Higher Education Experiences of Students with Autism Spectrum Disorder: Challenges, Benefits and Support Needs

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Abstract

The transition into higher education constitutes a precarious life stage for students with autism spectrum disorder (ASD). Research on how students with ASD navigate college life is needed for the development of adequate support. This study investigated the challenges and support needs of 23 students with ASD in higher education through semi-structured interviews. Data were analyzed following the principles of Grounded Theory. Students faced difficulties with new situations and unexpected changes, social relationships, problems with information processing and time management and had doubts about disclosure. Facing these challenges simultaneously in the domains of education, student life and daily (independent) living, had a major impact on students' well being. Besides these challenges, students also reported benefits that contributed to success in the three domains. They pointed out to a set of recommendations for support. These findings are linked with previous research and implications for higher education institutions are extrapolated on the basis of these findings.

Key Words

ASD, higher education, qualitative research, students' challenges, benefits, support needs and recommendations

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Introduction

Autism spectrum disorder (ASD) refers to a class of neurodevelopmental disorders characterized by deficiencies in social interaction and communication, as well as the presence of behaviors, activities and interests that are repetitive and restrictive (American Psychiatric Association; APA, 2013). Recent studies estimate the prevalence of ASD between 0.6 to 1%, (Brugha et al., 2011; Davidovitch, Hemo, Elsabbagh, Manninhg-Coutney, & Fombonne, 2013; Fombonne, Quircke, & Hagen, 2011). According to recent data of the Centers for Disease Control and Prevention (CDC), 1 out of every 68 children (1.47%) in the United States has ASD, a significant increase in reference to the past 10 years (CDC, 2014; Schieve et al., 2012). Factors contributing to the increased prevalence of ASD include heightened public awareness, changes in diagnostic criteria, and improved ability to diagnose ASD among individuals without an intellectual disability (Pinder-Amaker, 2014). Most likely due to the increase in prevalence, the effect of (early) treatment programs and the introduction of disability legislation in education, a growing number of students with ASD is enrolling in higher education (Adreon & Durocher, 2007; Barnhill, 2014; Pillay & Bhat, 2012; Van Bergeijk, Klin & Volkmar, 2008). With the improved identification of ASD among individuals with no intellectual disability, it is assumed that the number of college students diagnosed with ASD will continue to increase even further (Barnhill, 2014; Pugliese & White, 2014).

Although students with ASD have the potential to perform well academically, they are at a heightened risk for academic and personal failure during the college years (Kapp, Gantman, & Laugeson, 2011; Pinder-Amaker, 2014). Compared to other disability categories, students with ASD have decreased graduation and employment rates (Sanford et al., 2011; Shattuck et al., 2012; Taylor & Seltzer, 2011) and they are more likely to develop psychopathological disorders (Friedman, Warfield, & Parish, 2013; Pinder-Amaker, 2014;

Shattuck et al., 2012). The core features and the psychiatric risks of ASD, coupled with new stresses and demands of higher education (e.g., increasing independence, international mobility, living in residence) pose significant challenges to students with ASD (Kapp et al., 2011; Pinder-Amaker, 2014). Challenges frequently reported include non-academic issues such as difficulties with social skills, interpersonal deficits, organizational and time management difficulties, lacking self-advocacy skills and sensory overload, as well as problems meeting academic demands (Fleischer, 2012; Gelbar, Smith, & Reichow, 2014; Madriaga 2010; Madriaga & Goodley 2010; Taylor 2005). To address these challenges, universities and colleges must provide appropriate interventions and supports that differ from those provided for students with other types of disabilities (Barnhil, 2014; Friedman et al., 2013; Van Bergeijk et al., 2008).

With the introduction of disability discrimination legislation (e.g., UN - Convention on the Rights of Persons with Disabilities), institutions have put a lot effort into making their education and activities more accessible for students with disabilities by providing them an equal opportunity to participate (Pillay & Bath, 2012). While many universities and colleges are quite adept at making reasonable accommodations for students with learning disabilities (Van Bergeijk et al., 2008), institutions for higher education struggle with how to support the growing group of students with ASD (Barnhill, 2014; Pugliese & White, 2014; White, Ollendick, & Bray, 2011). The invisibility and the heterogeneity of this group with ASD make it difficult to estimate which specific challenges students with ASD face, and which accommodations and support initiatives are appropriate. Although the number of manuals and interventions for college and university students with ASD has increased (e.g., Pugliese & White, 2014; Zager & Alpern, 2010), current postsecondary interventions remain sparse, are theoretically distinct, and their effect has yet to be empirically confirmed (Gelbar et al., 2014; Pinder-Amaker, 2014). As more and more students with ASD enroll in higher education and

since they are at a heightened risk for academic and personal failure, there is an urgent need for evidence-based interventions so that these students can successfully navigate college life, ensuring their quality of life during this period (Barnhill, 2014; Chiang, Cheung, Hickson, Xiang, & Tsai, 2012).

In order to gain a thorough understanding of the needs of students with ASD without overlooking important needs, and in order to avoid the development of inadequate and stigmatizing support systems, several researchers (e.g., Griffith, 2011; Humphrey & Lewis, 2008; Madriaga, 2010) have recommended to include the perspectives of individuals with disabilities as a systematic part of any intervention-orientated research (Müller, Schuler & Yates, 2008). Although elaborate research exists in youth with more severe forms of ASD, research charting the perspectives of students with ASD in higher education is scarce and fragmented (Gelbar et al., 2014; Pinder-Amaker, 2014). A systematic review of the literature (Gelbar et al., 2014) found only 20 studies describing the experiences of in total no more than 69 college students with ASD. Most of these studies either focus only on students with Asperger's syndrome who are studying at a single university, conduct a case study methodology (18 studies) with samples varying from one to eight students, or only examine a single topic of college or university experience (e.g., academic support, access to common areas, etc.). Given the heterogeneity of ASD and the psychiatric risks coupled to ASD, it is necessary to investigate in a more systematic way the experiences and support needs of a larger group of students with ASD, at the same time taking into account a wide variety of aspects of college and university life (Gelbar et al., 2014).

Study Aims

The objective of this study was to gain a thorough understanding of how universities and colleges can optimally support students with ASD, seen from their own perspective. We

investigated in a systematic way (1) the challenges students with ASD face during the transition to higher education and in college or university itself, and (2) their academic and social support needs. The college or university experience was defined broadly and included education, student life and daily (independent) living. This wide perspective allowed us to enter the students' life and understand their daily struggles and uplifts as students with ASD in higher education. A better understanding of students' experiences and support needs will allow for a development of interventions that is tailored to the specific needs of this group of students.

