What are the challenges and successes reported by autistic students at university?: a literature review

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Editorial comment

Brian Irvine is a PhD student at the University of Birmingham researching Specialist (Autism) Mentoring at HE and Dr Andrea MacLeod is his supervisor. This paper is part of the literature review that Brian created to inform his thesis on the experience of autistic students at university. It reviews 78 papers in which autistic students give their first-hand accounts of life at university. It identifies which aspects are a challenge and the benefits and successes reported by some of the students. From their accounts, recommendations are made as to what universities can do to enhance the life of autistic students and, in doing so, improve the experience for all.

Introduction

Research on the autistic experience of higher education has grown considerably and presents a sizeable body of literature for metanalysis. In this paper, we present a thematic analysis of the accounts of autistic students, extracted from 78 systematically selected, qualitative papers.

In the academic year, 2019–20, there were 14,360 autistic students who disclosed their diagnosis to UK universities, a sizeable demographic, having grown 15-fold in a decade (HESA, 2010, 2020). This increased prevalence has prompted a corresponding academic interest in their experiences. Previous literature reviews have mapped out some of the challenges and barriers that autistic students can face (Anderson et al, 2017, 2019) and the autistic strengths that are academically beneficial in a university context, but these reviews also drew attention to the paucity and fragmented nature of research into autism and higher education (Chown and Beavan, 2012; Gelbar et al, 2014).

Importance of the student voice

The literature review of qualitative research presented in this paper seeks to find out from the autistic students themselves about the challenges and the joys of university. In autism studies, there has been a historical disregard of the expertise held by the autistic people (Milton, 2014). This paper aims to give precedence to the accounts from autistic student themselves. It is of little surprise that such data often reports on struggles as young people encounter both newfound autonomy and the potentially transformative experience of university.

Autistic experience of higher education cannot be described simply in terms of academic metrics but also requires a consideration of other aspects of university life. For many, living away from home, having to relate to other students in hall, lectures and tutorials, getting used to a large amount of unstructured time, understanding what is required academically and dealing with the demands made to join in the social aspects of university life are all serious challenge for many autistic students.

That said, the papers report that some students rise to the challenge and find ways of managing situations which cause anxiety. As yet, many universities do not have well developed systems to support autistic students and often the onus is on the student to seek advice, which in itself is a barrier for many. Some papers report that support may only be offered when a crisis occurs when the better option is to ascertain from the start of a student's studies, what the student's needs might be and for this to be reviewed at regular intervals.

Selection process

Following PRISMA guidelines, an exhaustive search of EBSCO, the NAS database, Research Autism and Google Scholar retrieved relevant literature on derivations of autism and higher education (Moher et al, 2009),

see *Table 1*. From the initial 512 papers, 237 full-text documents remained after removing duplicates and papers that conflated research within a university with research about universities. A total of 150 papers were excluded as they had no direct quotes from autistic students, leaving a set of 78 papers for this thematic analysis. From these 78 papers, quotes from autistic students were extracted and thematically coded following the methodology of Braun and Clarke (2006).

Findings

Fourteen studies interviewed mentee-mentor dyads, one study considered parental concerns alongside the views of students (Camarena and Sarigiani, 2009) and one reported the views of both students and staff (Knott and Taylor, 2014). From the 78 papers reviewed,

