



HAL
open science

“I just need a little more support”: A thematic analysis of autistic students’ experience of university in France

Emma Mcpeake, Kristopher Lamore, Emilie Boujut, Joelle El Khoury,
Catherine Pellenq, Marie-Hélène Plumet, Emilie Cappe

► To cite this version:

Emma Mcpeake, Kristopher Lamore, Emilie Boujut, Joelle El Khoury, Catherine Pellenq, et al.. “I just need a little more support”: A thematic analysis of autistic students’ experience of university in France. *Research in Autism Spectrum Disorders*, 2023, 105, pp.102172. 10.1016/j.rasd.2023.102172 . hal-04112150

HAL Id: hal-04112150

<https://hal.science/hal-04112150>

Submitted on 18 Sep 2023

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L’archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d’enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

“I just need a little more support”:**A Thematic Analysis of Autistic Students' Experience of University in France**

Emma McPeake¹, Kristopher Lamore^{1,2}, Emilie Boujut^{1,3}, Joëlle Khoury¹, Catherine Pellenq⁴, Marie-Hélène Plumet¹ and Emilie Cappe^{1,5}

¹Université Paris Cité, Laboratoire de Psychopathologie et Processus de Santé, F-92100
Boulogne-Billancourt, France

²Univ. Lille, CNRS, UMR 9193 – SCALab – Sciences Cognitives et Sciences Affectives, F-59000
Lille, France

³Cergy Paris Université – INSPE, F-78100 Saint Germain en Laye, France

⁴Université Grenoble-Alpes, Laboratoire de Recherche sur les Apprentissages en contexte, F-
38400 Grenoble, France

⁵Institut universitaire de France (IUF)

Author Note

Emma McPeake  <https://orcid.org/0000-0002-7179-4448>

Kristopher Lamore  <https://orcid.org/0000-0002-8878-2662>

Emilie Boujut  <https://orcid.org/0000-0003-3532-0437>

Catherine Pellenq  <https://orcid.org/0000-0002-5999-0366>

Marie-Hélène Plumet  <https://orcid.org/0000-0003-3804-2866>

Emilie Cappe  <https://orcid.org/0000-0002-4792-8653>

Correspondence concerning this article should be addressed to Pr. Emilie Cappe, Laboratoire de Psychopathologie et Processus de Santé, Institut de Psychologie, Université Paris Cité, 71 avenue Edouard Vaillant, 92774 Boulogne-Billancourt, France. Email: emilie.cappe@u-paris.fr

Abstract

Background: Whilst little is known about the experience and needs of autistic students in France, limited research has explored the experiences of autistic students in French higher education. The current study sought to fill this gap in the literature using a qualitative research design to ask: how do autistic students experience higher education in France?

Method: Semi-structured interviews were conducted with 15 autistic students (8 female, 2 male & 5 'other').

Results: Thematic analysis identified four themes: Searching for belonging, Autism identity and disclosure, Managing anxiety and fatigue, and Working with others. The analysis describes the complex journey that participants faced when accessing and completing higher education in France. Whilst the journey was often characterized by intense anxiety and fatigue, the experience of university could also facilitate access to new academic interests, and the opportunity to connect with likeminded individuals perhaps for the first time.

Conclusions: Results from the current study can contribute to the development of policy and practice that aims to better support autistic students in higher education. Of note, autistic students highlighted their elevated risk of drop-out owing to anxiety and fatigue caused by: difficulties planning and managing workload, sensorial overwhelm and administrative stress. Participants therefore highlighted the need for proactive personalized support and the need for supportive peer relationships.

Keywords: autism, university, higher education, college, qualitative, France

Introduction

During the academic year 2020-2021, autistic¹ students represented 2.5% of students declaring a disability in higher education in France compared to 1.9% in 2017 (Ministère de l'Enseignement supérieur et de la Recherche, 2022; Secrétariat d'état chargé des Personnes Handicapées, 2018). The number of autistic students attending higher education in France thus appears to be on the rise. Indeed, whilst the number of autistic students attending university has been increasing internationally (Bakker et al., 2019; Jackson et al., 2018; White et al., 2011), there has been growing research interest into the experiences and needs of such students, with a view to learning how to provide appropriate support (Briel & Getzel, 2014).

The current body of literature has illuminated the range of social and academic challenges faced by autistic students in higher education, including difficulties with group work, peer relationships, ambiguous instructions, time management and navigating a lack of structure at university (Cai & Richdale, 2016; Bolourian et al., 2018; Chown et al., 2017; Gelbar et al., 2014; Kim et al., 2021, Lambe et al., 2019; Vincent et al., 2017; Vincent, 2019; Ward & Webster, 2018). These challenges therefore appear to be related to core features of autism profiles, as they relate to challenges in social interactions and executive dysfunction (APA, 2013). However, it is important to note that as well as challenges, positive attributes such as a detail-focused cognitive style and high intellectual functioning can also be associated with autism (Happé & Vital, 2009; Lorenz & Heinitz, 2014; South et al., 2005).

Whilst intellectually capable students can represent strong university candidates, unmitigated challenges associated with autism can place students at increased risk of drop out (Jackson et al., 2018; Sanford et al., 2011). According to a qualitative study conducted in the UK, autistic students who dropped out of university reported that difficulties accessing a diagnosis may have contributed; diagnostic disclosure often being essential to receive appropriate support (Cage & Howes, 2020). Yet, students who did have a formal diagnosis at time of drop-out, reported that poor understanding of autism amongst university staff and peers, co-morbid mental health difficulties and an 'outsider status' were likely to have contributed (Cage & Howes, 2020). Indeed, research on autistic students' experience of 'belonging' at university has highlighted the toll of having to 'mask' one's autistic identity in order to achieve belonging; or conversely feeling belonging when one did not feel obliged to 'mask' their identity (Pesonen et al.,

2020). Survey research with autistic students has also indicated that less social identification at university is a factor that places students at higher risk of dropping out (Cage et al., 2020).

Additionally, employment outcomes for autistic people remain poor (Allen & Coney, 2019; Eaves & Ho, 2008; Sanford et al., 2011; Taylor & Seltzer, 2011). According to Allen & Coney (2019), graduates with social deficits are the least likely to be employed full-time compared to graduates with other disabilities. Owing to difficulties in social interactions, autistic students may therefore require additional support at university to later attain more successful employment outcomes (Bolourian et al., 2018). Indeed, autistic Australian students identified difficulties in social interactions as being at the forefront of challenges in their higher education, as they reported feeling academically but not socially supported (Cai & Richdale, 2016). Similarly, European research has also indicated that university employment support is not meeting autistic students' highly individual needs (Pesonen et al., 2021).