Method

Methodological Approach

Since we were interested in the experiences from the students' own frame of reference, rather than testing variables contributing to success in college experience, a qualitative research design was adopted for this study. Because we wanted to give students with ASD sufficient opportunity to speak freely about their experiences, and because we wanted them to come up with unanticipated topics, data were collected through semi-structured interviews. According to Barriball and While (1994), semi-structured interviews are suitable for the exploration of respondents' perceptions and opinions regarding complex and sensitive issues. Since only limited theoretical and empirical research exists on ASD and higher education, principles of the Grounded Theory Approach (GTA: Bogdan & Biklen, 1998; Corbin & Strauss, 2008) were used as a guiding approach for data analysis. Grounded Theory is a qualitative methodology that uses the inductive process of identifying analytical themes or patterns as they emerge from data (Corbin & Strauss, 2008). The added value of the inductive analysis in this study was that this approach offered the potential to generate a framework of how students with ASD experience navigating in higher education. In doing so, we hoped to

gain new insights and recommendations for effective support for students with ASD in higher education.

Participants

For this study, we intentionally sampled students who were attending higher education at the time of the research, or had done so previously for at least one year. Former students were not excluded. Three additional inclusion criteria were formulated: a formal diagnosis by a multidisciplinary team of experienced clinicians; the fulfillment of the DSM-IV-TR criteria for autistic disorder, Asperger's syndrome, or PDD-NOS (APA, 2000); and no diagnosed intellectual disability. Recruitment was conducted through the Flemish user organization for ASD, two counseling services of ASD and three Disability Offices attached to 3 different higher education institutions (1 university and 2 university colleges). According to the principles of convenience sampling, every student who volunteered for the study and who met the inclusion criteria, was selected for this study. Participants were 23 young adults with ASD, 17 men and 6 women living in Flanders (Dutch-speaking part of Belgium), the majority of whom were between 18 and 25 years old and still attending university or university college (hereinafter called 'colleges') at the time of the interviews. Four of the six former students were employed, two of them in the actual area of expertise of their diploma. The sample was diverse both in terms of age of first diagnosis and field of study (Health care, Education, Business Sciences, Art and History, Politics and Sociology, Law and Criminology, Industry and Technology and Human Sciences). All students except one received or had received some form of support at their college or university.

Data Collection

In order to collect data in a standardized way and to facilitate participants to share their experiences, an interview schedule was developed for this study. An extract from the

interview schedule is presented in Appendix A. According to the aims of the study, the interview schedule focused on the topics ‘education’, ‘student life’ and ‘daily (independent) living’. The schedule also included a section on ‘transition to employment’. Each topic had an introduction explaining the purpose and focus of the topic and consisted of a series of open-ended questions and various prompts to elicit information about what challenges students with ASD faced, how they coped with these, their opinions of the support that they had received, and the possible support facilities they would recommend for the future. When participants contacted the researchers, expressed interest and met the general eligibility criteria a consent form and information sheets with details of the study were discussed with the participants, after which written consent was gained. Interviews took place at their home or in the disability office according to each participant’s preference. To maintain consistency, researcher 1 conducted all interviews using the interview schedule. Prior to each interview, participants were informed they could refuse to answer any question that made them feel uncomfortable. Each interview started with an introduction in which the researcher reminded the interviewee of the purpose of the interview and ensured the comfort level of the participant. To maintain sufficient openness for the students to speak freely about their experiences and to give them the opportunity to come up with unanticipated topics and generate new discussion, the interview schedule was handled flexibly. All interviews were recorded digitally. Interview length ranged from 26 minutes to 147 minutes (mean = 78 minutes). Interviews were transcribed verbatim after which transcripts were made anonymous and checked for accuracy. Field notes provided details and descriptions of each interview and the participant.

Analysis

Data were analyzed following the principles of Grounded Theory (Bogdan & Biklen, 1998; Corbin & Straus, 2008; Miles & Huberman, 1994; Mortelmans, 2011). In a first phase,

individual interview data were subjected to a process of open coding by two independent researchers. After a thorough first reading of the interview transcripts, the researchers read the transcripts several times carefully line-by-line, noting nodes and comments in the margins. In a second phase, researcher 2 conducted intensive analyses with NVIVO 10, a qualitative data management software program (QSR International 2012). This process of open and axial coding resulted in a first figure of themes, representing and explaining the students' experiences. Table 1 represents an abstract of the coding book, showing the frequency of each theme. In the third and last phase, individual member check interviews were conducted. Three participants, already interviewed by researcher 1, were invited by the two researchers to discuss individually the figure and the links between the themes. Based upon the information of the member check interviews, the researchers refined the figure representing the students' experiences in higher education (see Figure 1).

[Insert Table 1 about here]

Adequacy of the Research Process

We ensured rigor by incorporating procedures to address credibility, transferability and dependability (Corbin &Straus, 2008; Lincoln, 1995). For addressing credibility, we triangulated data by using trained researchers for data collection and analysis, and we conducted individual member check interviews. Transferability was enhanced both by including participants from different geographical regions of the country and different institutions of higher education, and by ensuring participants reflected a variety of characteristics (e.g., age, gender, field of study). To ensure dependability, the two researchers regularly discussed their findings in order to achieve consensus on themes, as well as to reduce inherent biases in the personal interpretation of interview transcripts.

Ethical Standards

The Ethical Committee of the faculty of Psychology and Educational Sciences of Ghent University granted ethical approval to the study. Prior to data collection, the purpose of the study and ethical issues regarding anonymity and confidentiality were discussed with the participants. Full voluntary informed consent was gained from the participants. Participants were given the right and freedom to withdraw without any reason at any time during the study.

Results

In essence, the life of a student consists of three major aspects: education, student life and daily (independent) living. As illustrated by Figure 1, in each domain four themes of challenges emerged from analysis. However, for the students, the three domains were deemed inseparable, and the challenge consisted precisely in the simultaneous combination of tasks and challenges in the three domains, resulting in major mental health issues. Students underscored the need for extra support and coaching both in the transition to higher education as in higher education itself. After analysis, six themes of support recommendations remained. Apart from challenges and support needs, however, students also reported strengths and talents that contributed to benefits in all three domains. In the subsequent sections we will describe the challenges, the benefits and the support needs discussed by the participants. Comments in italics are direct quotes from participants, for which pseudonyms were used.

[Insert Figure 1 about here]

Challenges

Challenge 1. Struggling with New Situations and Unexpected Changes

Difficulties to Oversee the Large Amount of New Information

During the transition to higher education, students experienced difficulties in overseeing the large ammount of choices, and faced challenges estimating the consequences of the choices made.