Table 1: Search process

PRISMA recording for search terms {'autism' or 'autistic' OR 'asd' or 'Asperger' or 'HFA'} and {'higher education' or 'college' or 'university' or 'post secondary' or 'postsecondary'}
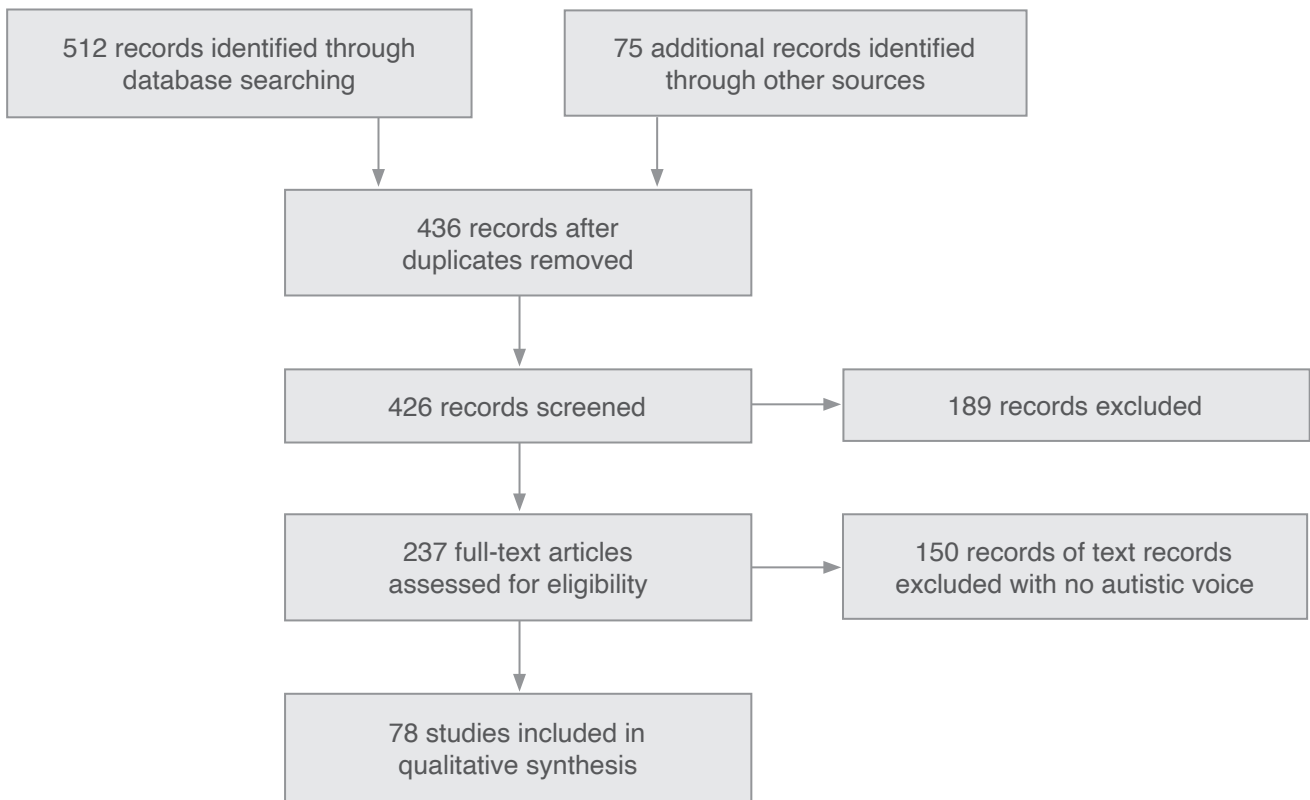
72 studies interviewed autistic students and 15 reported on student focus groups. Coding this body of work resulted in three domains, as follows:

- barriers at university
- challenges at university
- factors for success

Barriers in higher education

The main barriers clustered around non-inclusive university cultures. Imperfect university culture includes negative attitudes, with poor teaching practice and an unthinking bureaucracy. Autistic students encountered staff who considered university attendance to indicate there was no need for support (Accardo, Bean, et al, 2019; Alverson et al, 2019; Beardon and Edmonds, 2007; Bolourian et al, 2018; Gurbuz et al, 2019; Lawson, 2010; Rutherford, 2013). Students in these studies described outdated notions of autism. For example:

> "My psychology test literally had 'autistics don't use words like think or feel', as a 'correct answer' on the test"(Gelbar et al, 2015, page 49).

Feelings of othering were rife (Cage and Howes, 2020; Cribb et al, 2019; Sayman, 2015; Vincent et al, 2017). Several studies referred to the lack of adjustments to teaching practice. There were assumptions about group work, a lack of handouts before lectures, and last minute changes to the timetable (Beardon and Edmonds, 2007; Casement et al, 2017; Cullen, 2015; Fabri et al, 2020; Gurbuz et al, 2019; Jansen et al, 2018; LeGary, 2017; Madriaga and Goodley, 2010; Sarrett, 2018). Students expressed the sentiment that the

> "administration ignores these issues or feels that one should just have to put up with some discomfort from time to time" (Gurbuz et al, 2019, page 625).

