLs:09): Base-Year Data File Documentation (NCES 2011328). Retrieved from the National Center for Education Statistics: https://nces.ed.gov/surveys/hsls09/pdf/2011328_2.pdf.
- Kanne, S. M., Christ, S. E., & Reiersen, A. M. (2009). Psychiatric symptoms and psychosocial difficulties in young adults with autistic traits. *Journal of Autism and Developmental Disorders, Topics in Language Disorders, 39*, 827–833. doi:10.1007/s10803-008-0688-x.
- Kimball, E. W., Wells, R. S., Ostiguy, B. J., Manly, C. A., & Lauterbach, A. A. (2016). Students with disabilities in higher education: A review of the literature and an agenda for future research. In *Higher education: Handbook of theory and research, Vol. 31* (pp. 91-156). Springer.
- Kogan, M. D., Vladutiu, C. J., Schieve, L. A., Ghandour, R. M., Blumberg, S. J., Zablotsky, B., ... & Lu, M. C. (2018). The prevalence of parent-reported autism spectrum disorder among US children. *Pediatrics, 142*(6), 1-11.
- Kuder, S. J., & Accardo, A. (2018). What works for college students with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*(3), 722-731.
- Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry, 56*(6), 466-474.
- McLeod, J.D., Meanwell, E. & Hawbaker, A. J. (2019). The experiences of college students on the Autism Spectrum: A comparison to their neurotypical peers. *Journal of Autism and Developmental Disorders*. Advance online publication. doi:10.1007/s10803-019-03910-8

- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Annals of Internal Medicine*, *151*(4), 264-269.
- Morrison, J. Q., Sansosti, F. J., & Hadley, W. M. (2009). Parent perceptions of the anticipated needs and expectations for support for their college-bound students with Asperger's Syndrome. *Journal of Postsecondary Education and Disability*, *22*(2), 78-87.
- Nevill, R. E. A., & White, S. W. (2011). College students' openness toward Autism Spectrum Disorders: Improving peer acceptance. *Journal of Autism and Developmental Disorders*, *41*(12), 1619–1628. doi: 10.1007/s10803-011-1189-x
- Newman, L., Wagner, M., Knokey, A. M., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011). The post-high school outcomes of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2). NCSER 2011-3005. *National Center for Special Education Research*.
- Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., . . . Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*. Advance online publication. doi:10.1177/1362361319830523
- Papay, C.K., & Bambara, L. M. (2011). Postsecondary education for transition-age students with intellectual and other developmental disabilities: A national survey. *Education and Training in Autism and Developmental Disabilities*, *46*(1), 78-93.
- Roberts, K. D. (2010). Topic areas to consider when planning transition from high school to postsecondary education for students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *25*(3), 158-162.

- Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., Edwards, A. D., Wei, X., ... & Yu, J. W. (2015). Characteristics of two-year college students on the autism spectrum and their support services experiences. *Autism Research and Treatment*, 2015, 1-10. doi: 10.1155/2015/391693
- Schwitzer, A., & Thomas, C. (1998). Implementation, utilization, and outcomes of a minority freshman peer mentor program at a predominantly white university. *Journal of The First-Year Experience & Students in Transition*, 10(1), 31-50.
- Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an Autism Spectrum Disorder. *Pediatrics*, 129(6), 1042–1049.
- Soke, G. N., Maenner, M. J., Christensen, D., Kurzius-Spencer, M., & Schieve, L. A. (2018). Prevalence of co-occurring medical and behavioral conditions/symptoms among 4- and 8-year-old children with autism spectrum disorder in selected areas of the United States in 2010. *Journal of Autism and Developmental Disorders*, 48(8), 2663-2676. doi:10.1007/s10803-018-3521-1
- Stodden, R. A., Yamamoto, K. K., Folk, E., Kong, E., & Otsuji, D. (2013). Pursuing quality evidence: Applying single-subject quality indicators to non-experimental qualitative educational research. *Education and Training in Autism and Developmental Disabilities* 48, 491-503.
- Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 41, 566–574. doi: 10.1007/s10803-010-1070-3.

