STUDEREN MET ASS IN HET HOGER ONDERWIJS:

OMGAAN MET DE UITDAGINGEN

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door MARTINE IJPEMA

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STUDYING WITH ASD IN HIGHER EDUCATION:

RISE TO THE CHALLENGE

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by MARTINE IJPEMA

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“There is autism and the person underneath it. Together that makes one person and it’s behaviour. Not the autism, not its personality, but the combination of the two.”

Ben (21), student
ABSTRACT

Recent studies show an increase of students with Autism Spectrum Disorder (ASD) in higher education. Even though the number of students with ASD in higher education increases, students with ASD have significantly lower chances of graduating from higher education compared to students without ASD. This implies that there is a growing need for better support for students with ASD in higher education. In this study we explored the difficulties students with ASD experience in higher education and what can improve the quality of life of these students in (transition to) higher education. To answer this main issue, we selected the following three research questions: (1) which difficulties in communication do students with ASD experience? (2) which difficulties in processing information do students with ASD experience? (3) which difficulties in structuring their lives do students with ASD experience? We ran a qualitative study according to the principles of the Grounded Theory. We held both focus groups with student coaches (n = 4), with student support services (n = 5) and with parents (n = 2) and semi-structured in-depth interviews with students with ASD (n = 10). Recommendations for guidance of students with ASD in (transition to) higher education are discussed.

INTRODUCTION

Recent studies show an increasing number of students with Autism Spectrum Disorder (ASD) in higher education (Roberts, 2010; VanBergeijk, Klin & Volkmar, 2008; Annual Report Student Services KU Leuven, 2010). About 1% of the population has ASD (Baron-Cohen et al., 2009; Kogan et al., 2009). Prevalence of students with ASD in higher education is very variable. Of all the students with ASD, about 34% enters high education according to Shattuck and colleagues (2012). Chiang et al. (2012) estimated this amount around 40%.

Even though the number of students with ASD in higher education increases, students with ASD have significantly lower chances of graduating from higher education compared to students without ASD (Howlin, Alcock, & Burkin, 2005). Individuals with ASD cope with
problems in social communication and show repetitive and stereotype behaviours and/or interests (American Psychiatric Association, 2013).

Although certain symptoms of ASD can become apparent at a later age, when the social demands and expectations are higher (Worley, 2012), most studies on ASD still involve children. There are fewer studies available concerning the specific needs of young adults with ASD or higher education students with ASD (Adreon & Durocher, 2007; Taylor, 2009).

Higher education demands more independency, which relates to a different way of studying than during high school. Many students experience this as very instructive, but it comes with extra problems for students with ASD. Independency asks for planning and organisation skills, self-regulation strategies, metacognition and advanced social and communicative skills. Without extra guidance, this could lead to problems for students with ASD. Many young adults with ASD are intellectually capable to participate in higher education but they seem to get stuck once they are in (van Bergeijk, Klin, & Volkmar, 2008). Where students with ASD in high school often receive guidance (mostly founded from a personal budget), students in college have to take care of their own, while their difficulties do not disappear with the transition from high school to college (Boswijk, Breetveld, & Mensink, 2007).

Boswijk, Breetveld and Mensink (2007) reported difficulties with planning, organising, co-operating with other students and distinguishing main issues from side issues in a group of higher education students with ASD. According to Roberts (2010) higher education students with ASD prefer studying and working individually. A substantial number of students report difficulties with group work. Van Bergeijk, Klin and Volkmar (2008) argued that students with ASD experience difficulties in study and curriculum planning. Roberts (2010) confirmed the planning problems students with ASD encounter. According to her, this corresponds to the fact that students with ASD lack self-regulation and metacognitive knowledge about their learning strategies. Furthermore, selecting efficient solution strategies is difficult for students with ASD (Bramham et al., 2009). According to van Hees, Moyson & Roeyers (2015), lack of time management and daily organization hinders the development of new routines and unexpected
changes pose a major challenge for students with ASD. Students with ASD also suffer from sensory overload (flickering lights, sound of typing on laptop keyboards, etc.) and experience mental health issues (van Hees et al., 2015). Adreon and Durocher (2007) found that students with ASD have difficulties understanding non-verbal communication (like eye contact, gestures, body language) and have difficulties understanding subtle social cues and keeping to common social rules. Furthermore, students with ASD prefer to process information in parts and fail to see the coherence between the different elements (Evers et al., 2014).