Challenges

Three interrelated challenges were identified (see *Table 2*):

- social networking
- figuring out what to do
- stress

Table 2 :   High level themes emerging from the literature review on the autistic experience of higher education

Theme	Number of papers theme occurs in	Total references to theme coded
Barriers to success:	44	243
campus environment	20	66
diagnosis	18	29
imperfect university culture	25	109
limited support	15	35
Challenges:	50	227
a dull life in halls	9	11
becoming disengaged	3	3
figuring out what to do	23	42
internalised deficit narrative	16	24
mental health needs	11	17
nightmare networking	25	63
sensory overload	8	9
stress	17	49
Factors for success:	62	418
a well rounded campus network	40	218
peace and quiet	18	36
unfolding of self	44	162
self advocacy	26	60
All themes from autistic students	78	936

Social networking

The anxiety about social networking was often couched in terms of a hyper-awareness of others, a professed awkwardness, or a social discomfort that could reach panic (Alverson et al, 2019; Anderson, 2018; Bailey et al, 2019; Hastwell et al, 2012, 2017; Kelly et al, 2018; Lei and Russell, 2021; Vincent et al, 2017). This also meant that students were reluctant to approach tutors and that group work was particularly challenging (Casement et al, 2017; Hastwell et al, 2012; Madriaga and Goodley, 2010; Pionke et al, 2019; Rosqvist, 2019; Ward and Webster, 2018). There were also concerns over hallmates and shared housing (Accardo, Kuder, et al, 2019; Bailey et al, 2019; Beardon and Edmonds, 2007; Bolourian et al, 2018; Drake, 2014; Lambe et al, 2019). This could result in isolation, stress and mental health issues (Kelly et al, 2018; Ward and Webster, 2018) which might lead ultimately to a withdrawal from their studies (Gurbuz et al, 2019).

Figuring out what to do

Many autistic individuals find having a routine is preferable to having a lot of unstructured time. However, at university, workloads are often uneven, meaning routines are broken, and there is often much unstructured time.

(Alverson et al, 2019; Beardon and Edmonds, 2007; Bolourian et al, 2018; Cage and Howes, 2020; Cai and Richdale, 2016; Kuo et al, 2016; Lambe et al, 2019). In response, some students try to get used to not having a routine.

> "I tried to resist, and do things without planning. But sometimes it's hard to decide in which cases to allow yourself that kind of structure and comfort, and in which cases you should push yourself instead." (Van Hees et al, 2015, page 12)

Anxiety was frequently mentioned:

> "If I am […] anxious about something that I need to do, I will be totally focused on thinking about that." (Hastwell et al, 2017, page 58)

There were some highlights, but then the comments from other students might reduce their enjoyment. For example, there was the joyous distraction of getting "distracted by all the books" (Anderson, 2018, page 652). However, this joy could be brought low by the attitudes of others:

> "I often got crap from a lot of people from undergrad when I would be studying all the time happily, because I enjoyed what I was doing." (Rutherford, 2013, page 46)

Expectations of university versus reality

The anticipated student experience was not always borne out in practice. One said:

> "I always thought that university would be meeting people who were like me, and we'd be really politically active, and we'd stay up really late t alking passionately about all these books that we'd read and stuff, and it wasn't like that." (Cage and Howes, 2020, page 7).

Some talked about the lack of acceptance by others, a struggle to make social connections, or having such a focus on their work that this led to self exclusion (Bailey et al, 2019, 2019; Cage et al, 2020; Gurbuz et al, 2019; Rutherford, 2013). For some autistic students this was a self protective strategy or reflected an ambivalence about relationships (Alverson et al, 2019; Cage and Howes, 2020; Cribb et al, 2019; Hastwell et al, 2017; Lizotte, 2018). In many cases, a life in halls was lonely (Beardon and Edmonds, 2007; Bolourian et al, 2018; Cage et al, 2020; Casement et al, 2017; Cullen, 2015; Gelbar et al, 2015; Gurbuz et al, 2019; Jackson et al, 2018; MacLeod, 2016; Simmeborn Fleischer, 2012; Stice and Lavner, 2019). Contrary to past literature on autism which suggests that autistic students lack a desire for friendship, many autistic students wanted to meet others and experience feelings of loneliness.

However, being with other students often resulted in sensory overload (Anderson, 2018; Bolourian et al, 2018; Grandin, 1990; Hastwell et al, 2012; Jansen et al, 2018; Van Hees et al, 2015). This, together with the academic demands, information overload, perfectionism (for some), exams, and the continual churn of change, could render the university environment a crucible for long term anxiety (Berry, 2018; Gurbuz et al, 2019; Jansen et al, 2018; Lawson, 2010; LeGary, 2017; Rutherford, 2013; Van Hees et al, 2015).

"I am perpetually stressed and fairly unhappy, which leads to secondary problems – tiredness, depression, negative interaction with people, to name but a few" (Hastwell et al, 2012, page 60).