Owing to the heterogeneity of autism profiles (Masi et al., 2017), successful supports for university students often require a personalised approach. Modifications to the university environment are therefore recommended as opposed to behaviour change interventions in an effort to be more inclusive of neurodivergent profiles (Anderson et al., 2018). Indeed, in a qualitative study conducted by MacLeod et al. (2017), autistic students reported that minor personalised adjustments (e.g., staff taking the time to explain ambiguous instructions) was the difference between success and failure for students. Other factors contributing to autistic students experience of 'success' at university are a strong sense of personal determination, understanding and empathy from others, self-awareness, supportive peer relationships and effective coping strategies (Ward & Webster, 2018). Whilst barriers to a 'successful' experience have been attributed to feelings of anxiety and depression (Cage & Howes, 2020; Ward & Webster, 2018).

Although a number of qualitative research studies investigating the experience and needs of autistic students in post-secondary education have been conducted in a variety of countries (e.g. Australia, Canada, UK, USA) (Cai & Richdale, 2016; Bolourian et al., 2018; Chown et al., 2017; Gelbar et al., 2014; Lambe et al., 2019; Vincent et al., 2017; Vincent et al., 2019; Ward & Webster, 2018), qualitative research is necessarily context specific, and is therefore unlikely to account for cultural variations that impact the experience and needs of autistic students in France. Therefore, we cannot

assume that previous research reflects autistic students' experiences in the French national context. Given cultural variation between French and Anglo-Saxon cultures, in addition to differences in the educational system (Armstrong, 2005; Siepmann, 2006), it would therefore appear pertinent to examine the experience of autistic students within a French academic environment.

Being an autistic student in France

In 2005, France implemented national legislation permitting students with disabilities to access mainstream education (loi du 11 février 2005). This legislation led to a rapid and significant increase in the numbers of students with disabilities receiving a mainstream education at both primary and secondary level (Direction de l'Évaluation, de la Prospective et de la Performance, 2016). As of 2022, there are currently 430, 000 students with special needs enrolled in mainstream education in France (Ministère de l'éducation nationale et de la jeunesse, 2023). As educational opportunities for autistic students have therefore increased since 2005, a growing number of autistic students would be expected to access higher education. Nevertheless, limited attention has been paid to the development of support services for autistic adults in France.

Following strong criticism from the Council of Europe which highlighted a lack of employment support and opportunities for autistic adults in France (Autisme France, 2014), the French government included the 'Aspie-Friendly' project in the national 2018-2022 plan for autism (Secrétariat d'état chargé des Personnes Handicapées, 2018). The project aims to promote the inclusion of autistic students without intellectual disability (formerly 'Asperger's Syndrome) in French universities (Aspie-Friendly, n.d.). As of 2022, 25 of 100 or so French universities have so far elected to participate in the project. Aspie-Friendly provides personalised support to autistic students based on their individual support needs and provides outreach training for university students & professionals to increase awareness and understanding of autism on university campuses (Aspie-Friendly, n.d.). An Aspie-Friendly service exists within each of the 25 universities currently enrolled in the project as a local point of contact for autistic students.

Despite the implementation of such measures, little research has explored the experience and needs of autistic students in the French university environment. Whilst Anonymous et al. (2022) administered an open-ended questionnaire in a structured interview with autistic students, this study was conducted at a single university in Grenoble and responses were immediately transcribed by the person

administering the questionnaire. As interviews were not audio recorded and transcribed, participant responses may therefore not have been recorded accurately.

The current study therefore aims to overcome these limitations, using semi-structured interviews in a qualitative research design. Underpinned by a phenomenological epistemology, this approach aims to describe the lived experience of a phenomenon, not as it is factually accurate but as it is experienced and perceived by those who live it (Rodriguez & Smith, 2018). Certainly, in the “new era” of autism research, it is imperative to engage autistic people and to directly solicit their lived experience of phenomena related to their everyday reality (Pellicano et al., 2018). Semi-structured interviews thus facilitate rich in-depth subjective accounts of participant experiences, which contrary to the structured approach used by Anonymous et al. (2022), provided the opportunity for participants to identify and discuss aspects of the university experience which were perceived as important to them. Through thematic analysis of the research data, the study aimed to report common patterns in university experiences as well as points of divergence that shed light on how best to support autistic students at university.

Method

Method and findings are reported as per the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007).

Participants

Interviews were conducted with a purposive sample of 15 autistic adults enrolled in university in France who met the following inclusion criteria: (1) diagnosis or pre-diagnosis of autism from a certified professional, (2) currently enrolled in a university in France. Participants were recruited via mail sent to students having declared autism diagnosis to university disability support services in universities located in Paris, Clermont-Ferrand and Grenoble regions, and online through relevant social media forums. Autism diagnosis was confirmed through contact with disability services or through viewing medical certification. Participants were aged between 20 and 35 years ($M = 23.6$, $SD = 4.23$) and were 8 female, 2 male and 5 ‘other’. A fictional name was generated for each participant and identifying information has been redacted to preserve anonymity. See table 1 for socio-demographic information.

Procedure

Seven interviews were conducted face-to-face at the Institut de Psychologie at the university of Paris Cité, whilst nine participants elected to participate via Zoom. Interviews were conducted once between February and June 2022, took on average 1hr 16mins to complete (range: 51-145 mins) and were conducted in French with the exception of two international students (Mario & Sonia) who elected to participate in English. Interviews were conducted by E.M., a female neurotypical masters student in Clinical Psychology and supervised by E.C. a female neurotypical professor in psychology and qualitative researcher in the field of autism.

An interview guide developed for the purposes of the current study following a review of the literature was used to explore topics such as 1) the transition to higher education, 2) experience of academic coursework, 3) peer relationships and 4) supports/needs in the current university environment. See table 2 for a sample of interview questions.

Underpinned by a phenomenological epistemology, a semi-structured style was used to probe participant responses and check researcher understanding. The guide was thus used flexibly to obtain rich in-depth subjective accounts of experience, whilst also providing adequate structure for autistic participants who may find unstructured communication challenging (Griffith et al., 2012). Interview questions were therefore adapted to each participant with the goal of exploring the main topic areas identified from the literature review. Interviews were audio recorded and transcribed by a company specialized in verbatim transcription. Interviews were checked for accuracy by E.M.

Ethics

Ethical approval was obtained from XXX (*details removed to ensure blind review*). Participants were not personally known to the research team. Preliminary contact was made with each participant to verbally outline the study and answer any questions. In addition to providing written informed consent, all participants were informed at the beginning of the interview (1) they could stop the interview at any moment, (2) they were not obliged to discuss any topics with which they felt uncomfortable and (3) they could ask for clarification on any questions that didn't seem clear.

Data Analysis

Autistic students' lived experiences of university in France were analysed using thematic analysis,

a method for analysing patterns and themes in textual data (Braun & Clarke, 2006). From a phenomenological perspective, the analysis was data-driven and guided by methodological principles such as openness, a reflective attitude and awareness and questioning of pre-conceptions (Sundler et al., 2019). The goal was therefore to describe patterns pertaining to the lived experience of participants of the phenomenon of university study in France as an autistic person (Rodriguez & Smith, 2018; Sundler et al., 2019).