Students with ASD are in need for extra support in higher education. By providing students with ASD with guidance educational failure and social marginalization can be prevented. Otherwise, much potential stays unused. Van Bergeijk and colleagues (2008) noted that students with ASD can, academically and socially, complete their study positively with a carefully planned transition and adjusted educational facilities. Chiang et al. (2012) proved that these adjustments have positive long-term-effects for students with ASD. They showed that a successful transition from high school to higher education leads to better employment and affects positively their quality of life.

In this study we explored the difficulties students with ASD experience in higher education and what can improve the quality of life of these students in (transition to) higher education. To answer this main issue, we selected the following three research questions: (1) which difficulties in communication do students with ASD experience? (2) which difficulties in processing information do students with ASD experience? (3) which difficulties in structuring their lives do students with ASD experience? With the answers to these three questions, we can formulate recommendations to support students with ASD in (transition to) higher education.

**METHOD**

We ran a qualitative study according to the principles of the Grounded Theory (Glaser & Strauss, 1967). Not only students with ASD but also parents, student coaches and student services were involved. We focused on the transition from high school to higher
education. We held both focus groups and in-depth interviews. Focus groups were organized to stimulate, a debate between the participants. The information generated in the focus groups was used to create a semi-structured in-depth interview, which was administered only from the students with ASD. This study was part of a larger project about ASD in higher education (Tops, Noens, & Baeyens, 2014) and approved by the local Ethics Committee. Participation was on a voluntary basis. Permission to use a voice recorder and the results of the study was asked by means of an informed consent. All participants gave informed consent. Anonymity of the participants was ensured using false names.

**Focus groups**

**Participants**

We organised three focus groups: (1) with student coaches (n = 4), (2) with student support services (n = 5) and (3) with parents (n = 2). Three individuals participated in more than one focus group, being both a parent of a child with ASD and a student coach or an employee of a student support service. Participants in the focus groups were chosen by means of a judgement sample. All were required to have large experience with the guidance of normally gifted young adults with ASD in (transition to) higher education.

The first author of the project was present as discussion leader in all focus groups accompanied by two bachelor students in Applied Psychology. All had experience with or were trained in qualitative research.

**Instrument**

Focus groups were organised around a list of themes, which were selected after a thorough literature research (including Academic Search Premier (EBSCO), PsychInfo, ScienceDirect and Web of Knowledge). Following search terms were used: ‘ASD’ OR ‘autism’ OR ‘autistic’ AND ‘(higher) education’ OR ‘school’ AND ‘transition’. Available studies were first selected by publication date and scientific value. Further selection was based on relevance of titles and abstract. Withheld themes concluded specific features of ASD, strengths and weaknesses of students with ASD and difficulties in school for people with ASD.
Procedure

The first author led the focus group, starting with a brief presentation of the project and the research goals of the study. Each focus group lasted for about one and a half hour and was recorded by a camcorder.

Analysis

Conversations were transcribed and decoded verbatim by two bachelor students in Applied Psychology, who were also present during the focus group. Statements of the participants of the focus groups were labelled and categorized within each theme. Possible relations between the labels and categories were noted and sorted. This resulted in a large collection of themes and subthemes about the possible difficulties of students with ASD in higher education (table 1).