Some papers reported on autistic students' struggles with mental health and anxiety (Adreon and Durocher, 2007; Berry, 2018; Cai and Richdale, 2016; Hastwell et al, 2012; 2017).

Factors in the success of autistic students

Over 80 per cent of the papers reviewed reported on students successes and the actions that universities could take to ensure that autistic students flourished. Some students felt that they 'found' themselves and understood themselves better during their time at university.

"I think the best thing, apart from getting a degree of course, is that I've actually finally found myself" (Casement et al, 2017, page 85).

Three key factors for success were identified:

- an inclusive and supportive culture

- the journey of education in 'unfolding of the 'self'

- a real need for peace and quiet

An inclusive and supportive culture

This included supportive tutors, specialist support, parental encouragement and friendships with other students. There were many comments on the enjoyment of academic work in a way that played to their strengths (eg having a single focus and love of the topic or monotropism or exceptional recall (Gurbuz et al, 2019; Lawson, 2010; MacLeod, 2016; Van Hees et al, 2015). Furthermore, there was a valuing of individuality often present within academic environments (Bailey et al, 2019; Beardon and Edmonds, 2007; Gelbar et al, 2014; Gurbuz et al, 2019; Lizotte, 2018; MacLeod, 2016; Rutherford, 2013):

"I've never had a box, I don't even know what a box is, I've always thought outside the box" (MacLeod, 2016, page 80).

"I would say that going to university objectively is fantastic […] you are going to be allowed to be more eccentric than you would be elsewhere, which is brilliant." (Casement et al, 2017, page 81).

Previous school experiences of some students had led to staff and others having low expectations and some students were keen to counter this.

"I've got a lot of bad memories of people in education […] And that's what drives you forward. It's like, 'I will show you'" (MacLeod et al, 2017, page 8)

As such, success was framed as proving that their own way of doing things is valuable to others and to themselves (Simmeborn Fleischer, 2012). Academic success in these accounts was not regarded as the be-all and end-all, simply one part of an unfolding life story.

"I think that for me now it's less towards getting the top grade… I guess that goal then kind of became more, just kind of wanting to have good personal connections and just be happy." (Lei and Russell, 2021, page 7)

Good personal connections, and tutors and mentors who were willing to try and understand were hugely important (Accardo, Kuder, et al, 2019; Beardon and Edmonds, 2007, 2007; Boven, 2018; Casement et al, 2017, 2017; Essex and Melham, 2019; MacLeod, 2016, 2016; Qian et al, 2018; Rutherford, 2013; Sayman, 2015; Vincent et al, 2017; Ward and Webster, 2018), as were the friendships in which autistic students felt accepted for who they were (Berry, 2018; Cribb et al, 2019; Drake, 2014; MacLeod, 2016; Rutherford, 2013).

Supportive campus culture emerged in the literature as 'kindness', manifested in academics who invested time to talk to students and in support staff who could help navigate the bureaucracy (Beardon and Edmonds, 2007; Perepa, 2018). Kindness within informal support networks was also key, from parents giving latitude to allow autistic students to figure things

out for themselves, and when fellow students explicitly let autistic students know that their presence in the learning community was valued (MacLeod, 2016; Rutherford, 2013).

An 'unfolding of the self'

Such cultural kindness often supported an 'unfolding of the self', emerging in the many stories of autistic students' success in higher education. Successful autistic students recounted a wish "to go to university to sort of get away and start anew" (MacLeod et al, 2017, page 5). Once there, their expressed longing for friends who would be "very understanding because they care about me" often became a reality (Rutherford, 2013, page 81). University as a place of acceptance where students felt understood by others became a refrain in the papers that focused on the success of autistic students (Berry, 2018; Cribb et al, 2019; Lambe et al, 2019; Lei et al, 2018; MacLeod, 2016; MacLeod et al, 2017; Rutherford, 2013). Understanding here seemed to 'unfold' to a sense of belonging which was further bolstered by having opportunities to make a difference by contributing to their community, and "to find something that we have a purpose for" (Berry, 2018, page 86). Students were proud of their persistence and diligence (Gelbar et al, 2014; Gurbuz et al, 2019; MacLeod et al, 2017; Rutherford, 2013).

> "Has it been overwhelming, stressful and traumatic? Absolutely! Though, I'm not thinking about giving up. I will achieve this through sheer determination"
> (Ward and Webster, 2018, page 382).