Because of my passion for history the career decision went smoothly. From the fifth year of secondary education on, I already knew that I would study history. The other choices, however, were very difficult. I had doubts about whether or not to start living independently, if and when and to whom I would disclose my autism, and which specific support I would ask for. My parents had to provide guidance regarding these decisions. (Erik, aged 27, university)

Students were frightened because they were to leave behind familiar surroundings, people and structures, and had to face many new situations.

For me, the transition to higher education was very scary at first. On the one hand I was afraid I couldn't cope with the material, on the other I was very intimidated by the social aspect and by the large group of new people. (Linda, aged 23, university)

Searching for New Structures and Routines

Students immediately searched for new structures and routines within all three life domains. However, the lack of structure and predictability in typical higher education programmes made time management and daily organization difficult. It also hindered the development of new routines and the many unexpected changes posed a major challenge.

Yesterday a lesson was cancelled. First the lesson was supposed to happen, and then it was not, and finally it was cancelled. I was really confused during the entire day. I could not cope with the change. I got a bit stuck. I tried to do something different instead, but at that moment I became so upset by the loss of structure that I could not do anything else for the rest of the

day. So that's the disadvantage in higher education. It is often last-minute. (Joyce, aged 21, university college)

Day-to-day activities required a lot of time and energy. The newer the activity and the more new activities needed to be taken into account and organized, the more students felt overwhelmed and the more their management of activities failed.

At the start there are new lessons and new people, and there is also living in student accommodation. That was quite hard for me. You're alone, you have to study and have to cook. I ate spaghetti every day, because I did not know what to buy in the store. I felt lonely, I couldn't sleep nor study, and I forgot appointments. In fact, it was actually too much. (Dorothé, aged 20, university college)

Forcibly Getting Rid of Structure

In spite of the need for structure and predictability, students pushed themselves to get rid of structure instead. They 'trained' themselves to cope with unexpected things and live with less planning in order to handle unexpected occurrences better and make it further in life.

Dealing with structures is a struggle. On the one hand you have a need for them, but on the other it is important not to give in to that need for structure. Otherwise, you risk not to trying out any new things. Consequently, 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. During my studies, I participated in the international Erasmus exchange programme. I was in fact really frightened to go. In retrospect, I am glad that I did it, because it prevents you from getting stuck in a rut intellectually, and because you meet new people from different countries and push your own limits. If you don't push yourself many times, you are in danger of never trying new things and you might not make any progress in life. (Linda, aged 23, university)

Worries about the Transition to Employment

When starting higher education, students already worried about the next transition. They doubted if and how it would be possible to instantly create a new structure and routine at their future workplace. They were convinced that difficulties in understanding the social rules and expectations would result in problems.

I think starting working later on could be a problem. I have always lived in a structure that was provided for me by others: infant school, elementary and secondary school, even in higher education. But after graduation, what will happen then? There will be no such structure. At that point everything will be new then, and open. I will have to organize my own life. That really frightens me. I could try to excel now and be a high performer at university. But once I will have finished my education, I fear that I will not know how to organize my life, and will end up with the beggars in the railway station. (David, aged 19, university)

Challenge 2. Exhausting but Necessary Social Contacts

Striving Hard to Fit in

Students expressed a clear need for friendships and relationships. They realized how important having a social network is in order to feel a sense of belonging and they were striving hard to 'fit in'. By observing and analyzing social interactions and situations, they developed an array of scripts that enabled them to react adequately in various situations, especially on campus.

People with ASD definitely have a need for social contact. The problem is that, at a very fundamental level, we do not know how to achieve this. I just keep thinking how to react in social situations. I taught myself the art of small talk: you see other people, you read books, you watch movies. You just look at what people do in a situation, and you adopt it, you act in

the same way. But it was not really 'me'. In the beginning I felt as if I was just "doing anything". But after some time it became a thing of my own. (Leon, aged 23, university)

Conversations with fellow students generally proceeded more smoothly than in high school thanks to shared interests in the field of study. In that respect, higher education was a relief.

During the first lecture on mathematics that I attended, I sat there my mouth agape. I was surrounded by people just like me, who were eager to learn about the things taught in class. That was absolutely beautiful. I did not go to a lecture. I went to a playground. That was really wonderful! (Leon, aged 23, university)

Difficulties Managing Social Demands

Despite all sorts of social efforts, the inability to read social cues caused diverse problems. Students mentioned difficulties in knowing when it was appropriate to ask questions in the course, how to address professors after the course, how to know what other people expected, in initiating and sustaining conversations, etc.

You work on a project in a group to solve a problem. But besides the fact that you have to solve something, you also have to actively consider: "How am I functioning in the group?" That causes extra stress, and is yet another energy cost that you have to invest to perform well in a group project. You need to find an answer to the set problem, but you also have to make sure you are functioning in a group properly. So, yes, that is quite difficult. (Leon, aged 23, university)

Group projects and participation in activities organized by students' unions were a great issue. Nevertheless, many students forced themselves to take part in these activities, because they regarded them as opportunities to socially engage with other students.

The ordinary student life of going out and going to pubs, doing normal things with other students, is absolutely not that easy for me. My fellow students quite often ask me to go out with them, but in 90% of the cases I refuse because I'm constantly worrying about what the evening will be like. Where will these people want to go? Will it be easy for me to get in and out of that place? When I commit myself to going out - because you have to go out now and then and have a good time - worries turn out to be unjustified most of the time. Such an evening out can actually go smoothly and very spontaneously, and can really be a pleasant experience. (Rik, aged 24, university)

Students stuck carefully to their engagements and found it particularly difficult when others did not respect agreements.

Awareness of Social Problems

The awareness of their social problems, the fear of saying the wrong things and the need to recover from anxiety and the extra strains, had a negative impact on students' confidence to socially engage with others and to invest further in maintaining contact and friendships. Students did not have access to an extended social network. Social contacts were often restricted to a few interesting meetings on campus. Students felt lonely, and experienced difficulties liberating themselves from that social isolation. Online conversations via Facebook or chat programs were perceived as both easier and worthwhile.

I'm a lonely person socially. I do not meet many people. I'm lonely. Still, in my contact with people I'm quite open. I must admit that I would like to have more social contacts, but I am very uncertain. I'm not really enterprising, rather hesitant. I do not take the initiative. But if there is an offer, I accept it and want to go out. (Pol, aged 22, university college)

Challenge 3. Processing Information and Time Management in Fits and Starts

Students faced academic and daily challenges, which they attributed to a different way of processing information, problems with time management and to sensory overload.