Using an inductive approach, an initial coding framework was developed by E.M. following Braun & Clarke's (2006) recommendations, following immersion in the data and systematic coding of conceptually meaningful data segments on interview transcripts. Figure 1 provides examples of codes that were used in the coding process. Themes were subsequently developed and refined iteratively using NVivo 12 (QSR international Pty Ltd., 2018) to group codes that reflected meaningfully latent patterns in the data.

In accordance with standards for quality research (O'Connor & Joffe, 2020), the initial coding framework was systematically applied to four interview transcripts by two independent coders (E.M. & J.K.) and refined to improve precision through reflexive dialogue. Both coders were neurotypical trainee clinical psychologists with limited experience supporting autistic students at university. Coding was supervised by E.C. an experienced Clinical Psychologist and researcher in the domain of Autism.

Intercoder reliability was calculated using NVivo 12 (QSR international Pty Ltd., 2018) and reached a satisfactory 0.71 Kappa co-efficient (McHugh, 2012).

Results

Four main themes comprising 10 sub-themes were identified from interview data. Themes describe participants' search for belonging, the importance of peer relationships and the complexity of collaborating academically with others at university. See figure 2 for theme map.

Theme 1: 'Searching for belonging'.

This first theme captures experiences of searching for belonging and attempts to integrate and adapt to new higher education environments as an autistic person (n=15).

Opportunity for 'a new start'.

Higher education for participants was experienced as a "new start" that could be either "a lot of change to handle at once" or "the best decision of my life". Whilst all participants discussed the newness of the experience, this newness could be experienced as either a positive or a negative event. Positive experiences centred upon newfound autonomy, access to academic interests, and experiences of belonging for the first-time.

'I didn't have to be somebody else like I had to be in high school'. (Eva, 22 years old)

'When I left my family and all the familiar places that I used to know, to just go and live my life.... It was great... My time in high school was intense. For me it was exhausting, so it's true that being able to be more autonomous, as opposed to having people tell me what to do all the time, that straight away suited me.' (Sandrine, 21 years old)

Negative experiences nevertheless centered upon having to learn a new social code, lack of interest in subject matter or having to learn the structure of the university without adequate support:

'When we arrive and we're not familiar with how the university functions, it's like, why is there an office for this and for that? We will send you to this person and then that person. There are too many people. It's too complicated.' (Samantha, 30 years old)

Completing higher education.

For many participants, attempting to integrate and adapt to the university environment could aggravate or provoke mental health challenges such as anxiety and depression, consequently raising the risk of drop out. The majority of participants (n=12) therefore discussed a complicated journey and difficulties completing higher education.

'A year and a half in, the anxiety got the better of me and I no longer knew where I was going ... So, I took a year out to think and to recover... And after I enrolled here.' (Sandrine, 21 years old)

Participants reported a strong risk of dropping out when their fatigue or mental health difficulties became so overwhelming, they were unable to seek support:

'As I was unable to keep up with the class and given that I didn't disclose my autism diagnosis to professors, with my level of fatigue I just didn't have the strength to explain. So eventually, I decided to stop going to class completely with the intention of working from home. However, I

couldn't really work from home because I was completely exhausted.' (Melissa, 20 years old)

Without adequate support participants could perceive dropping out as the only option:

'I missed a class at the beginning of the year as I was sick for three weeks with sinusitis. And the fact that I missed one class meant that I couldn't validate the whole year... my education has always gone badly so I'm used to it.' (Matthieu, 20 years old)

However, risk of drop-out could be mitigated when participants were granted a personalised schedule and allowed to repeat subjects that they had previously failed.

'It's going to be long [laughs]. And if it takes me three years to complete the first year of my undergraduate degree, so be it!' [Melissa, 20 years old]

The importance of empathic peers.

Social integration or lack thereof formed an important feature of the university experience for almost all participants (n=14). Having a friend at university could "boost motivation" and represent a "reassuring presence". However, friendships tended to blossom best when the other person was "on the same wavelength", such as a fellow "neurodivergent" or someone who has experienced their own psychological difficulties:

'We have our own view of the world, and we understand each other because be it a queer, depressed or anxious person or what not, I am not afraid to share my pain with them.' (Sandrine, 21 years old)

'I can't manage to make any friends [at university]. If I do, it's never very deep if they aren't autistic.' (Damien, 35 years old)

Friends at university could play an important role helping autistic students to "accept themselves" and advocate for what they need. Having contact with other students could therefore mitigate mental health difficulties, particularly when students' energy was depleted and unable to seek help:

'I suppose not a lot of people would have noticed that I was no longer there, apart from my classmates who for the most part were very worried. One classmate who I now consider to be a friend used to come and check on me to see if I was still alive.' (Melissa, 20 years old)

However, participants reported needing support engaging with other students, often initially attempting to "blend into the background" and "talking to no-one". Peer relationships usually developed

then when another student had made the first move:

'I almost didn't integrate... If I didn't come across this person who made the first move because she saw I was all alone, I think it would have been much more difficult... even if I want to be alone and all that, I still need others.' (Eva, 22 years old)

Lack of social integration thus led to participants feeling 'lonely', 'anxious' and/or "excluded" which could affect their capacity to apply themselves academically:

'I tell myself that university is just for getting an education. Sometimes we don't get along with people, shame ... It's just how it is. However, if for example, people become friends with each other and I'm the only one left out, well that is going to affect my work. That's when it's going to become a problem.' (Clara, 21 years old)

Theme 2: Autism identity and disclosure.

This theme captures how participants experienced support needs related to autism and their decision to disclose their diagnosis to the university (n=15).

Perception of support needs.

All participants reflected on their support needs in a higher education environment, with the majority (n=14) reflecting that without additional support, completing their higher education would represent a significant challenge. Only one participant reported never accessing additional support as obtaining a late diagnosis discouraged her from disclosing. However not asking for additional support was a decision this participant potentially regretted:

'I got diagnosed at the beginning of my final year [masters]. So, I said to myself, what would be the point of talking about it in my final year?... But maybe I should have disclosed it to get out of the final group project... I think that could have saved me three months of feeling sick...'
(Catherine, 23 years old)

Indeed, some participants expressed hesitations about accessing additional support that they feared would not be accessible later "in the real world" and/or it was a "question of pride".

'I was always top of the class, always the one to work hard, I always found it easy. It's true though that now to find myself in a position where I need extra support, it destroys my image of being a model student.' (Sandrine, 21 years old)

Nevertheless, hesitations were mixed with ambivalence as all, but one participant previously mentioned, reported benefiting from extra support. However, support needs were viewed as being highly individual, that should be personalised to compensate for individual difficulties.

'They offered me extra time in exams and a note taker, and I didn't accept... I prefer to have normal time in the exams... I'll ask for it if I realize all of a sudden that I have a problem with the time but I don't have a problem with the time.' (Artur, 20 years old)

Disclosing autism at university.