- Taylor, J. L., & Seltzer, M. M. (2012). Developing a vocational index for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(12), 2669-2679.
- Tight, M. (2018). Higher education journals: An emerging field. *International Higher Education*, 94, 22-24.
- Trembath, D., Germano, C., Johanson, G., & Dissanayake, C. (2012). The experience of anxiety in young adults with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 27(4), 213-224.
- VanBergeijk, E., Klin, A., & Volkmar, F. (2008). Supporting more able students on the autism spectrum: College and beyond. *Journal of Autism and Developmental Disorders*, 38(7), 1359-1370.
- Van Hees, V., Moyson, T., & Roeyers, H. (2014). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders*, 45, 1673-1688.
- Vohra, R., Madhavan, S., & Sambamoorthi, U. (2017). Comorbidity prevalence, healthcare utilization, and expenditures of medicaid enrolled adults with autism spectrum disorders. *Autism*, 21(8), 995-1009. doi:10.1177/1362361316665222.
- Wagner, M., Newman, L., Cameto, R., Garza, N., and Levine, P. (2005). After high school: A first look at the postschool experiences of youth with disabilities. A report from the National Longitudinal Transition Study-2 (NLTS2) Menlo Park, CA: SRI International. Available at www.nlts2.org/reports/2005_04/nlts2_report_2005_04_complete.pdf.
- Wehman, P., Schall, C., Carr, S., Targett, P., West, M., & Cifu, G. (2014). Transition from school to adulthood for youth with Autism Spectrum Disorder: What we know and what we need to know. *Journal of Disability Policy Studies*, 25(1), 30-40.

- Wei, X., Wagner, M., Hudson, L., Yu, J. W., & Javitz, H. (2016). The effect of transition planning participation and goal-setting on college enrollment among youth with Autism Spectrum Disorders. *Remedial and Special Education, 37*(1), 3-14.
- Wei, X., Christiano, E. R., Jennifer, W. Y., Blackorby, J., Shattuck, P., & Newman, L. A. (2014). Postsecondary pathways and persistence for STEM versus non-STEM majors: Among college students with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 44*(5), 1159-1167.
- Wei, X., Jennifer, W. Y., Shattuck, P., McCracken, M., & Blackorby, J. (2013). Science, technology, engineering, and mathematics (STEM) participation among college students with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(7), 1539-1546.
- White, S. W., Ollendick, T. H., & Bray, B. C. (2011). College students on the autism spectrum: Prevalence and associated problems. *Autism, 15*(6), 683-701.
- Zevallos, A. L., & Washburn, M. (2014). Creating a culture of student success: The SEEK scholars peer mentoring program. *About Campus, 18*(6), 25-29.

Table 1
Distribution of 21 Reviewed Articles Across Journals

Journal	<i>n</i>
<i>Journal of Autism and Developmental Disorders</i>	11
<i>Focus on Autism and Other Developmental Disabilities</i>	8
<i>Journal of Disability Policy Studies</i>	1
<i>Education and Training in Autism and Developmental Disabilities</i>	1

NOTE: Although our search included 16 journals, only the four listed in this table had articles that met our inclusion criteria. The 16 journals included in our initial search included: *College Student Affairs Journal*; *Computers & Education*; *Cyberpsychology, Behavior, and Social Networking*; *Education and Training in Autism and Developmental Disabilities*; *Educational Technology Research & Development*; *Exceptional Children*; *Focus on Autism and Other Developmental Disabilities*; *Journal of American College Health*; *Journal of Autism and Developmental Disabilities*; *Journal of College Student Development*; *Journal of Disability Policy Studies*; *Journal of Higher Education*; *Journal of Special Education Technology*; *Remedial and Special Education*; *Research in Higher Education*; and *Review of Higher Education*.