Processing Information in Fits and Starts

My brain functions as if it were a computer network. In fact, there is one central computer within which you still have 7 or so other computers. They can be switched off, but actually they are on screen saver at that time ... If I sit in class, one computer deals with what the professor talks about, another computer watches what appears on the board, another is focused on the hum of fellow students, another on what I should write down, another computer on the sound of the lights in the auditorium, and there is also one computer that records what my neighbour is asking me or saying to me ... and the central computer which then has to process everything ... (Max, aged 20, university)

Students tended to focus on numerous little details and often needed more time for seeing or applying coherence to the information they perceived. This especially affected following courses, studying and exams, but also daily living.

Processing information happens in fits and starts. I have difficulties distinguishing between what is important and what is less important. For example, when I study for a course I find it difficult to separate essentials from side issues ... the other day, I was preparing my geology exam. I read something about a volcanic eruption. This volcanic eruption was no more than a small anecdote in the course. I investigated that eruption to find out all about it. But that was of no use whatsoever on the exam. I encounter those kinds of situations quite often. I become so focused on something that is of no importance at all. To me, at that time, that detail means the world. (Rik, aged 24, university)

Time Management in Fits and Starts

While there were students who meticulously planned everything, there were other students who could not make a time schedule and procrastinated before taking on tasks. Students felt overwhelmed by the large amount of information and demands, and lacked flexible problem solving skills. At an academic level, difficult courses were considered those that required reflective thinking, and internships or work placements those in which lot of different competences had to be integrated.

When I was working on my thesis, that was quite a project. I rushed into it head over heels, but I drowned in it very quickly because I felt completely overwhelmed by all the information I was receiving. I simply could not process all that material, I could not turn it into a viable structure. (Erik, aged 27, university)

Sensory Overload

Students also suffered from sensory overload, caused by flickering lights, the sound of typing on laptop keyboards, etc. The sensory issues also had an impact on the three domains (e.g., not eating in the cafeteria, avoiding pubs, not studying at the library, the need to sit in the front of the classroom, etc.), and caused fatigue and stress from which students needed time to recover.

For me it is especially difficult to filter stimuli when there are many people present. They simply create too much noise. There is a lot of movement so that visually, you see a lot of things happening simultaneously. As a consequence, I cannot concentrate on anything else. I cannot filter it out. It takes up all the space in my mind. During the first year of university, I could not stand classes in auditoria. I only went to a lecture once or twice if subjects were taught in a large auditorium. (Linda, aged 23, university)

Challenge 4. Doubts about Disclosure

A Resistance to Disclose

A lack of knowledge regarding ASD, an ignorance and many types of generalizations about what ASD really is, doubts concerning privacy, a lack of supportive policies and the wish to make a fresh start, were all reasons why students decided not to disclose their diagnosis to their social contacts. Especially for students who were able to hide their ASD well and who knew how to compensate for their weaknesses, it was difficult to talk about it.

I do not easily tell people that I have autism because of the reaction I usually get when I actually do. People who say: 'No, that can't be right, you don't have autism', they obviously know nothing about autism. 'Oh, you have autism, so you can fly over London and make a complete drawing of the entire city afterwards?' No, I cannot. I have no special superpowers. Not at all. No special tics either. There is no need to look for them because I don't have them. (Rik, age 24, university)

Disclosure for Support

Students only appeared to disclose their ASD when they felt that they could not cope with the stress any longer, when they felt safe or when they experienced a specific support need. Students disclosed their ASD to the Disability Office to apply for 'reasonable accommodations', but did not disclose their ASD during contact with peers and academic staffs. This was mostly due to past negative perceptions and comments, the fear of stigmatization, prejudice, rejection or negative recommendations. However, in some cases disclosure of ASD to fellow students and professors, resulted in several benefits.

It was actually a mistake of mine to have difficulties talking about it in the beginning of my university career. Especially not telling professors about it was wrong, because from the moment I disclosed my autism to my supervisor, he was able to understand me better. From that moment on he had the patience to allow me to work on my thesis in peace and quiet, at my own pace. I really recommend disclosure to people. (Erik, aged 27, university)

When I finally made up my mind to stop pretending. In that moment, such an enormous weight fell off my shoulders. Because you can finally stop being who you ought to be. Instead, you can be who you are. (Leon, aged 23, university)

Challenge 5. Mental health issues

Feeling Overwhelmed, Stressed, Anxious, Depressed, Tired and Isolated

As mentioned above, the students perceived the three domains as inseparable, and the challenge consisted precisely in the simultaneous combination of tasks and challenges in the three domains.

I experience a lot of stress. Especially in organizing everything: going to the store, going to classes, having to study and cook and also having to invest in social life. You have to organize it all by yourself. That entails a lot of stress. (Leon, aged 23, university)

Facing all these things means that you get exhausted extremely easily. This is a greatly underestimated problem. The fact that you need to recover from every little task, such as doing the dishes, is still not accepted, and certainly not if you do not present with obvious difficulties. (Linda, aged 23, university)

Students mentioned feeling overwhelmed, isolated, tired, stressed, depressed, and anxious, at the same time experiencing panic attacks and sweating.

I remember that I had a panic attack just before my first exam. I was out of control. I was afraid to enter the auditorium. I called my dad in a panic. He told me what to do. Thanks to his guidance, I took my exam. (Erik, aged 27, university)

At the moment of enrollment, I still remember how I actually broke out in a sweat attack, even though it was not exactly warm inside that room. I started sweating and sweating, it was

pouring off me. Just because of the stress, but also because of the stress release: Phew... it's not going too badly after all. (Rik, aged 24, university)

The stress, anxiety and fatigue often became so overwhelming that students genuinely worn out, causing a disturbance of balance between studies, student life and daily living. Disrupted circadian rhythm, depression and reduced self-care were no exception.

I have been through very difficult periods in my student days. When I was living in student accommodation for example, it actually took me a half semester figuring out how to behave towards other students. I was suddenly incapable of doing many things that I was able to do before I started living in a student flat. I did not know how to live anymore. How to wash, my hygiene, cooking, eating: I ate uncooked pasta and rice. Horribly distasteful! I stocked my empty plastic bottles in the closet because I was afraid to throw them in the recycling bin in the kitchen. I delayed having a shower or going to the toilet until the last moment. I did not know how to behave anymore. I had completely lost all structure. That lasted until sometime in the second semester of the first year. (Erik, aged 27, university)

Students emphasized the difficulty to separate the three domains from each other, and were well willing to participate intensively in all domains, but this was impossible related to increased burden. In order to get the three domains more under control, students clearly preferred living at home the first year, so they could become accustomed to the challenges in the two other domains before adding living challenges, and often switched to a reduced course load.