**Table 1. Collection of themes and subthemes after the focus groups were held**

<table>
<thead>
<tr>
<th>Communication</th>
<th>Information processing</th>
<th>Structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group assignments</td>
<td>Focus on details</td>
<td>Time management</td>
</tr>
<tr>
<td>Interpreting language</td>
<td>Distractions</td>
<td>Routines</td>
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<td>Presenting in front of class</td>
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<td>Changes</td>
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<td>Traffic</td>
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<td><strong>Blackboard</strong></td>
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<td></td>
<td><strong>Coping &amp; guidance</strong></td>
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**bold** = main themes, **non-bold** = subthemes within the main themes

Semi-structured in-depth interviews

Participants

The participants of the interviews (n = 10, 7 men) were also chosen by means of a judgement sample. All participants had a formal diagnosis of ASD, according to the criteria valid
at that time, reconfirmed by an independent child psychiatrist. The age of first definite diagnosis varied considerably. All participants were between the ages of 18 and 25 years (mean 21.25 years). The students with ASD were asked to talk about their experience concerning (transition to) higher education with ASD. There was no relevance in having a control group in this study, since experiences cannot be compared to each other.

Instrument

Themes and subthemes from the focus groups were used to prepare a semi-structured interview. Questions were formulated as concrete as possible. Afterwards, formulations and clarity of the interview were checked by two higher education students with ASD, who did not participate in this study.

Questions concerned diagnosis of ASD (when, guidance, self-perception, comorbidity), information about the family (heredity), data from primary school, high school and higher education (school career, possible difficulties, reactions of the teachers and other students on ASD, guidance), experiences in higher education (way of studying, planning, guidance, difficulties) and self-perception on the diagnosis of ASD.

Because of the structure of the interview, a certain degree of standardization was present in the interview. On the other hand, there was room for elaboration on the personal experiences of the student. Talking about several topics at the same time was considered no problem, provided that the interviewer was able to understand the material. In this way, the interviews were allowed to take a natural course.

Procedure

Participants received the interview schedule on beforehand, so they could prepare themselves and to avoid stress overload on the moment of the interview. They were instructed explicitly to not prepare for more than one hour and to not think ahead of answers on all the questions. The interview itself took place in a quiet, low-stimulus room. Statements of the students with ASD were sometimes expanded. As a result, not all questions were asked to all students.
Every interview lasted between 45 to 120 minutes and was audio-recorded. Information gathered through the interviews was brought together with the earlier gathered information from the focus groups and processed in the results.

Analysis

The interviews were transcribed verbatim and analysed according to the principles of the Grounded Theory (Glaser & Strauss, 1967). Statements of the students with ASD were labelled, categorized and compared. Possible relations between the labels and categories were noted and sorted. This resulted in a large collection of information about the experiences of students with ASD in higher education.

RESULTS

Different topics were discussed during the focus groups and the semi-structured in-depth interviews, concerning the challenges for students with ASD in (transition to) higher education. Direct quotes from participants were outlined in boxes.

Social communication problems

A core symptom of autism is problems with social communication (APA, 2013). Students with ASD as well as experts in the focus groups mentioned social communication problems as one of the main problems of students with ASD in higher education. Group assignments and collaborations with peer students were problematic for the students with ASD. Students with ASD mentioned difficulties in social contacts and communication with the other group members. Moreover some of the ASD students preferred to keep control over the group assignment and had difficulties to relinquish parts of the assignment to other group members beside themselves.

"Communication with the group was bad. And they thought of me as the worst. That I was a lazy person and that I let them do all the work."
Ben (21), student
Students with ASD often encountered misunderstandings or wrongly interpreted intentions of others. This could lead to a behaviour which was seen as odd by others.

“I often do not see the difference in teasing and bullying.”
Steven (25), student

It always takes a while to understand people. I often see what they mean, but it takes a while to process and respond correctly.
Ben (21), student

Presenting before a group also left many students with ASD in distress, especially when they were asked to have interaction with the group. Students with ASD often did not understand the intentions of some members of the group. Having interaction with other members of the group led to unpredictability for the students with ASD. This unpredictability made the students with ASD anxious and left them in distress.

Some of the questioned students with ASD had to deal with a lot of stress, because they lacked social communication skills. This stress led to procrastination and flight behaviour. The students with ASD started to avoid interaction with other people, did not finish their group assessments and returned to their trusted fixed patterns. This led to even more social isolation.