Furthermore, there were reports of increased self-awareness, self-acceptance and a growing confidence in the students' own abilities (Accardo, Kuder, et al, 2019; Alverson et al, 2019; Bolourian et al, 2018; Casement et al, 2017; Hastwell et al, 2017; MacLeod, 2016; Rosqvist, 2019; Rutherford, 2013; Sayman, 2015; Vincent, 2019). This was radically liberating for some students.

> "I think just having a better ability to know that if things do go wrong that I can deal with it, whereas before I thought the world would end"
> (Vincent, 2019, page 1581).

Owning their diagnosis

Successful autistic students discussed owning a diagnosis, doing things their own way and choosing their own support (Gurbuz et al, 2019; Hastwell et al, 2017; Hotez et al, 2018; MacLeod, 2016; Rosqvist, 2019). Alongside these actions of self-advocacy, autistic students also presented narratives of wider advocacy. Involvement with a wider autistic community via social media was described, alongside support given to siblings or as parents of autistic children themselves, while advocacy on campus emerged from being openly autistic in an academic or a friendship context (Berry, 2018; MacLeod, 2016; Rutherford, 2013).

The need for peace and quiet

Many of the successes reported would probably not have been possible without the last element of 'peace and quiet'. Campus life can be less rushed without the family pressures of home (Berry, 2018). For most students that move into student accommodation it is the first time that they can have a place to call their own (Drake, 2014; Lei et al, 2018). Though in these accounts, it was not seen simply as a place of solitude.

> "I like that I simultaneously have space to be alone if I need to, but am also in a supportive environment of friends."
> (Gelbar et al, 2015, page 49).

When noisy hall mates broke the sanctuary, students often found a refuge in the library (Anderson, 2018; Madriaga, 2010), particularly sound dampened cubicles which they could reserve and "have utter quiet" (Anderson, 2018, page 650). In these sanctuaries, they found time to be calm, a place to minimise unnecessary socialisation, and a base for following their special interests (Hastwell et al, 2017; Lambe et al, 2019; Simmeborn Fleischer, 2012).

Discussion

Almost 62 per cent of the papers opened with a mantra of 'a growing number of autistic students'. There is good reason for this. In 2000/01, only 80 undergraduate students had disclosed an autism diagnosis to UK universities. In 2020/21, that number has risen to 14,590 undergraduates and 2,095 postgraduates

(HESA, 2002, 2020). With this sizeable population, perhaps it is time to acknowledge that there are many autistic students already at university and we need to ensure that we have universities in which they thrive.

Previous literature recounts the experience of autistic students meeting the hard edge of the 'double empathy problem' (Milton, 2012). If a learning community does not seek to understand autistic needs, autistic students are alienated from the institution; students' responding to that alienation with self-isolation leads to cultures in which autistic understanding is not sought. While universities may be able to reduce stigma by nudging whole student populations with diversity training, there is a pressing need for educators to better understand their autistic students (Gillespie-Lynch et al, 2015). There is no shortage of advice; 29 per cent of the papers give recommendations for designing better learning. With the rise of autistic self advocates, specialist mentors and autism counsellors becoming firm features in many universities, the resources are there but not sufficiently assimilated into the design and teaching practice of universities. Institutions may have specialist mentoring in place, but access to support often follows a crisis, rather than being offered as a preventative. Going to university is often the moment in which autistic students start to take on the mantle of self advocacy, but without nurturing forums, students can find this very hard and may not relay their needs to anyone and potentially leave the course.

Concluding comments

Literature reflecting the autistic experience of university is entering a new phase. Where it was once focused mainly on collating disparate, autistic voices in several institutions, it can be contended that the relatively high number of autistic students has reached a critical phase in which university institutions need to turn their academic lens back onto their own practice. In doing so, there is an opportunity to fully develop the idea of autism gain, as a subset of Goodley's disability gain and socially just pedagogies (Goodley, 2014; Madriaga and Goodley, 2010). It may be that our hyper-alert autistic students are acting as cultural sentinels whose struggles reveal the faults within the system. Some have referred to autistic pupils as being 'canaries in the coalmine' who detect poor practice and it often said that non-autistic students too would benefit from the adjustments that are made. Not every student has the same learning style and many need support in understanding what is required for assignments. Those who are perfectionists can spend many, many hours on crafting their work leading to exhaustion. Perhaps this is utopian thinking, but universities have the capacity to foster slow learning that values the quiet (Berg and Seeber, 2016). There is a need to mitigate the rush of campus life to allow sanctuaries within the complex ecosystems of universities so that all may flourish. Tutors and mentors are perfectly positioned to aid the reflective journey of learning, which holds space for flourishing students' unfolding of self. Maybe you have seen this ideal being lost among an institutional juggernaut and, if so, take solace; supporting our autistic students is not only just, it is an agent of change. Universities in which autistic students flourish are those where all students can flourish.