Benefits

Despite these numerous challenges, students also mentioned talents and strengths, which they correlated with their specific way of information processing, and which contributed positively to all three domains. Qualities such as a strong memory, focus

precision and an eye for detail, dedication, the ability of putting one's mind to a subject, analytical skills, and remarkable powers of observation contributed to their ability to excel in specific courses and disciplines, and to deliver work that meets high academic standards.

Apparently, I am very good with numbers and at comparing values, instantly noticing how these will evolve in a graph. I am much better at that than other in my class. My eyesight is also different from other people's. For example, I can distinguish different colours through a microscope more clearly. One time when we were studying cells in a histology seminar, I could faintly distinguish the nucleus, even though the lecturer could not. I then had to make it clear to her that I had seen the nucleus through the microscope in spite of the fact that she could not. It has its advantages and disadvantages. (Peter, aged 21, university college)

Students also mentioned qualities such as sincerity, impartiality, and the willingness to listen to others. They reported that these abilities benefitted their lives and daily living, because they were highly valued by their friends and families.

Friends often come to me to tell me their story. A lot of my friends say me that they talk to me easily because we can have an open conversation. I am free of bias, in the sense that I just honestly tell them the way things are. I do not beat around the bush, I am not unfriendly, just honest. (Rosa, aged 21, university)

Support Recommendations

Recommendation 1. A Personalized Approach

Students emphasized that support services should implement a thoroughly personalized approach, in which individualization and comprehensiveness are keywords. The voice of the student should be given a more place during the transition process and staff

should be given ample opportunity to take the personal preferences into account when setting transition goals.

I always say: 'If there are 6 million autistic people, you have 6 million different types. It is a really large tree and I represent only one tiny twig of that tree. A tiny outgrowth on a branch, a unique type.' That's what I am. Everyone has to accept this with his or her own autism. (Rik, aged 24, university)

As mentioned above, students reported a lack of insight into ASD among lecturers and student counselors and stressed out that, without a high level of knowledge, support services were unlikely to function successfully. It was suggested that an awareness program could contribute to breaking down the perceived stigma and could at the same time highlight the talents of students with ASD. The latter might prevent staff's limited perception of ASD, which was very often reported to be the case.

Recommendation 2. A Safe and Transparent Environment with Sufficient Planning and Clear Communication

Given that new situations are very unpredictable and cause uncertainty, stress and anxiety, students emphasized the necessity for institutions to provide a safe and transparent education and living environment.

Prior to participating in the new activities, we should be familiarized with the expectations of the new environments by the support staff. This can be done by providing a detailed description of the activities and codes on how to behave during these activities, conducting a tour of the campus and identifying peaceful places, seeing the residence hall, etc. (Yves, aged 19, university college)

Proactively providing planning tools, clear communication and concrete information, contributed to students' understanding of what was expected of them, and to their development of new routines. Additionally, having a contact person who was sufficiently familiar with ASD who the student could turn to with questions or at times of confusion, contributed to them feeling safe.

Recommendation 3. Academic Accommodations

To overcome academic difficulties students applied for academic accommodations or reasonable adjustments, which they found imperative for their academic success and wellbeing at university or college. The most requested and granted accommodations include additional time in written exams, extra preparation time for oral exams, a wider distribution spread of exams in time (ideally with a couple of days between every exam), having access to a separate exam room and the option of doing alternative assignments instead of group work. Students highlighted that staff and other students need to understand the diversity and complexity of ASD, and should listen to students' experiences on what is useful. Measures that work well for one student may not be appropriate for another student.

Recommendation 4. Coaching in Education, Student Life and Daily Living

Besides being granted accommodations, students experienced a need for coaching, both in the transition to, and as well as in higher education itself. Students preferred one designated person, a personal coach, to monitor and support their activities in the three domains.

The university college has a student counselor and our contact is just very personal. I can simply go to the consultation without any obligations, and she will ask how she can help. So yes, some guidance is good and necessary, rather than send an email if you have a problem. I

do not find it easy to ask for help, because I can not always explain what I need, sometimes I do not even realize I need some support. (Lieve, aged 20, university college)

Students stressed out that the coaching should focus on support with making choices (e.g., selecting a major, living in residence), enhancing study approaches, daily and vocational organization and skills, clarifying ambiguities and providing feedback on difficulties and advice.

I find large projects most difficult, for which not all tasks are defined in a concrete way. If I do not know exactly on which task I need to perform and how exactly to do this, I will easily procrastinate until the very last moment. It is difficult to turn an abstract idea or task into concrete actions in an effective way, and to know exactly what is expected. I think one of the most important things is to be given clear and specific feedback. Look, this particular aspect of your work is good. This is bad. Specific instructions from a coach are very important. (Linda, aged 23, university)

Students believed less strongly in group training (e.g., social skills training) and clearly preferred to exchange experiences with other students with ASD in a support group. They were also in favour of gaining, as well as get further insight into how the characteristics of their ASD affected their information processing. Students were well aware of their responsibilities in higher education, and were often willing to be self-directed in their decisions and learning. While a certain degree of coaching was necessary for their optimal functioning, many students also acknowledged that students with ASD will have to make compromises.

People with autism should certainly be aware that a world beyond their own exists as well. You are going to have to live together with other people. You are going to have to collaborate

with others, and they will not be able to work according to your pattern. Otherwise things will get very difficult. (Rik, aged 24, university)

Recommendation 5. Adequate Psychosocial Support

I believe it to be very important for people with autism to have access to psychological support. Because of the exhaustion, and because of the stress, this kind of support is really necessary to prevent or cope with depression. (Linda, age 23, university)

Students found this critical support with their psychiatrist or psychologist they had often been visiting for quite a long time, but some students were confronted with limitted therapist availability. Students highlighted the importance of support from their parents and family as their 'real caregivers', and often attended a college near their home to continue making use of this support.

Recommendation 6. Leisure Activities and a Sufficient Amount of Rest

The most common strategy for managing anxiety and stress for students was the escape by distraction. Students emphasized the importance to make time for leisure activities, and mentioned the importance of exploring activities others than those in their areas of strong interest.

When too many of those things keep coming at me, I really need to relax. When I start to run I have to make less of an effort here (points at head) and more there (points at heart). So, I try balancing things out again. After running, I am much calmer as well. I can think in a normal way again. I get back to a state where the craziest things are no longer milling through in my head. Instead, my mind goes back to normal. (Leon, aged 23, university)

Sufficient rest to recuperate was also recommended. All students except one embarked a full-time course when enrolling in higher education, but almost half of them switched to a

reduced course load.