Table 2
Overview of 21 Articles Reviewed

Author, Year	Journal	Country	Method	Primary Placement
Ames et al., 2015	<i>Focus on Autism and Other Developmental Disabilities</i>	Canada	Mixed Methods	Evaluation of Interventions (Action)
Barnhill, 2016	<i>Focus on Autism and Other Developmental Disabilities</i>	USA	Quantitative	Evaluation of Interventions (Action)
Baron-Cohen et al., 2001	<i>Journal of Autism and Developmental Disorders</i>	Australia	Quantitative	Evaluation of Interventions (Action)
Butler & Gillis, 2011	<i>Journal of Autism and Developmental Disorders</i>	USA	Quantitative	Definition of the Population Needs / Issues (Insight)
Camarena & Sarigiani, 2009	<i>Focus on Autism and Other Developmental Disabilities</i>	USA	Mixed Methods	Definition of the Population Needs / Issues (Insight)
Chiang et al., 2012	<i>Journal of Autism and Developmental Disorders</i>	USA	Quantitative	Indications of College Success (Insight)
Gillespie-Lynch et al., 2015	<i>Journal of Autism and Developmental Disorders</i>	USA	Qualitative	Proposed Intervention(s) (Action)
Gobbo & Shmulsky, 2014	<i>Focus on Autism and Other Developmental Disabilities</i>	USA	Qualitative	Applicable Theories (Action)
Hart et al., 2010	<i>Focus on Autism and Other Developmental Disabilities</i>	N/A	Scholarly	Evaluation of Interventions (Action)
Hendricks & Wehman, 2009	<i>Focus on Autism and Other Developmental Disabilities</i>	N/A	Scholarly	Domains of Activity/Life (Action)
Kanne et al., 2009	<i>Journal of Autism and Developmental Disorders</i>	USA	Mixed Methods	Description of the Population (Insight)

Nevill & White 2011	<i>Journal of Autism and Developmental Disorders</i>	USA	Quantitative	Analyses of College-Related Experiences (Insight)
Papay & Bambara, 2011	<i>Education and Training in Autism and Developmental Disabilities</i>	USA	Quantitative	Evaluation of Interventions (Action)
Roberts, 2010	<i>Focus on Autism and Other Developmental Disabilities</i>	N/A	Scholarly	Definition of Population Needs / Issues (Insight)
Taylor & Seltzer, 2011	<i>Journal of Autism and Developmental Disorders</i>	USA	Quantitative	Domains of Activity/Life (Action)
Taylor & Seltzer, 2012	<i>Journal of Autism and Developmental Disorders</i>	USA	Qualitative	Domains of Activity/Life (Action)
Trembath et al., 2012	<i>Focus on Autism and Other Developmental Disabilities</i>	Australia	Qualitative	Definition of Population Needs / Issues (Insight)
VanBergeijk et al., 2008	<i>Journal of Autism and Developmental Disorders</i>	N/A	Scholarly	Proposed Intervention(s) (Action)
Van Hees et al., 2014	<i>Journal of Autism and Developmental Disorders</i>	Belgium	Qualitative	Definition of the Population Needs / Issues (Insight)
Wehman et al., 2014	<i>Journal of Disability Policy Studies</i>	N/A	Scholarly	Proposed Intervention(s) (Action)
Wei et al., 2013	<i>Journal of Autism and Developmental Disorders</i>	USA	Quantitative	Description of Population (Insight)

Note: The Barnhill (2016) article was published “online-first” in 2014, and was thus included in our analyses. Country refers to the national context in which empirical data were collected.

Table 3
Distribution of Methods and Primary Theme of Articles Identified through Search

Category from Framework	Qual.	Quant.	Mixed	Scholarly	Total
Insight					
Description of the Population	0	2	0	0	2
Indications of College Success	0	1	0	0	1
Analyses of College-Related Experiences	0	1	0	0	1
Definition of the Population Needs/Issues	2	1	1	1	5
Insight Total	2	5	1	1	9
Action					
Domains of Activity/Life	0	1	1	1	3
Applicable Theories	1	0	0	0	1
Evaluation of Interventions	0	3	1	1	5
Proposed Interventions	0	0	1	2	3
Action Total	1	4	3	4	12
Grand Total	3	9	4	5	21