All participants discussed the decision to disclose autism to university, with all but one participant previously discussed, withholding disclosure on account of receiving a late diagnosis. For all participants, disclosure of autism to the university was motivated by access to additional supports. However, if participants disclosed their autism, professors were only informed of the students' right to these supports and not of the nature of their 'disability'. This created additional work for those participants (n=8) who wished for individual professors to understand their individual particularities and how they functioned in class:

'What I do is, I send mails before the semester begins, it's really exhausting because I have to find all their mails, then I have to write something. And in the mail, I put 'Voila, I'm going to do this in class eh, don't be surprised etc.'... and then I'm already exhausted before the semester begins.' (Amandine, 23 years old)

However, another solution was asking the "Aspie-Friendly" service to disclose autism diagnosis on students' behalf as one participant had successfully requested:

'It's a little bit uncomfortable to say to a professor... that's why I asked Aspie-Friendly to do it for me.' (Mario, 29 years old)

Whilst the remaining participants, considered that they didn't have the "opportunity" to discuss their difficulties with individual professors owing to the "distance" between students and professors, with one participant remarking that she "didn't know how" to approach the subject. Nevertheless, for those who did disclose on an individual basis, participants were motivated to do so in order to access more understanding and empathy from others:

'After years of searching, I decided ok that's what's wrong with me. So, if people want to interact

with me, they have to know that my interactions are going to be weird.' (Mario, 29 years old)

Theme 3: Managing anxiety and fatigue

This theme captures experiences of anxiety and fatigue generated by the higher education environment and how participants subsequently coped (n=14).

The importance of structured work.

For the majority of participants (n=14), difficulties planning and managing university workload contributed to intense feelings of anxiety and fatigue.

'If one professor gives us work every two weeks...for us autistics it's going to take three weeks! And it's going to be three weeks that we are under stress so then we have to have a pause. But if he gives again at the end of the second week, I'll get to the point where I am now where I can't go to his classes.' (Mario, 29 years old)

Almost all participants therefore viewed having extra time as desirable to help mitigate feelings of anxiety and fatigue. However, if extra time was afforded to students, it was often during exams and/or by enabling students to do their degree part-time. Whilst extra time in exams was appreciated by almost all participants, a part-time degree could come at the cost of a lack of structure to university life, contributing to the fatigue that it was originally intended to alleviate:

'I don't think I would be able to succeed otherwise. But at the same time, it's a big problem because I'm never really in class... when we don't have any structure, in fact, we can easily burn-out.' (Clara, 21 years old)

Further, when it came to academic work, participants indicated a strong preference for structured course content or academic work drawing upon "reason" or "logic" as it was difficult "knowing what to revise".

'When I know what to learn, when you say to me, 'learn this definition by heart', I can do it... but if I have not kept up with the class during the whole semester and there are only three weeks left before exams... I will feel completely overwhelmed and I won't know how to revise... it gives me major anxiety.' (Sandrine, 21 years old)

Managing sensory overload.

The majority of participants (n=13) also reported various challenges with sensorial particularities

such as sensitivity to light and noise at university. These sensitivities often drained students' energy and/or provoked anxiety:

'There's a lot of noise, even between classes. I recently had a massive panic attack because I was waiting in the corridor and there was too much noise. And the lights in fact for me are, how to say.... it's hell for me. The lights in class are super strong, those neon lights. They are super strong, and they are on all the time, whether it's day or night.' (Amandine, 23 years old)

Participants could thus find themselves trying to adapt to higher education environments through the use of various technology such as noise-cancelling headphones.

'At the beginning I said to myself, I can manage with all the noise, but eventually I got so tired that I couldn't deal with it anymore. So, I wear my headphones now all the time and it's much better. It was one of my best investments.' (Melissa, 20 years old)

However, having a quiet room available to students where they could isolate and recover from sensorial overwhelm was also considered to be important. Whilst some participants reported benefiting from a special room reserved for students with disabilities (n=3), others had to try to find their own solutions.

'I would have liked to have a, I normally ask for it but it wasn't available at the university, to have a place I could go when I was not feeling good. There was no silent room. I mean I was able to find a room with computers, very open room but there was always someone there when I went there.' (Sonia, 25 years old)

The importance of intermediary support.

In addition to dealing with fatigue and stress caused from challenges adapting to higher education environments, participants (n= 12) often endured further fatigue and/or anxiety from trying to access supports.

'If I want to have a separate room, I have to ask the secretary three weeks before the exam.... But in fact, I can't, meaning half of the time I will forget or whatever and then it's too late.'
(Amandine, 23 years old)

Participants therefore reported the need for an identifiable person that can inform them of services and advocate for what they need.

'I would have liked to have someone as a, like if you have any problems with your masters you could talk to this teacher and that wasn't said.' (Sonia, 25 years old)

However, intermediary services such as 'Aspie-Friendly' do exist and when students engaged with such services, they played a critical role in alleviating the administrative and social stress associated with accessing support. Nevertheless, despite strong interest from all participants, accessing supports like Aspie-Friendly could also prove to be challenging with participants procrastinating contact:

'I received the mails informing me that it [Aspie-Friendly] exists but I saw that there was a lot to read, and my coursework takes me so much time and I don't have, each time I would forget to read it and I would forget to look at the email, what it's all about. But otherwise, it interests me greatly.' (Lara, 22 years old)

For participants without the support of an intermediary service such as Aspie-Friendly, confusion often prevailed about what services were available and for whom, with several students speaking of a need to "increase the visibility of disability support services" often discovering various supports by chance:

'They didn't mention the kitchen or the relaxation room, I think the person must have forgotten or didn't realize that it wasn't obvious. Eh it's obvious that it's for them but they didn't really explain that students can use it.' (Lara, 22 years old)

'I found support from the medical service... There was one time I forget my diazepam, so I went there ... before I didn't know I could go there.' (Sonia, 25 years old)

Theme 4: Working with others.

The majority of participants spoke in depth about their experiences working with others (n=10). This theme captures participants complex and sometimes contradictory needs when it comes to collaborating academically with others.

Participating in group work.

Whilst the majority of participants discussed experiences participating in group work (n=10), difficulties in social interactions meant that some participants did not interact as much with other group members thereby giving the impression that they were not invested in group work. Two participants recounted experiences where group members even went above them to speak to professors about their

lack of participation, with one participant eventually being asked to leave the group:

'And I was kicked out by my colleagues from one group work... I didn't trust them, so I just didn't participate too much for that group work and my colleagues talked to the teacher and the teacher made me produce, like eh I had to produce something alone in order to pass the subject.' (Sonia, 25 years old)

However, for the same participant, re-orienting her academic career to study a different subject enabled her to meet different people who were more "tolerant and open-minded" and thus she was able to meet up with them "on the weekends for group work or for having fun". Group work therefore could facilitate relationships when working with the right people and was most often a positive experience when working in small numbers and/or with other students who did not interpret difficulties interacting with others as being a lack of investment in the work.