I have never taken on a full examination period. I was always been able to postpone exams. In fact, each year, I had three examination periods. One in January, one in June and one in September. And they were needed. Part-time courses that now exist are necessary for students with ASD because you need your rest. (Jolanda, aged 20, university college)

Discussion

A first aim of the study was to identify challenges concerning the general college and university experience (education, student life and daily living) of students with ASD, both in transition to and in higher education itself. In line with previous research (Fleischer, 2012; Madriaga, 2010; Madriaga & Goodley 2010; Taylor, 2005) we found that students who fare in college or university face difficulties with meeting the social and academic demands placed on them and struggle with sensory overload and time management. These challenges are clearly linked to the core features of ASD (APA, 2013) and the unique cognitive style of individuals with ASD, which is characterized by weak central coherence (Happé & Frith, 2006), difficulties with theory of mind (Astington & Jenkins, 1995; Hill & Frith, 2003; Senju, 2013), and impairments of executive function (Ozonoff, Pennington, & Rogers, 1991; Hill, 1994; Rosenthal et al., 2013). The results also correspond with the general research outcomes that throughout adulthood, individuals with ASD continue to struggle with issues related to communication, social skills, repetitive behaviors, resistance to change and sensory challenges (Levy & Perry, 2011; Magiatia, Taya, & Howlin, 2014). However, their different way of processing information also gives rise to some exceptional skills and talents, such as a strong memory, focus precision and an eye for detail, dedication, the ability of putting one's mind to a subject, analytical skills, remarkable powers of observation etc. and enables

students with ASD to excel in academic courses and disciplines and to deliver very high quality work (Happé & Vital, 2009).

Students with ASD experienced doubts about disclosure (challenge four) and faced mental health issues. In line with Matthews (2009) and Tinklin and colleagues (2005), students with ASD appeared reluctant to disclose their disability to academic staff and peers, and only decided to disclose when they could not cope with the stress any longer, when they felt safe and when experiencing a specific support need. Because many students did not disclose their diagnosis, they were constantly trying hard to hide the challenges they faced, which caused stress and anxiety.

A remarkable fact is the high level of importance students attributed to the mental health issues represented in Figure 1. They spoke a lot about fatigue, loneliness, feeling overwhelmed and depressed, with stress and anxiety being the most reported symptoms. The large amount of stress for students with ASD in a university context has been described in previous research (e.g., Glennon, 2001), but is not yet examined (Pinder-Amaker, 2014). Even though we did not investigate this topic directly, our study provided a good insight into when and how students experience stress and anxiety. They predominantly attributed the stress and anxiety to each of the four challenges in each domain, and to the difficulties facing these challenges in the three domains simultaneously. Students felt overwhelmed, and stress, anxiety and fatigue often became so excessive that they experienced feeling thoroughly worn out. As such, the study confirms that the transition into higher education constitutes a vulnerable period for youth with ASD (e.g., Pinder-Amaker, 2014; Friedman et al., 2013) and corresponds with the findings that stress is related to managing the decrease in planning and routine, to handling increased academic and social demands in unfamiliar situations and to organizing own time and tasks (Glennon, 2001; Pugliese & White, 2014). Moreover, it confirms the findings of Gillott and Standen (2007), who examined anxiety and stress among

adults with ASD and found that increased levels of anxiety impede the ability to cope with everyday stressors and demands.

In line with Camarena and Sarigiani (2009) who conducted a qualitative research on the aspirations of students with ASD and their parents about post-secondary education, it is highly striking that students with ASD were more concerned about dealing with their social rather than with academic challenges. Students realized how important having a social network is in order to feel a sense of belonging. This clear need for meaningful friendships and relationships is in line with research outcome that many adults with ASD desire social contacts (Tobin, Drager, & Richardson, 2014), and confirms the suggestion that the desire for social relations increases in many young adults with ASD (McGovern & Sigman, 2005). The awareness of their social difficulties, the fear of saying the wrong things, and the need to recover from additional stressors and distress all had a negative impact on students' confidence to socially engage with others and to invest further in maintaining contacts and friendships. The scarcity of relationships led to high levels of loneliness and is in accordance with the finding that individuals with ASD develop heightened awareness of social isolation throughout adolescence and (young) adulthood (e.g., Mazurek, 2014; Tobin et al., 2014; Whitehouse, Durkin, Jaquet, & Ziatas, 2009). Our study also confirms that informal support from families, friends and acquaintances is an important factor in relieving feelings of isolation and loneliness (Tobin et al., 2014).

The second aim of the study was to identify support needs of students with ASD, both in transition to and in higher education itself. Students with ASD in higher education were willing to fit in the three domains, as well as to become self-directed in their decisions and learning. They invested a lot effort in searching for ways of dealing with the challenges themselves, but faced difficulties, especially with regard to flexible problem solving skills and determining their own boundaries. Without support they quickly "drowned". Students

recognized this risk and emphasized the need for an individualized approach; a safe and transparent environment with sufficient planning and clear communication; academic accommodations; coaching within all the three domains; psychosocial support; and a sufficient amount of rest and leisure. The six themes of recommendations (see Figure 1) fit well with the recommendations from clinicians and practitioners, found in the reviews by Adreon and Durocher (2007) and Van Bergeijk, Klin and Volkmar (2008), who recommend an individualized college plan that delineates academic modifications, independent-living skills, socialization skills and goals, vocational goals and mental health support. However, instead of training, students preferred individual coaching, as well as meeting other students with ASD to listen to their experiences and to discuss how they solve their problems. In order to gain more experiences that are free from anxiety and excessive stress, students pointed to the importance of being provided with clear information and planning well in advance. They also stressed the need for psychosocial support from professionals, as well as from their parents (as 'real caregivers') and a contact person on campus (the disability provider). Many researchers confirmed the crucial role of parents during the transition into adulthood (Chiang et al., 2012; Doren, Gau, & Lindstrom, 2012; Taylor, 2005; Smith & Anderson, 2014) and the role of a ‘point person’ on campus to whom the student could go for advice and support (Adreon & Durocher, 2007).