Information processing

Students with ASD tend to focus on details when studying. They often fail to see the coherence between the information they get. This hinders them in following courses, in studying and in taking exams, but also in daily life.
“When, for example, we got an assignment or question. I thought about it in a very complicated way, while the answer only had to be one simple sentence."
Ben (21), student

“And I wanted to know all the details. It was difficult to separate the main issue from the side issues.”
Steven (25), student

“When I have a word I don’t understand, I will analyse it in every possible way to recognize a word that I do know.”
Tom (19), student

Students with ASD are easily distracted. Instead of paying attention to the information given, the students with ASD pay attention to other things that interest or annoy them in the classroom.

“Because in a big classroom you’re so far away from the teacher and you think ‘why should I listen, while I can build a whole paradise on this desk, which is way too small by the way’.”
Tom (19), student

Problems with structure

People with ASD are comfortable with structure in their lives, as are students with ASD. This was also one of the main issues that the students with ASD and the experts in the focus groups discussed. Lack of structure and predictability in higher education made time management and daily routines difficult. Especially time management was a returning topic in the interviews and focus groups.

“They don’t know when to start an assignment. To them, two weeks seems like forever and that’s why they don’t start.”
Peter, student coach

“I cannot make myself a planning. Or I forget it and then I have to do it in the last second. Then I can’t oversee it anymore.”
Bart (20), student

Not only planning and time management are important, but the focus group experts also stated that students with ASD often did not know what to do with their intermediate hours.

“I know a student with ASD who sits on a bench in the hallway when he has a free hour. He just sits and waits there until his schedule says he has class again.”
Peter, pedagogue
Unexpected changes posed a major challenge for the students with ASD. A returning topic here was predictability. Higher education asks for more independency, but for the students with ASD that means leaving behind their familiar people and structures. They get into, for them, completely new situations. The students with ASD tried new structures. Many of these new structures depended on the school’s time table. But the unpredictability of higher education led to new anxiety and stress.

“When they come to class and the teacher appears to be ill, they have a hard time coping with it. Those are big dilemma’s. It also causes problems when the lesson has changed to another day or will start a bit later.”
Sarah, student coach

“It suddenly comes at you, indeed. You have to switch to something new so quickly and that causes a lot of anxiety.”
Ben (21), student

“The students with ASD mainly think of the ‘here and now’. As soon as it turns to ‘if-then’, it’s difficult for them. They have to think ‘if this happens, what will be the consequence?’, but they can’t.”
Peter, student coach

Getting through traffic is another important stressor for students with ASD. An overload of sensory stimuli is the cause of this stress.

“I’d rather take the bike. Because with a bike you’re on your own. You leave when you leave and when it takes ten minutes to arrive, it will also take you ten minutes to arrive. When you take the bus, you have to leave early because you have to wait for it to come, the bus could be delayed or the bus drives too slow, oh well…”
Bart (20), student

Self-acceptance

An important topic that was discussed in the focus groups and by the students with ASD was self-acceptance. Some students with ASD accept who they are and have learned to live with ASD.

“I just wanted to deal with it. I was kind of tired of it. I just wanted to move on in life.”
Ben (21), student
But others are afraid to tell other people about their ASD or even deny they have ASD. Participants in the focus groups noted that student coaches often feel something is wrong, but they cannot help until the student with ASD comes to them and tells them. Sometimes students with ASD express no need for guidance, because they do not want to tell more people about their ASD. The participants of the focus groups also mentioned that students with ASD do not want to tell anyone, because they do not want to be different. They do not want their friends to know and they do not want special support, because they do not want to stand out.

"Nobody knew. Looking back now, that was not good. I should’ve told people way earlier. Maybe I was afraid to be treated differently or to be seen differently. I don’t know.”

Bart (20), student

**Blackboard**

Experts in the focus group mentioned Blackboard as a major challenge for students with ASD. The digital network is hard to work with. All the information shows up on the Blackboard and despite the fact that the students with ASD learn to work with it in high school, they have many difficulties understanding it. The problems were not caused by the technical aspects of the Blackboards, rather by the amount of information they contain. A lot of information appears at the same time on the same page and students with ASD had a lot of difficulties finding the relevant information. The experts in the focus group guided several students with ASD who could not cope with the information on Blackboard. It could take hours for the students to find what they needed. Focussing on the details is one of the reasons why Blackboard does not work for students with ASD. As soon as the internet opens, students with ASD find it hard to not get distracted. Also, Blackboards are confusing. Too much information is provided at the same page (notes, Powerpoint presentations, schedule changes, etc.) and so students with ASD get lost.