'The group work in pairs went so much better... I was really stressed out about the evaluation so there were a few moments where I stopped replying to messages. And that wasn't a problem for her [group member]. It's true that it can be hard to work with me because there will be moments when I just won't reply, because for me it's stressful to send a message... and it didn't bother her at all.' (Clara, 21 years old)

The importance of tutor-type support.

Despite difficulties working with others, many participants reported difficulties working alone in a French academic environment that places heavy emphasis on notetaking (n=9).

'It's the note-taking that is my greatest difficulty. It takes me a crazy long time.' (Clara, 21 years old)

This student thus resorted to taking audio recordings in an effort to transcribe her classes. Having the support of a "note-taker" therefore did not provide sufficient support:

'The way she takes notes doesn't suit me at all... her notes are not very detailed. In fact, I not only need more detailed notes but really, I need things written down that are not necessarily the most important, but that are important for me, my own understanding.' (Clara, 21 years old)

Indeed, a note-taking environment meant participants could have difficulties with the speed of classes and/or having to learn their notes by heart:

'When there is something I don't understand in class, it blocks me, and it annoys me to not understand so I can be blocked for hours... I think the teachers go too fast... they teach like it's obvious but often there are things which are... aren't explained ... and so I have difficulty to follow class and to link up all the concepts together. I find it too fast.' (Artur, 20 years old)

Participants therefore reported a strong desire to work collaboratively with another individual who could support them in their academic work.

'I have a billion ideas in my head and I'm never able to choose which ones are pertinent. I'm too scared. In fact, I would need to know, I don't know, go to see someone, and say, 'here are my ideas, what do you think?' And they say, 'Ok, that- that's good, do that one'.' (Amandine, 23 years old)

'During the revision period, I was like, but I need a coach who is available 24 hours a day to help me manage my schedule and my revision!' (Sandrine, 21 years old)

Whilst one participant reported engaging with privately paid for tuition, the majority of students reported trying to engage with professors for extra support. However, this was not always a reliable strategy as some professors were either unable or unwilling to invest the extra time to help students:

'I said I didn't understand anything, and he didn't take it very well. And he told me basically that I needed to just work it out myself.' (Artur, 20 years old)

Difficulties working alone therefore contributed to revision strategies based on procrastination and/or "all-nighters" where participants would stay up all night to revise before an exam. Such strategies only served to enhance previously discussed feelings of anxiety and fatigue. Indeed, one participant even reported attempting suicide after experiencing her first university exam.

'I had a big panic attack and that Monday night; I had a suicide attempt. Which meant that I was hospitalized for the whole week and so I couldn't go to the rest of my exams.' (Sandrine, 21 years old)

Therefore, without adequate personalised tutor-type support, participants could struggle in the French academic environment.

'I think university should look on and cut down on the necessity of us working by ourselves'.
(Mario, 29 years old)

Discussion

As one of the first studies to explore the phenomenon of university study as an autistic person in France, this study makes an important contribution to the literature. Importantly, the study highlights the complex journey that autistic students may face when accessing and completing higher education in a French university environment. Indeed, whilst autistic students in other studies may have reported difficulties with the sudden lack of structure at university (Cai & Richdale, 2016; Kim et al., 2021), the participants in the current study reported appreciating a newfound sense of personal autonomy in contrast to their secondary education. This finding thus highlights the importance of considering cultural context (Yardley, 2000) and differing educational systems when interpreting the practical implications of qualitative research. In contrast with other studies (Bolourian et al., 2018; Cage & Howes, 2020; Anonymous et al., 2022), the newness of the university experience could be experienced as a positive event, facilitating access to academic interests, and allowing students to connect with likeminded individuals and achieve a sense of belonging, perhaps for the first time. Consistent with previous research, the presence of supportive social relationships was a key factor in achieving a sense of 'belonging' at university (Pesonen et al., 2020).

Further consistent with previous research (Cage & Howes, 2020; Jackson et al., 2018; Anonymous et al., 2022; Sanford et al., 2011), participants reported difficulties completing higher education and consequently described an elevated risk of drop-out. Dealing with the pressures of university life without adequate support could therefore contribute to a perceived inevitability of drop-out if proactive support was not provided by the university (Anderson et al., 2018; Cage & Howes, 2020). This may suggest that autistic students may require regular contact with a university support worker or peers to identify and mitigate risk of drop-out. Indeed, previous research has indicated the potential usefulness of autistic students being paired with peer advocates (Anderson et al., 2018) and the use of structured support programs to help students make the transition to higher education (Kim et al., 2021).

Certainly, social integration and supportive peer relationships are factors that can serve to mitigate mental health difficulties and promote an autistic students' chance of 'success' at university (Ward & Webster, 2018; Pesonen et al., 2021). Participants in the current study therefore reported benefiting from and/or expressed a need to experience supportive peer relationships, particularly with

likeminded individuals such as other autistic students. Indeed, autistic adults may even express a preference to interact with other autistic peers due to opportunities for enhanced mutual understanding (Crompton et al., 2020). Nevertheless, participants reported difficulties developing peer relationships if another student did not make the first move. Owing to difficulties in social interactions, autistic students may therefore require regular structured opportunities to help initiate meeting other autistic and/or neurotypical peers.

However, to identify such students and provide appropriate support, autistic students must first be willing to disclose their diagnosis to the university. Whilst the majority of participants in the current study perceived receiving additional support as essential to their success, diagnostic disclosure was often a complex process. Despite officially disclosing their diagnosis to the institution, certain staff members such as university professors were not informed of the nature of the students' 'disability'. Consistent with previous research (Anonymous et al., 2022), this could lead to confusion, with the majority of participants motivated to disclose their diagnosis to individual professors in an effort to access more empathy and understanding. This extra layer of disclosure however was often considered a tedious and energy consuming process. Participants therefore identified needing support managing the administrative stress associated with disclosure. Therefore, the current study along with others (Anonymous et al., 2022) underscore the importance of intermediary services such as Aspie-Friendly (n.d.), who play a pivotal role in helping students disclose their diagnosis to professors and underlines the necessity of providing adequate training and information to university professors on the subject of autism, with a view to enhancing empathy and understanding towards autistic students (Anonymous et al., 2022).

Further, autistic students are particularly susceptible to stress and often experience comorbid mental health challenges (Cage & Howes, 2020; Hollocks et al., 2019; Mantzalas et al., 2022; Ward & Webster, 2018). For participants in the current study, difficulties planning and managing workload, sensory overstimulation and administrative stress associated with accessing supports were all identified as significant sources of stress. Whilst support needs of autistic university students are highly individual (MacLeod et al., 2017; Pesonen et al., 2020), additional supports in the form of extra time and personalised schedules were often appreciated. Other critical support included having a quiet room in which to combat anxiety, fatigue and sensorial overwhelm. Whilst a quiet room was available in some

universities, it was not available in others. Availability of various supports was therefore heterogenous, often dependent on services available, according to the university campus.