Recommendations for Institutions for Higher Education

As a result of this research we can formulate several recommendations for institutions for higher education. Firstly, there is a need for more extensive and effective coaching of students with ASD. The study clearly shows that the provision of reasonable accommodations and the study skills training (academic support) is insufficient, as it currently exists in (name deleted to maintain the integrity of the review process). Support must extend beyond academic interventions, and also offer transitional support, support in student life and daily

living. Secondly, students should be involved in the transition planning in order to discuss which support has proved effective for them in the past, and how that can be implemented in higher education. This can be realized by working with an individualized college plan (see Pinder-Amaker, 2014). Thirdly, students prefer individual coaching in all three domains to training programs. Given that students with ASD are at a heightened risk for academic and personal failure during the college years, it extends the recommendation that the coach meets the student regularly, supervises the challenges and activities in all three domains, both in the transition to and in higher education itself. The coach may clarify ambiguities, provide advice and feedback on difficulties, and monitor the well being of the student in order to avoid the risk of additional psychopathology. Furthermore, students highlight the need for adequate individual psychological support to overcome mental health issues. Since the entitlement to the children's service system ends in the transition to adulthood (Friedman et al., 2013; Pinder-Amaker, 2014), it is important that adequate psychological support services are available in the course of the college period. Students also point out the need for support groups where they can meet other students with ASD and where they can share experiences and discuss how they solve their problems. Finally, there is a need for a better awareness among staff and students about ASD, and the way in which it can affects navigating in college. Awareness programs could help to break the current stereotypes, stigma and misunderstanding about students with ASD. Moreover, it is both beneficial and important for an academic environment to nurture an atmosphere where students are given the opportunity to disclose to others who they are in a safe way, and encouraged to be themselves, instead of feeling the need to hide their identity.

Limitations and Future Research

Some limitations should be acknowledged when interpreting the results of this study. Firstly, although the participants in our study were taking different majors at different

universities and university colleges, lived in different geographical areas in (name deleted to maintain the integrity of the review process), and varied in age and diagnostic subcategory, a selection bias may have affected our findings. Students who participated in the interviews were those willing to attend a scheduled meeting and discuss their experiences (Morrison, Sansosti, & Hadley, 2009). The sample may have reflected those who were more actively participating in transition planning or possessed a higher level of insight regarding their ASD (Morrison et al., 2009). Most participants had a very good understanding of their ASD. Secondly, our study relied on self-report qualitative data only. Given that students with ASD experience difficulties with theory of mind and mentioned problems with reflective thinking, it would also be valuable to examine the perceptions of their parents, of their disability providers and of the informal network which supports them, in order to identify additional opinions and support needs. Given the significant role that students gave to their parents, and the fact that some studies demonstrated that parents' involvement had a positive influence in postsecondary education outcome (Chiang et al., 2012; Doren et al., 2012), it would be appropriate for future research to focus on parent's potential role in the transition to higher education. Thirdly, the use of a qualitative research only measures perceptions of the participants, and does not allow for a more direct measurement of the actual presence or absence of factors within college or university environments that are supportive or challenging (Morrison et al., 2009). Future studies should thus ideally also include standardized measures (e.g., stress and anxiety) to achieve a wider characterization of the experiences and outcome of students. Finally, future research should also focus on the development of evidence-based intervention services to moderate the impact of mental health issues, in which their impact on mental health and academic outcomes among students with ASD must be evaluated (Pinder-Amaker, 2014).

Conclusion

The current study provided a better insight into how students with ASD fare in higher education, and has added valuable information to the growing body of literature on students' perspectives on challenges and effective support in higher education for students with ASD. The main strength of the study is that we systematically examined first-person accounts on the holistic college and university experience. This wide perspective clarifies the ways in which students correlate the various challenges and which aspects they find meaningful and supportive to include in their support plan in order to moderate the impact of challenges and mental health issues. The wide perspective also provided insight into the strengths and talents of students with ASD due to a different way of processing information. These abilities were shown to contribute to benefits in the three domains. In addition to this clinical value, the study has an educational and a social value as well. The experiences of students significantly enhance our understanding of what it means to study with ASD. This can now be passed on to academic staff, counselors and the students' wider networks. If these partners take into account the unique and individual needs and strengths of a student with ASD and offer appropriate support and accommodations in education, student life and daily living, young adults with ASD will potentially show higher retention and an enhanced quality of life. Taking into account the recommendations of students with ASD, will not only benefit other students with ASD, but can also contribute to a better, more accessible and inclusive education.

Conflict of interest

The authors declare that they have no conflict of interest.