References

Accardo, A L (2017) College-bound young adults with ASD: self-reported factors promoting and inhibiting success *DADD Online Journal.*

Accardo, A L, Bean, K, Cook, B, et al (2019) College access, success and equity for students on the Autism Spectrum *Journal of Autism and Developmental Disorders* 49, 4877–4890.

Accardo, A L, Kuder, S J and Woodruff, J (2019) Accommodations and support services preferred by college students with autism spectrum disorder *Autism*, 23 (3) 574–583.

Adreon, D and Durocher, J S (2007) Evaluating the college transition needs of individuals with high-functioning autism spectrum disorders *Intervention in School and Clinic* 42 (5) 271–279.

Alverson, C Y, Lindstrom, L E and Hirano, K A (2019) High school to college: transition experiences of young adults with autism *Focus on Autism and Other Developmental Disabilities* 34 (1) 52–64.

Anderson, A (2018) Autism and the academic library: a study of online communication *College & Research Libraries* 79 (5), 645–658.

Anderson, A H, Stephenson, J, and 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.

Anderson, A H, Stephenson, J, Carter, M and Carlon, S (2019) A systematic literature review of empirical research on postsecondary students with Autism Spectrum Disorder *Journal of Autism and Developmental Disorders* 49 (4) 1531–1558.

Bailey, K M, Frost, K M, Casagrande, K and Ingersoll, B (2019) The relationship between social experience and subjective well-being in autistic college students: a mixed methods study *Autism 24 (5) 1081–1092.*

Beardon, L and Edmonds, G (2007) *ASPECT consultancy report* A National Report on the Needs of Adults with Asperger Syndrome.

Berg, M and Seeber, B K (2016) *The slow professor: challenging the culture of speed in the academy* University of Toronto Press.

Berry, K M (2018) Experiences of students with Autism Spectrum Disorder in Mississippi Community Colleges [Ed D, The University of Mississippi] available from http://search.proquest.com/docview/2063147608/abstract/7E2D770249244FDPQ/1.

Bolourian, Y, Zeedyk, S M and Blacher, J (2018) Autism and the university experience: narratives from students with neurodevelopmental disorders *Journal of Autism and Developmental Disorders* 48 (10) 3330–3343.

Boven, F (2018) Special interests and inclusive academic learning: an autistic perspective *Advances in Autism* 4 (4).

Braun, V and Clarke, V (2006) Using thematic analysis in psychology *Qualitative Research in Psychology* 3 (2) 77–101.

Cage, E, De Andres, M and Mahoney, P (2020) Understanding the factors that affect university completion for autistic people. Research in Autism Spectrum Disorders, 72.

Cage, E and Howes, J (2020). Dropping out and moving on: a qualitative study of autistic people's experiences of university *Autism* 24 (7) 1664–1675 .

Cai, R Y and Richdale, A L (2016) Educational experiences and needs of higher education students with Autism Spectrum Disorder *Journal of Autism and Developmental Disorders* 46 (1) 31–41.

Camarena, P M and 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.

Casement, S, Carpio de los Pinos, C and Forrester-Jones, R (2017) Experiences of university life for students with Asperger's Syndrome: a comparative study between Spain and England *International Journal of Inclusive Education* 21 (1) 73–89.

Chown, N and Beavan, N (2012) Intellectually capable but socially excluded? A review of the literature and research on students with autism in further education *Journal of Further and Higher Education* 36 (4) 477–493.

Cribb, S, Kenny, L and Pellicano, E (2019) 'I definitely feel more in control of my life': the perspectives of young autistic people and their parents on emerging adulthood *Autism: The International Journal of Research & Practice* 23 (7) 1765–1781.

Cullen, J A (2015) The Needs of College Students with Autism Spectrum Disorders and Asperger's Syndrome *Journal of Postsecondary Education and Disability* 28 (1) 89–101.

Drake, S (2014) College experience of academically successful students with autism *Journal of Autism* 1 (1) 5.

Essex, J and Melham, P (2019) Experiences of educational transition: young women with ASD, and the staff supporting them, speak *Support for Learning* 34 (1) 86–111.