Table 4
Distribution of Methods and Secondary Themes of Articles

Category from Framework	Qual.	Quant.	Mixed	Scholarly	Total
Insight					
Description of Population	1	4	1	2	8
Indications of College Success	2	2	2	1	7
Analyses of College-Related Experiences	0	2	1	1	4
Definition of the Population Needs/Issues	2	2	0	3	7
Insight Total	5	10	4	7	26
Action					
Domains of Activity/Life	0	3	0	0	3
Applicable Theories	0	2	0	1	3
Evaluation of Interventions	0	0	0	1	1
Proposed Interventions	0	3	0	2	5
Action Total	0	8	0	4	12
Grand Total	5	18	4	11	38

Note. Sum may be greater than 100%, as some studies included multiple secondary foci. Five studies featured no secondary foci.

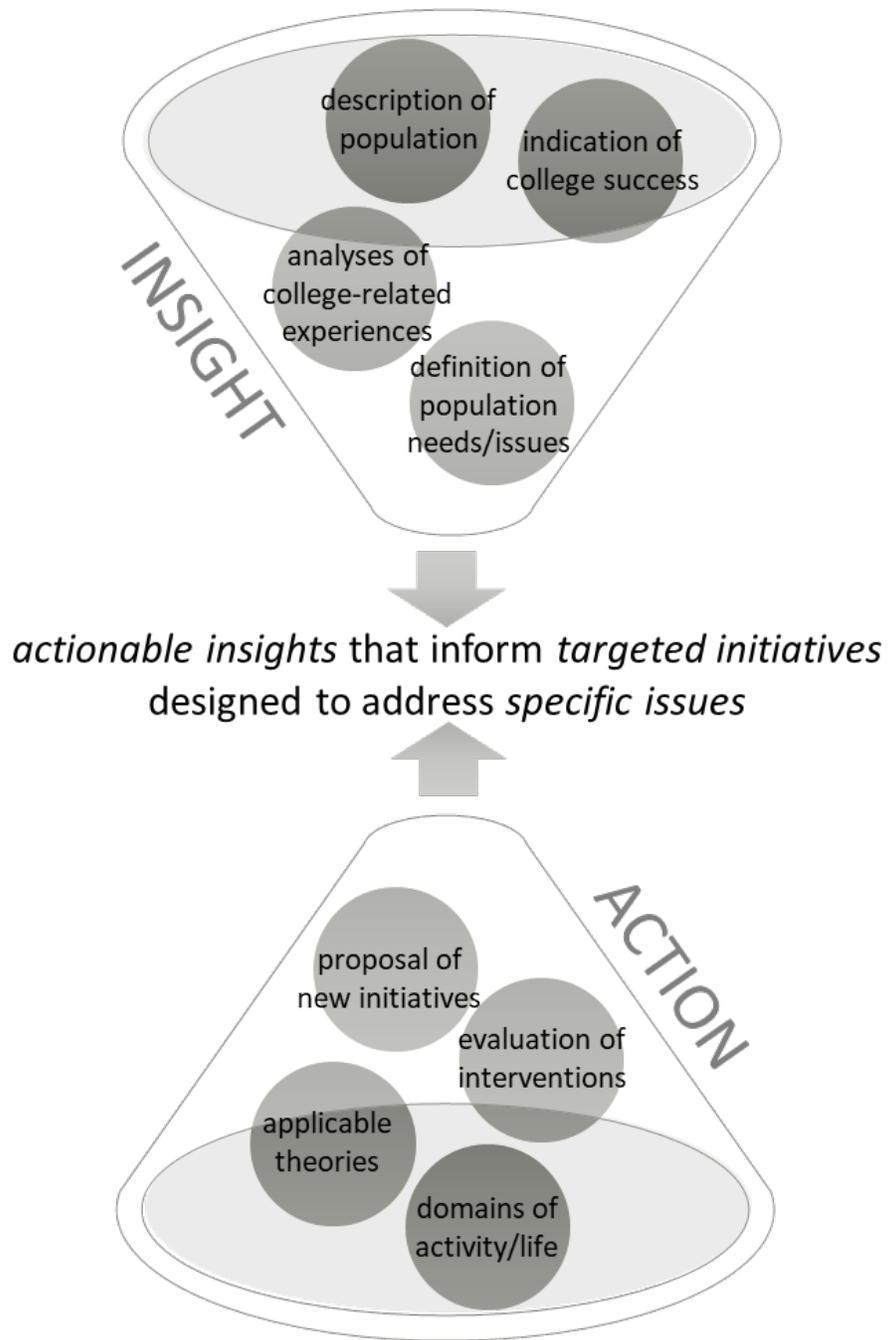


Figure 1. Framework for Actionable Insights

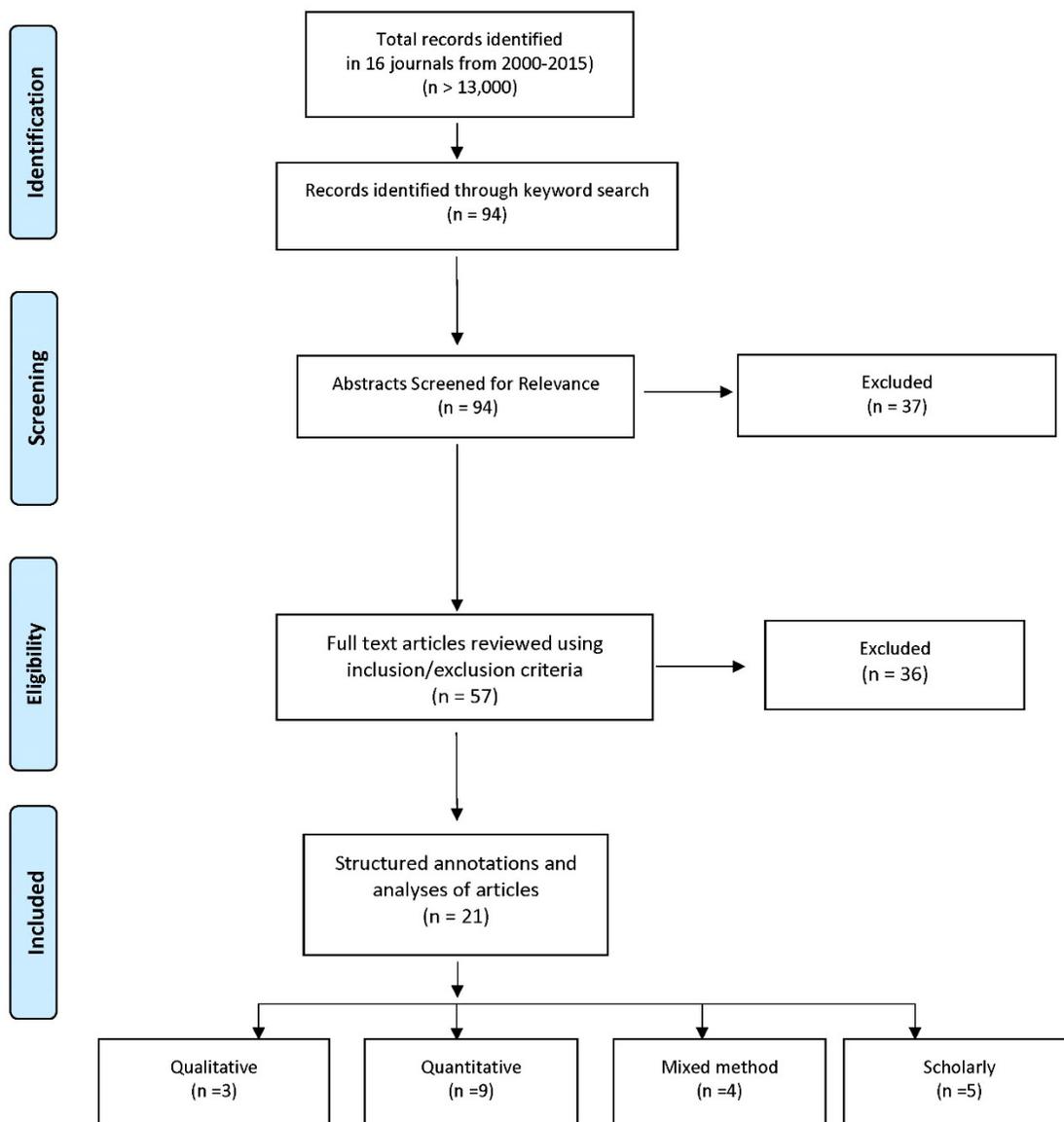


Figure 2. PRISMA Diagram

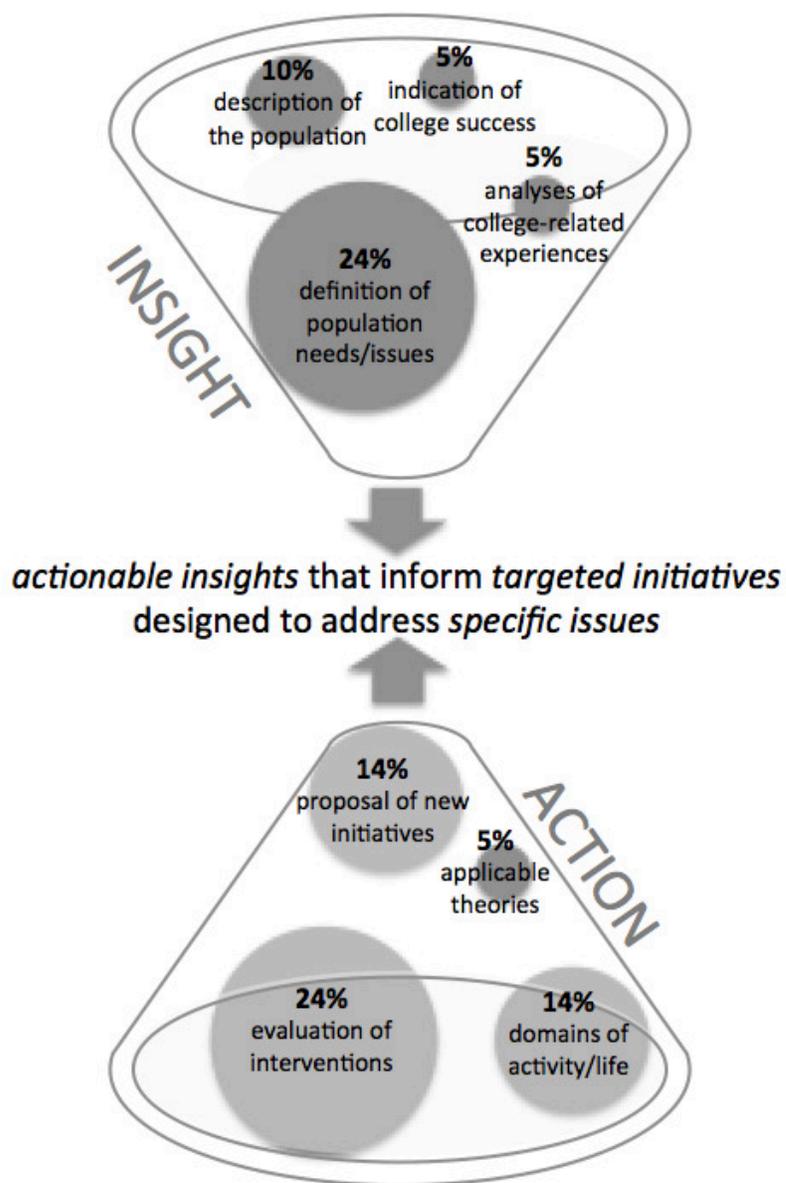


Figure 3. Distribution of Primary Article Foci Across Framework for Actionable Insights