*Coping and guidance*

To get where they are now, these students with ASD had some ways to cope with their problems caused by ASD.
“Fantasy mainly. I try to canalise it through writing books. And when I’m home alone I spend a lot of hours gaming and on Facebook and stuff like that.”
Tom (19), student

“So she had a couple of lists in different situations. Lists of how to cope with situations, how to feel safe and how to get along with others. She could compensate enough to do her job effectively.”
Hilde, teacher

Having the possibility to receive guidance in higher education is an important aspect of coping with the problems the students experience.

“In high school I got a student coach. That helped me a lot. Because else I would not have been who I am now. I would be a bigger autistic person than I am now. Just by seeing what autism actually is. And also that it is part of me. To give autism a place in my life.”
Tom (19), student

Experts in the focus groups mentioned they often did not know enough about the different types of autism that exist and thus about the different kinds of challenges students with ASD face. They often found it difficult to guide the students with ASD.

Despite the many challenges students with ASD face, they also mentioned strengths. A strong memory, eye for detail, dedication and analytical skills brought the students with ASD to where they are now and contributed positively to specific courses.

Support Needs

Academic Accommodations

To overcome academic difficulties, students with ASD express a need for accommodations in higher education. Students with ASD gave following suggestions: smaller classrooms, explanation about the exam questions (to avoid misinterpretation), extra time during exams and/or oral explanation afterwards and alternative individual assignments instead of group assignments. Another returning topic is finding the way in the schools. Being in time and knowing where to go leaves students with ASD often in distress.
Individualized Approach

Besides being granted accommodations and structure, students expressed a need for coaching. Student coaches already exist, but students with ASD mostly get help from them for no longer than two years. For some students with ASD two years is not enough to deal with the challenges they are facing in higher education. Having a coach for a longer period than two years is one of the wishes the students with ASD expressed. Having a coach or maybe even a classmate as personal guide gives the students with ASD the opportunity to imitate.

“I feel that he can compensate a lot because he is imitating us. The rest of the family, his friends and others.”
Kim, parent

Coaching does not only involve student coaches at the school. Cooperation with teachers and parents is of great importance. The students with ASD expressed a need for an individual approach.

Planning

Students with ASD mentioned it is important for them to have someone to help them with their planning and their time management. Experts in the focus groups agreed with this expressed need.

“Mainly organisation, I think. In high school it’s clear you’re in class from 08.30am through 4pm and you have a schedule for the whole week. I think that’s where it often goes wrong in higher education.”
Kim, parent

Information about the transition to higher education

Presenting the students with ASD with information about higher education in high school is a need expressed by the students themselves. Higher education is often a big question mark for them. They do not know what to expect, how it works and many things depend on the school’s size. Helping the students choosing the right education and choosing the right (amount
of) courses gives them the possibility to prepare for it. And that could prevent many moments of stress later on in higher education.

**DISCUSSION**

In this study we wanted to explore the difficulties students with ASD experience in higher education and what could possibly improve the quality of life of these students during this phase of their lives. We dealt with three research questions. The first question concerned difficulties in communication for students with ASD. In line with Adreon and Durocher (2007), we found that students with ASD have difficulties understanding non-verbal communication (like eye contact, gestures, body language) and have difficulties understanding subtle social cues and keeping to common social rules. Because of these difficulties, students with ASD experience a lot of stress when it comes to group assignments or presentations.

The second question concerned difficulties in information processing. In line with Evers and colleagues (2014), we found that people with ASD prefer to process information in detail and fail to see the coherence between the different elements. Because they process information in a different way than higher education expects them to, students with ASD experience a lot of stress.