Fabri, M, Fenton, G, Andrews, P and Beaton, M (2020) Experiences of higher education students on the autism spectrum: stories of low mood and high resilience *International Journal of Disability, Development and Education* 1–19.

Gelbar, N W, Smith, I and 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.

Gelbar, N W, Shefcyk, A and Reichow, B (2015) A comprehensive survey of current and former college students with autism spectrum disorders *The Yale Journal of Biology and Medicine* 88 (1) 45.

Gillespie-Lynch, K, Brooks, P J, Someki, F, Obeid, R, Shane-Simpson, C, Kapp, S K, Daou, N and Smith, D S (2015) Changing College Students' Conceptions of Autism: an online training to increase knowledge and decrease stigma *Journal of Autism and Developmental Disorders* 45 (8) 2553–2566.

Glaser, B G (1998) *Doing grounded theory: issues and discussions* Sociology Press.

Goodley, D (2014) *Dis/ability studies: theorising disablism and ableism* Routledge.

Grandin, T (1990) Needs of high functioning teenagers and adults with autism (tips from a recovered autistic) *Focus on Autistic Behavior* 5 (1) 1–16.

Gurbuz, E, Hanley, M and Riby, D M (2019) University students with autism: the social and academic experiences of university in the UK *Journal of Autism and Developmental Disorders* 49 (2) 617–631.

Hastwell, J, Martin, N, Baron-Cohen, S and Harding, J (2012) Giving Cambridge University students with Asperger syndrome a voice: a qualitative, interview-based study towards developing a model of best practice *Good Autism Practice Journal* 13 (1) 56–63.

Hastwell, J, Martin, N, Baron-Cohen, S and Harding, J (2017) Reflections on a university based social group for students with Asperger syndrome *Good Autism Practice Journal* 18 (1) 97–105.

HESA (2002) *Students in Higher Education 2000/01* available from www.hesa.ac.uk/data-and-analysis/publications/students-2000-01.

HESA (2010) *Students in Higher Education 2008/09* available from www.hesa.ac.uk/data-and-analysis/publications/students-2008-09.

HESA (2020) *Table 15—UK domiciled student enrolments by disability and sex 2014/15 to 2019/20* available from www.hesa.ac.uk/data-and-analysis/students/table-15.

Hotez, E, Shane-Simpson, C, Obeid, R et al (2018) Designing a summer transition program for incoming and current college students on the autism spectrum: a participatory approach *Frontiers in Psychology* 9, 46.

Jackson, S L J, Hart, L, Brown, J T and Volkmar, F R (2018) Brief report: self-reported academic, social and mental health experiences of post-secondary students with Autism Spectrum Disorder *Journal of Autism and Developmental Disorders* 48 (3) 643–650.

Jansen, D, Emmers, E, Petry, K, Mattys, L, Noens, I and Baeyens, D (2018) Functioning and participation of young adults with ASD in higher education according to the ICF framework *Journal of Further and Higher Education* 42 (2) 259–275.

Kelly, R, O'Malley, M P and Antonijevic, S (2018) 'Just trying to talk to people … It's the hardest': perspectives of adolescents with high-functioning autism spectrum disorder on their social communication skills *Child Language Teaching and Therapy* 34 (3) 319–334.

Knott, F Taylor, A (2014) Life at university with Asperger syndrome: a comparison of student and staff perspectives *International Journal of Inclusive Education* 18 (4) 411–426.

Kuo, C, Lin, C L T, Kuo, B J, Kuang, C and Dai, L T (2016) Learning experiences of young artists with ASD in a university enrichment program *Universal Journal of Educational Research* 4 (9) 2144–2162.

Lambe, S, Russell, A, Butler, C et al (2019) Autism and the transition to university from the student perspective *Autism* 23 (6) 1531–1541.

Lawson, J (2010) An investigation into behaviours which challenge at university: the impact of neurotypical expectations on autistic students *Good Autism Practice Journal* 11 (1).

LeGary, R A (2017) College students with Autism Spectrum Disorder: perceptions of social supports that buffer college-related stress and facilitate academic success J*ournal of Postsecondary Education and Disability* 30 (3) 251–268.

Lei, J, Calley, S, Brosnan, M, Ashwin, C and Russell, A (2018) Evaluation of a transition to university programme for students with Autism Spectrum Disorder *Journal of Autism and Developmental Disorders*.

Lei, J and Russell, A (2021). Understanding the role of self-determination in shaping university experiences for autistic and typically developing students in the United Kingdom *Autism* 25 (5) 1262–1278.