Furthermore, the current study highlights the complexities of autistic students participating in group work. Whilst some research has indicated that autistic university students may express a preference to participate in academic group work owing to the perceived structure of the activity (Lambe et al., 2019), others have highlighted group assignments as a source of potential difficulty for autistic students (Cai & Richdale, 2016; Anonymous et al., 2022). For participants in the current study, group assignments could be experienced positively or negatively or both. For autistic students who struggled to initiate contact with other students, group work facilitated contact with peers and occasionally even friendship. However, it could also represent a major source of stress and/or conflict. Consistent with previous research (Cai & Richdale, 2016; Anonymous et al., 2022), participants reported reducing their interactions with others when they were feeling stressed or anxious by the workload and/or interaction with other group members. Therefore, this information may be necessary to communicate to group members and/or professors working with autistic students in the future, in order to enhance empathy and understanding.

Further, the current study illuminated autistic students' difficulties to work autonomously in a French academic environment that places heavy emphasis on notetaking. Participants therefore identified the need for additional academic support to explain concepts and fill gaps in understanding. Nevertheless, should French policymakers adopt a more inclusive approach to university education, whereby all teaching materials, lectures and seminars were recorded and captured for repeated re-visiting, this would likely eliminate the need for such support and likely benefit all students.

Limitations and future directions

The current study has several strengths and limitations. A qualitative research design underpinned by a phenomenological epistemology facilitated an exploration of the lived experience of an under-researched population, with sensitivity paid to the French context as regards to current practices concerning autism and disability. Use of semi-structured interviews with those directly concerned by such practices therefore facilitated rich accounts of lived experience, which were probed and checked for researcher understanding. Further, the diverse age range of participants facilitated analysis of both first-

time experiences of university and students repeated multiple attempts to access and complete higher education.

Nevertheless, the results of the current study should also be interpreted in light of limitations such as the self-selection bias of participants, who may have been more pre-disposed and motivated to discuss difficulties and negative experiences associated with accessing higher education. Indeed, the majority of participants had disclosed their diagnosis to the university, therefore it is possible that autistic students who do not disclose do not experience the same difficulties. Moreover, it is difficult to identify to what extent the experiences of autistic students diverge or converge with that of neurotypical peers or that of other students with disabilities. These could represent avenues for future research.

Furthermore, the current study was predominantly researcher-led. It is therefore important to bear in mind the 'double empathy problem' whereby neurotypical individuals may fail to fully understand and engage with autistic perspectives (Milton, 2012). Future research in this area should consider participatory approaches which embed the perspective of autistic individuals in all stages of the research process from design through to analysis (Pickard et al., 2022).

Implications

Improving the employability of all higher education students has been defined as a key goal in the European Higher Education Area (European Commission, 2018). However, this can only be achieved for autistic students if they are first sufficiently supported to complete their higher education in the first place. The findings of the current study therefore suggest that much more needs to be done to support autistic students in university in France. Of note, autistic students highlighted their elevated risk of drop-out owing to anxiety and fatigue caused by: difficulties planning and managing workload, sensorial overwhelm and administrative stress. Findings of the current study indicate that autistic students are likely to require further support initiating contact with other students and are likely to benefit from disability support services capable of delivering proactive, personalized intermediary and tutor-type support.

Furthermore, policymakers in France should also consider implementing a more inclusive approach to education such as Universal Design for Learning (UDL). UDL is an inclusive education framework that acknowledges a normal diversity among all students regarding their approach to learning (Fornauf & Erickson, 2020). A more inclusive approach to education would therefore involve a multi-

modal approach to teaching and evaluation, particularly as the French academic environment still places heavy emphasis on academic lectures and note-taking practices. Indeed, a more inclusive approach is not only likely to benefit all students but may also reduce various challenges for autistic students associated with diagnostic disclosure.

Acknowledgements

The authors wish to thank participants for their participation in research interviews. The authors wish to also thank Anonymous and Anonymous for having taken the time to review the interview guide, as well as the network Anonymous for helping with participant recruitment. This work was supported by Anonymous [grant number].

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

References

- Anderson, K. A., Sosnowy, C., Kuo, A. A., & Shattuck, P. T. (2018). Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies. *Pediatrics*, 141(Supplement_4), S318–S327. <https://doi.org/10.1542/peds.2016-4300i>
- Aspie-Friendly*. (n.d.). Retrieved April 5, 2023, from <https://aspie-friendly.fr/> Allen, M. and K. Coney. (2019). *What Happens Next? A Report on the First Destinations of 2017 Disabled Graduates*. https://www.agcas.org.uk/write/MediaUploads/Resources/Disability%20TG/What_Happens_Next_report_2019.pdf
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>
- Armstrong, Felicity. (2005) Chapter 4 Pupil or 'Patient' : difference, disability and education in France in Barnes, C., & Mercer, G. (eds), *The Social Model of Disability: Europe and the Majority of the World*. pp. 49-64. The Disability Press. <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-EMW-Chapter-4.pdf>
- Autisme France. (2014). Communiqué sur la 5 ème condamnation de la France par le Conseil de l'Europe [Press release]. https://v1.all-in-web.fr/offres/doc_inline_src/577/CP_AF_5eme_condamnation_France_par_Conseil-Europe_02.2014.pdf
- Bakker, T., Krabbendam, L., Bhulai, S., & Begeer, S. (2019). Background and enrolment characteristics of students with autism in higher education. *Research in Autism Spectrum Disorders*, 67, 101424. <https://doi.org/10.1016/j.rasd.2019.101424>
- Bolourian, Y., Zeedyk, S. M., & Blacher, J. (2018). Autism and the University Experience: Narratives from Students with Neurodevelopmental Disorders. *Journal of Autism and Developmental Disorders*, 48(10), 3330–3343. <https://doi.org/10.1007/s10803-018-3599-5>
- Botha, M., Hanlon, J., & Williams, G. (2023). Does Language Matter? Identity-First Versus Person-First Language Use in Autism Research: A Response to Vivanti. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-020-04858-w>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in*

- Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Briel, L. W., & Getzel, E. E. (2014). In their own words: The career planning experiences of college students with ASD. *Journal of Vocational Rehabilitation*, 40(3), 195–202. <https://doi.org/10.3233/jvr-140684>
- Cage, E., De Andrés, M., & Mahoney, P. (2020). Understanding the factors that affect university completion for autistic people. *Research in Autism Spectrum Disorders*, 72, 101519. <https://doi.org/10.1016/j.rasd.2020.101519>
- Cage, E., & Howes, J. (2020). Dropping out and moving on: A qualitative study of autistic people's experiences of university. *Autism*, 24(7), 1664–1675. <https://doi.org/10.1177/1362361320918750>
- Cai, R. Y., & 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. <https://doi.org/10.1007/s10803-015-2535-1>
- Chown, N., Baker-Rogers, J., Hughes, L., Cossburn, K. N., & Byrne, P. (2017). The 'High Achievers' project: an assessment of the support for students with autism attending UK universities. *Journal of Further and Higher Education*, 42(6), 837–854. <https://doi.org/10.1080/0309877x.2017.1323191>
- Crompton, C. J., Hallett, S., Ropar, D., Flynn, E., & Fletcher-Watson, S. (2020). 'I never realised everybody felt as happy as I do when I am around autistic people': A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism*, 24(6), 1438–1448. <https://doi.org/10.1177/1362361320908976>
- Direction de l'Évaluation, de la Prospective et de la Performance. (2016). Note d'information no. 36. Ministère de l'éducation nationale et de la jeunesse. Retrieved April 5, 2023, from <https://www.education.gouv.fr/depuis-la-loi-de-2005-la-scolarisation-des-enfants-en-situation-de-handicap-tres-fortement-progresse-2018>
- Eaves, L. C., & Ho, H. H. (2008). Young Adult Outcome of Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 38(4), 739–747. <https://doi.org/10.1007/s10803-007-0441-x>
- EC (European Commission). 2018. The European Higher Education Area in 2018: Bologna Process Implementation Report. Brussels: EACEA European Unit of Eurydice. Accessed 14 January

2020. https://eacea.ec.europa.eu/national-policies/eurydice/content/european-higher-education-area-2018-bologna-process-implementation-report_en
- Fornauf, B., & Dangora Erickson, J. (2020). Toward an Inclusive Pedagogy Through Universal Design for Learning in Higher Education: A Review of the Literature. *Journal of Postsecondary Education and Disability*, 33(2), 183–199. <https://files.eric.ed.gov/fulltext/EJ1273677.pdf>
- 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. <https://doi.org/10.1007/s10803-014-2135-5>
- Griffith, G. M., Totsika, V., Nash, S., & Hastings, R. P. (2011). 'I just don't fit anywhere': support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism*, 16(5), 532–546. <https://doi.org/10.1177/1362361311405223>
- Happé, F., & Vital, P. (2009). What aspects of autism predispose to talent? *Philosophical Transactions of the Royal Society B: Biological Sciences*, 364(1522), 1369–1375. <https://doi.org/10.1098/rstb.2008.0332>
- Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. *Psychological Medicine*, 49(4), 559–572. <https://doi.org/10.1017/s0033291718002283>
- Jackson, S. L. J., Hart, L., Brown, J. T., & 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. <https://doi.org/10.1007/s10803-017-3315-x>
- Kim, S. Y., Crowley, S. K., & Jia, W. (2021). Autistic undergraduate students' transition and adjustment to higher education institutions. *Research in Autism Spectrum Disorders*, 89, 101883. <https://doi.org/10.1016/j.rasd.2021.101883>
- Loi n°2005-102 du 11 février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées (JORF N°36 du 12 février 2005).
- Lambe, S., Russell, A., Butler, C., Fletcher, S., Ashwin, C., & Brosnan, M. (2018). Autism and the

- transition to university from the student perspective. *Autism*, 23(6), 1531–1541.
<https://doi.org/10.1177/1362361318803935>
- Lorenz, T., & Heinitz, K. (2014). *Aspergers – Different, Not Less: Occupational Strengths and Job Interests of Individuals with Asperger's Syndrome*. PLoS ONE, 9(6), e100358.
<https://doi.org/10.1371/journal.pone.0100358>
- MacLeod, A., Allan, J., Lewis, A., & 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. <https://doi.org/10.1080/13603116.2017.1396502>
- Mantzalas, J., Richdale, A. L., & Dissanayake, C. (2022). A conceptual model of risk and protective factors for autistic burnout. *Autism Research*. <https://doi.org/10.1002/aur.2722>
- Masi, A., DeMayo, M. M., Glozier, N., & Guastella, A. J. (2017). An Overview of Autism Spectrum Disorder, Heterogeneity and Treatment Options. *Neuroscience Bulletin*, 33(2), 183–193.
<https://doi.org/10.1007/s12264-017-0100-y>
- McHugh, M. L. (2012). Interrater reliability: the kappa statistic. *Biochemia Medica*, 276–282.
<https://doi.org/10.11613/bm.2012.031>
- Milton, D. (2012). On the ontological status of autism: the 'double empathy problem.' *Disability & Society*, 27(6), 883–887. <https://doi.org/10.1080/09687599.2012.710008>
- Ministère de l'éducation nationale et de la jeunesse. (2023). La scolarisation des élèves en situation de handicap. Retrieved April 5, 2023, from <https://www.education.gouv.fr/la-scolarisation-des-eleves-en-situation-de-handicap-1022>
- Ministère de l'Enseignement supérieur et de la Recherche. (2022). État de l'Enseignement supérieur, de la Recherche et de l'Innovation en France n°15. Retrieved April 5, 2023, from https://publication.enseignementsup-recherche.gouv.fr/eesr/FR/T243/les_etudiants_en_situation_de_handicap_dans_l_enseignement_superieur/
- O'Connor, C., & Joffe, H. (2020). Intercoder Reliability in Qualitative Research: Debates and Practical Guidelines. *International Journal of Qualitative Methods*, 19, 160940691989922.
<https://doi.org/10.1177/1609406919899220>

- Pellicano, L., Mandy, W., Bölte, S., Stahmer, A., Lounds Taylor, J., & Mandell, D. S. (2018). A new era for autism research, and for our journal. *Autism*, 22(2), 82–83.
<https://doi.org/10.1177/1362361317748556>
- Pesonen, H., Nieminen, J. H., Vincent, J., Waltz, M., Lahdelma, M., Syurina, E. V., & Fabri, M. (2020). A socio-political approach on autistic students' sense of belonging in higher education. *Teaching in Higher Education*, 1–19. <https://doi.org/10.1080/13562517.2020.1852205>
- Pesonen, H., Waltz, M., Fabri, M., Lahdelma, M., & Syurina, E. V. (2021). Students and graduates with autism: perceptions of support when preparing for transition from university to work. *European Journal of Special Needs Education*, 36(4), 531–546.
<https://doi.org/10.1080/08856257.2020.1769982>
- Pickard, H. R., Pellicano, E., Houting, J. D., & Crane, L. (2021). Participatory autism research: Early career and established researchers' views and experiences. *Autism*, 26(1), 75–87.
<https://doi.org/10.1177/13623613211019594>
- QSR International Pty Ltd. (2018) *NVivo (Version 12)*, <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
- Rodriguez, A., & Smith, J. (2018). Phenomenology as a healthcare research method. *Evidence Based Nursing*, 21(4), 96–98. <https://doi.org/10.1136/eb-2018-102990>
- Sanford, C., Newman, L., Wagner, M., Cameto, R., Knokey, A. M., & Shaver, D. (2011). *The Post-High School Outcomes of Young Adults With Disabilities up to 6 Years After High School*. Menlo Park, CA: SRI International. <https://ies.ed.gov/ncser/pubs/20113005/pdf/20113005.pdf>
- Secrétariat d'état chargé des Personnes Handicapées. (2018). Stratégie nationale pour l'Autisme au sein des troubles du neuro-développement. In handicap.gouv.fr. Retrieved April 5, 2023, from https://handicap.gouv.fr/sites/handicap/files/files-spip/pdf/strategie_nationale_autisme_2018.pdf
- Siepmann, D. (2006). Academic Writing and Culture: An Overview of Differences between English, French and German. *Meta*, 51(1), 131–150. <https://doi.org/10.7202/012998ar>
- South, M., Ozonoff, S., & McMahon, W. M. (2005). Repetitive Behavior Profiles in Asperger Syndrome and High-Functioning Autism. *Journal of Autism and Developmental Disorders*, 35(2), 145–158.
<https://doi.org/10.1007/s10803-004-1992-8>