The third question concerned difficulties in structuring their lives. Unexpected changes posed a major challenge for the students with ASD. This is in line with van Hees and colleagues (2015). The students with ASD live in the ‘here and now’ and have difficulties understanding the consequences of the ‘if-then’ situation. Students with ASD experience a lot of stress trying to be flexible in their thoughts and behaviour.

A remarkable note during this research: most challenges that were mentioned by the focus group experts were the bigger challenges of ASD. They were worried about the big transition to higher education or higher education itself. On the contrary, students with ASD experienced the ‘smaller’ things as most stressful. Things like cooking dinner, getting dressed in
the morning, getting through traffic or having too many distractions are the things that bothered
them most and which caused a lot of stress.

Through the interviews and focus groups we found out that students with ASD have
problems in the areas of social communication, processing information, structure and self-
acceptance. These problems can cause a lot of stress for the students with ASD. Stress has an
influence on their behaviour. Because of the stress and anxiety that students with ASD
experience in higher education, they try to avoid the things that cause this stress. The new
challenges, finding a new structure, meeting new people or finding new study strategies are
things that they will be avoiding. They try to cope with it by gaming a lot, spending time on their
areas of interest, or just ignore it. This causes them to drop out of higher education, either
because of the stress or the bad grades. And because there is limited coaching of these students
at the moment, they do not get the guidance they need to learn to cope with the challenges in a
positive way (e.g. not avoid them but solve them). This drop out has a negative influence on the
students' capabilities, increasing the stress they experience and that makes the circle vicious
(Fig. 1). This vicious circle needs to be broken to help students with ASD complete higher
education in a positive way.

![Figure 1. Vicious circle of students with ASD](image)

Recommendations to the guidance of students with ASD
A vicious circle develops because of the stress students with ASD experience. Students with ASD and experts in the focus group expressed support needs to break this vicious circle. They expressed a need for academic accommodations, an individualized approach, more coaching and more help in planning and structuring their life.

Academic accommodations include smaller classrooms, extra time during exams and/or oral explanation afterwards, explanation about exam questions (to avoid misinterpretations) and alternative individual assignments instead of group assignments. An adjustment to the Blackboards would also be an recommendation. Having one personalized page for the students with ASD would give them just the information they need without searching and getting lost. The personalized approach could include an awareness program for teachers, coaches and other people involved in the guidance of students with ASD. Enhancing study approaches together is an important recommendation to overcome planning difficulties.

Another important need expressed by students with ASD as well as the experts in the focus group is the need for more information about the transition to higher education and higher education itself. The students with ASD often do not know what to expect, how it works and many things depend on the school’s size. The students with ASD should be involved in planning the transition to higher education, in order to explain which support is effective for them. Helping them to make choices in education and in the (amount of) courses they take will reduce stress for them. This task asks for a coach who is well informed about ASD and its different challenges and also about the courses that exist.

The support for students with ASD must extend beyond academic interventions. It must be clear that the support is also needed in student life and daily living.

Limitations

Some limitations of this study should be acknowledged. We investigated a small group of students with ASD. The challenges they face seem to be in line with the literature, but we cannot be sure if these students mentioned all the challenges students with ASD face. To find out more
about the difficulties students with ASD face, we recommend to investigate a larger population of students with ASD. Also, the challenges these students face are individual. Every person with ASD is different and advices given should always be given to fit the one person you’re helping. The recommendations made above are not mandatory. Furthermore, we investigated a group of students with ASD who were willing to cooperate in this research. These students are probably already capable to live with the challenges they face and can compensate during moments of stress. To reach a group of students with ASD who are experiencing extreme stress is very hard, because these students will probably reject the idea of participating in a research. So there is a bias in our selection of students with ASD. Also, we got personalized experiences from the students and from the experts in the focus groups. It would be best to also follow a more standardized measure, for example for stress and anxiety.

Conclusion

This study contributed to the insight in difficulties students with ASD face in transition to or in higher education and has added information to the existing literature. The difficulties students with ASD face will always be personal, even though some recommendations can be applied to students with ASD in general. The recommendations made in this study are not mandatory, but will help the people in higher education to understand and coach each student with ASD in a better way.

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