Lizotte, M (2018) I am a college graduate: postsecondary experiences as described by adults with Autism Spectrum Disorders. *International Journal of Education and Practice* 6 (4) 179–191.

MacLeod, A G (2016) "Determined to succeed": perceptions of success from autistic adults [PhD Thesis, University of Birmingham] available from https://etheses.bham.ac.uk//id/eprint/6798/.

MacLeod, A G, Allan, J, Lewis, A and Robertson, C (2017) 'Here I come again': the cost of success for higher education students diagnosed with autism *International Journal of Inclusive Education* 22 (6) 683–697.

Madriaga, M (2010) 'I avoid pubs and the student union like the plague': students with Asperger Syndrome and their negotiation of university spaces *Children's Geographies* 8 (1) 39–50.

Madriaga, M and Goodley, D (2010) Moving beyond the minimum: socially just pedagogies and Asperger's syndrome in UK higher education *International Journal of Inclusive Education* 14 (2) 115–131.

Milton, D (2012) On the ontological status of autism: the 'double empathy problem' *Disability & Society* 27 (6) 883–887.

Milton, D (2014) Autistic expertise: a critical reflection on the production of knowledge in autism studies *Autism* 18 (7) 794–802.

Moher, D, Liberati, A, Tetzlaff, J et al (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA Statement *PLOS Medicine* 6 (7).

Perepa, P (2018) Perceptions of students with autism regarding higher education support services *The Journal of Inclusive Practice in Further and Higher Education* 10 (1) 20.

Pionke, J, Knight-Davis, S and Brantley, J (2019) Library involvement in an autism support program: a case study *College & Undergraduate Libraries* 26 (3) 221–233.

Qian, X, Clary, E, Johnson, D R and Echternacht, J K (2018) The use of a coaching model to support the academic success and social inclusion of Students with Intellectual Disabilities in Community and Technical College Settings *Journal of Postsecondary Education and Disability* 31 (3) 193–208.

Rosqvist, H B (2019) Knowing what to do: exploring meanings of development and peer support aimed at people with autism *International Journal of Inclusive Education* 23 (2) 174–187.

Rutherford, E N (2013) *An exploration of support factors available to higher education students with high functioning autism or Asperger Syndrome* [Ed D, Lamar University].

Sarrett, J C (2018) Autism and Accommodations in Higher Education: insights from the Autism Community *Journal of Autism and Developmental Disorders* 48 (3) 679–693.

Sayman, D M (2015) I still need my security teddy bear: experiences of an individual with Autism Spectrum Disorder in Higher Education *Learning Assistance Review* 20 (1) 77–98.

Simmeborn Fleischer, A (2012) Alienation and struggle: everyday student-life of three male students with Asperger Syndrome *Scandinavian Journal of Disability Research* 14 (2) 177–194.

Stice, L V Lavner, J A (2019) Social connectedness and loneliness mediate the association between autistic traits and internalizing symptoms among young adults J*ournal of Autism & Developmental Disorders* 49 (3) 1096–1110.

Strauss, A and Corbin, J (1994) Grounded theory methodology: an overview in N K Denzin and Y S Lincoln (eds) *Handbook of qualitative research* (17) 273–285.

Strauss, A L and Corbin, J M (1991) *Basics of qualitative research: grounded theory procedures and techniques (3rd ed)* SAGE.

Van Hees, V, Moyson, T and Roeyers, H (2015) Higher education experiences of students with Autism Spectrum Disorder: challenges, benefits and support needs *Journal of Autism and Developmental Disorders* 45 (6) 1673–1688.

Van Hees, V, Roeyers, H and De Mol, J (2018) Students with Autism Spectrum Disorder and their parents in the transition into higher education: impact on dynamics in the parent child relationship *Journal of Autism and Developmental Disorders* 48 (10) 3296–3310.

Vincent, J (2019) It's the fear of the unknown: transition from higher education for young autistic adults *Autism* 23 (6) 1575–1585.

Vincent, J, Potts, M, Fletcher, D et al (2017) 'I think autism is like running on Windows while everyone else is a Mac': using a participatory action research approach with students on the autistic spectrum to rearticulate autism and the lived experience of university *Educational Action Research* 25 (2) 300–315.

Ward, D and Webster, A (2018) Understanding the lived experiences of university students with Autism Spectrum Disorder (ASD): a phenomenological study *International Journal of Disability, Development and Education* 65 (4) 373–392.