- Sundler, A. J., Lindberg, E., Nilsson, C., & Palmér, L. (2019). Qualitative thematic analysis based on descriptive phenomenology. *Nursing Open*. <https://doi.org/10.1002/nop2.275>
- Tong, A., Sainsbury, P., Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- 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(5), 566–574. <https://doi.org/10.1007/s10803-010-1070-3>
- Vincent, J., Potts, M., Fletcher, D., Hodges, S., Howells, J., Mitchell, A., Mallon, B., & Ledger, T. (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. <https://doi.org/10.1080/09650792.2016.1153978>
- Vincent, J. (2019). It's the fear of the unknown: Transition from higher education for young autistic adults. *Autism*, 23(6), 1575–1585. <https://doi.org/10.1177/1362361318822498>
- Ward, D., & 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. <https://doi.org/10.1080/1034912x.2017.1403573>
- White, S. W., Ollendick, T. H., & Bray, B. C. (2011). College students on the autism spectrum. *Autism*, 15(6), 683–701. <https://doi.org/10.1177/1362361310393363>
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15(2), 215–228. <https://doi.org/10.1080/08870440008400302>

Footnotes

¹ We acknowledge debate exists on as to whether to use 'person-first' or 'identify-first' language when describing autism. In the absence of consensus, we have chosen the latter, as 'person-first' language may be seen to pathologize autistic people (Botha et al, 2023).

Table 1*Demographic Information for Participants (N = 15)*

Demographic characteristics	
Gender	
Male	2
Female	8
Other	5
Living situation	
Lives alone	8
Lives with parents	3
Lives with partner	3
Lives with flat mates	1
Currently enrolled in	
Undergraduate	9
Masters	6
University location	
Paris	9
Grenoble	5
Marseille	1
Course subject	
Mathematics	3
Science	3
Education	2
Languages	1
Law	1
Psychology	1
Engineering	1

Architecture	1
Music	1
Arts	1
Disability Support Services	
Dislosed diagnosis	14
Withheld disclosure	1

Table 2*Interview schedule*

Question	Possible prompts
How did you choose your university course?	<ul style="list-style-type: none"> • <i>What motivated your choice?</i> • <i>Why did you choose to go to university (and not another kind of higher education institution)?</i>
How did you experience the transition from secondary school to higher education?	<ul style="list-style-type: none"> • <i>What were the positive (or easy)/negative (or difficult) aspects of this change?</i> • <i>How did you deal with the transition?</i>
How are you currently finding university?	<ul style="list-style-type: none"> • <i>What are the positive (or easy)/negative (or difficult) aspects of your university experience?</i> • <i>How do you deal with difficulties?</i>
In relation to your autism, what are your support needs at university?	<ul style="list-style-type: none"> • <i>In relation to academic work; other students; university professors; administrative personnel (secretaries, library, support staff etc.); material needs (housing, restoration, transport, hobbies); the structure of the university (signage, university plan, predictability of events)?</i>

Figure 1

Examples of codes that were grouped for the theme 'Searching for Belonging'.

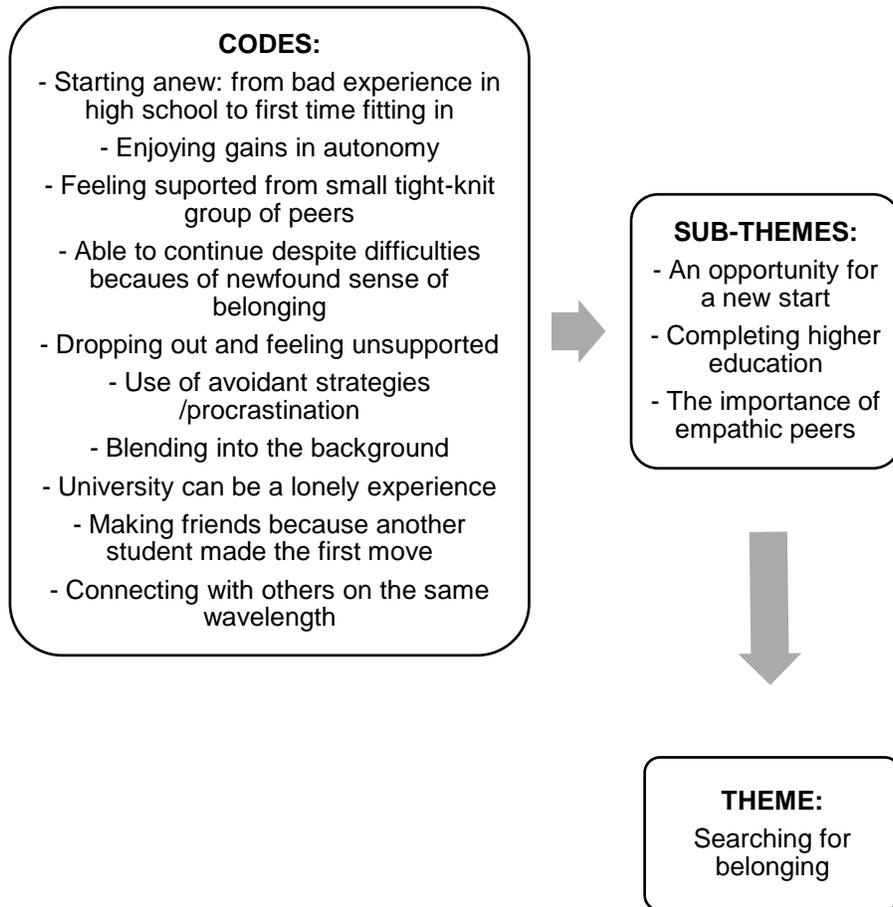


Figure 2

Themes and sub-themes from thematic analysis