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Figure Captions

Fig. 1 Higher education experiences of students with ASD

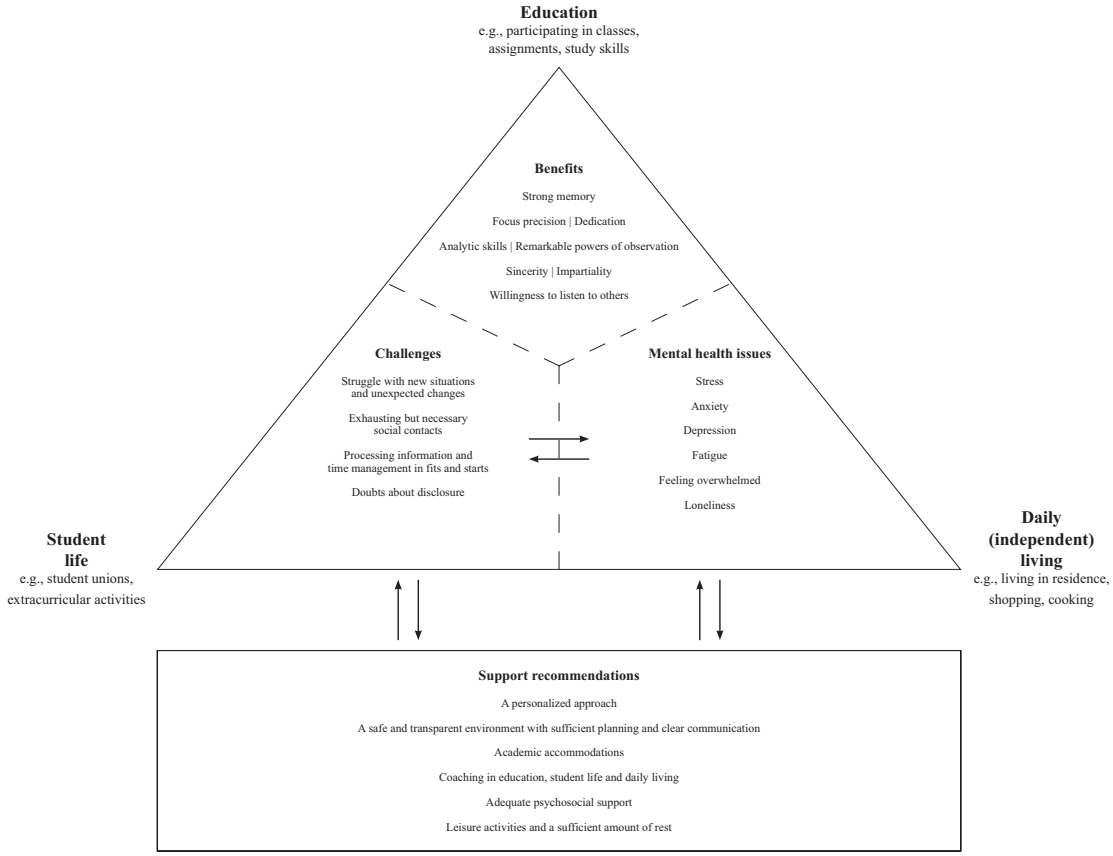


Fig. 1 Higher education experiences of students with ASD

Table Captions

Table 1 Frequency of themes and subthemes

Table 1 Frequency of themes and subthemes

Themes	Subthemes	Frequency
Struggling with new situations and unexpected changes		22
	Difficulties to oversee the large amount of new information	22
	Searching for new structures and routines	20
	Forcibly getting rid of structure	19
	Worries about transition to employment	20
Exhausting but necessary social contacts		21
	Striving hard to fit in	19
	Difficulties managing social demands	21
	Awareness of social problems	18
Processing information and time management in fits and starts		22
	Processing information in fits and starts	22
	Time management in fits and starts	20
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Appendix Captures

Appendix A Extract interview schedule

INTRODUCTION

The purpose of this interview is to gain a better understanding of college experiences of students with ASD, both academically and socially. We are interested in your experiences, in the challenges you have faced or still face and in factors that contributed to success in the domains of education, student life, daily living and the transition to work. Before we discuss your experiences and your recommendations, we are interested to get to know you better. We first will talk about your interests and hobbies, what you do for studies/work.

Open-ended questions
What are your interests and hobbies? What are your talents? What major classes do you take? Do you have a favorite class? What job would you like to do in the future?

Prompts
E.g., What are you really good at? Do you spend a lot of time on these interests? What are your dislikes? Are you satisfied with your choice of university major?

SECTION. EDUCATION

Introduction
The transition from secondary to higher education brings along many changes. We will first focus on 'education', participating in classes, exams, studying, etc. We would like to hear how the transition to postsecondary education was, which things went well, what your concerns were, which challenges or difficulties arose, and how you overcame specific difficulties. We would also like to know if you looked for support, and what your experiences were in this regard. We are also interested in your recommendations.

Open-ended questions
What are your experiences of participating in classes, completing assignments, studying, exams, etc.? Which challenges do you encounter? How difficult is it to manage these challenges? Have you asked your institution for support or help? Which support is effective for you? Are there particular support measures that are more effective for you? In which way are staff members helpful to you? Are there particular types of academic support that you wish you had received? Tell me about your support recommendations.

Prompts
E.g., What are your academic strengths/weaknesses? What are the greatest challenges for you? Do you think your ASD has an important impact? Are any of the challenges that you face related to misunderstandings about ASD? What are the procedures in your institution to apply for support? Is it easy to ask for assistance? Have you told the academic staff about your ASD? If so, what are their reactions? Do they have an accurate perception of ASD? Are they helpful to you? How did you choose the institution you are currently attending? What factors were crucial for your decision?

SECTION STUDENT LIFE

Introduction
In higher education, a large amount of new student activities on and outside the campus are organized, e.g., activities run by student clubs, international exchanges, etc. We would like to know if you participate in these activities, which aspects are going well, which challenges or difficulties arise, and how you overcome these. We also like to know if you have looked for support, and what your experiences have been in this regard. We are also interested to hear your support recommendations.

Open-ended questions
Are you involved in any club or any other social activities? Do you meet any of your fellow students outside the campus? Are you experiencing specific difficulties? Have you asked for support or help? What/who are important people/services/ that support you in student life? Which are the things that your college might offer to support students with ASD that would benefit certain aspects of student life? Tell me about your recommendations.

Prompts
E.g., What activities do you enjoy outside of school? How often do you participate in these activities? Do you have many social contacts? How is your contact with others? Do you find it easy to make friends? How important are your relationships? What do you experience as really challenging in student life? What are the greatest challenges? How difficult is it to manage these challenges? Do you think your ASD has an important impact on student life? Have you told your fellow students about your ASD? What are their reactions? Do they have an accurate perception of ASD? Are there students who are particularly helpful? How are they helpful to you? What are your social strengths/weaknesses? Are there particular support services that are more supportive for you? Are there any particular support measures that you wish you had received?

SECTION DAILY (INDEPENDENT) LIVING

Introduction
For many students, the transition to higher education also involves a change to independent living. In this topic are interested to find out more about your experiences related to daily (independent) living. We would like to know if you live independently, which aspects are going well, the types of challenges or difficulties that arise, and how you overcome specific difficulties. We would like to hear whether if you have looked for support, and what your experiences are in this respect. We would also like to know your support recommendations.

Open-ended questions
What is your daily living situation? Are you living independently? Which tasks do you take care of? Which tasks or situations do you find rather challenging? Which/who are important people/services/ that support you in your daily (independent) living? Which are issues that are really important for students with ASD? What are the general recommendations for services that regulate housing? What are your recommendations?

Prompts
E.g., Which factors have had an important impact on your decision to live in residence? How did you choose your housing? Which are the greatest challenges that you are faced with? Do you think your ASD has an important impact on daily living? How difficult is it to manage these challenges? Have you told your roommates about your ASD? How did they react? Do they have an accurate perception on ASD? Are there roommates who are particularly helpful or supportive? In what way are they helpful to you? Are there any particular support measures that you wish you had received?

SECTION TRANSITION TO EMPLOYMENT

Introduction
The transition to employment is another big step. In this theme we would like to hear about your aspirations or experiences regarding this transition. We would like to know which challenges or difficulties (could) arise, and how you overcome specific difficulties. We are also interested if you have looked for support, and what your experiences are in this respect. We also wish to hear your support recommendations.

Open-ended questions
What are your career aspirations? How did you experience the transition from college/university to employment? Have you asked for support? What are the issues for employers and colleagues? What are recommendations for the employers and colleagues?

Prompts
E.g., What type of employment would you like to have in the future? Do you plan to ask for support there? What are the greatest challenges? How difficult is it to manage these challenges? Do you think your ASD has an important impact on your work? Have you told your colleagues about your ASD? What are their reactions? Do they have an accurate perception of ASD? Are there colleagues who are particularly helpful or supportive? In which way are they helpful to you? Have there been situations in which they have not been helpful to you? Are their particular support measures that you wish you had received?

CONLUSION

Is there anything else that you would like to share with me about your college or university experience?