

Alienation and struggle: everyday student-life of three male students with Asperger Syndrome

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This article analyses how three students with Asperger Syndrome (AS) involved in higher education, in Sweden, perceive their everyday life as a student. The aim of the study was to describe the kind of support offered within a freedom of choice system to determine whether the support given by the university acts as a facilitator or as a barrier. The approach is a case study methodology. Nine interviews, three for each student, are analysed as narratives, based on units of meaning and categories. Two main themes emerged from the analysis: (1) The feeling of Alienation is characterized by the students' perceptions of being outsiders and having to deal with everyday student-life issues instead of engaging in their studies; (2) Struggle – the paradox of handling the feelings of belonging to a community and gaining confidence in being 'odd', but acknowledged. Conclusion: freedom of choice demanding logical reasoning can become a burden for students with AS and support given by the universities is sometimes perceived more as a barrier than as a facilitator.

Keywords: alienation; stigma; struggle; support; freedom of choice; higher education; Asperger Syndrome

Introduction

The main purpose of this case study is to describe the personal experiences of students with Asperger Syndrome (AS) in relation to conditions of offered support. AS is a diagnosis within the Autism Spectrum Disorder. AS is constituted in many ways, but there are three typical hallmarks for all persons with AS: difficulties with social interaction, difficulties with communication, and the fact that they have special interests that they are very engaged in, often at cost of managing daily life (Frith 1991; Lovett 2005).

At university in Sweden, the number of students with disability has increased in the last decade (Bjornsdottir and Svendsdottir 2008; Danermark, Antonson, and Lundström 2001; Konur 2006). Based on the number of students with disabilities that has been in contact with a coordinator, there are 955 students with cognitive difficulties, 330 students with other disabilities and 1475 other (Svalfors 2010). Whereas no one actually knows the proportion of the student population in universities that have AS, prevalence data estimate that 0.3–0.4 of the general

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population have AS (Kindwall 2010). Thus, based on the number of persons entering the university the number of persons with AS could be estimated to be around 3000 to 4000.

The Swedish Code of Status (SFS 2001:1286) includes a law of equal treatment to protect students against discrimination and stipulates equal rights to all students. Each university is required to have a coordinator offering students with disabilities individual consultations and discussions of needs of educational support. Universities must prepare annual plans that outline the actions that are needed to provide students with equal rights. In this plan it should be made clear how support for students with disabilities will be organized and who is responsible (Handikappsombudsmannen 2008; Högskoleverket 2008; Jämställdhetsombudsmannen 2008). The student is supposed to be an active participant in his/her planning. The demand for active participation in goal-directed planning may represent a problem for students with AS since they may have difficulties understanding the support systems (Lipka 2006; Wessel et al. 2009).

In Sweden a new legislation, LOV, has been implemented (Swedish Government Official Reports 2008, 25), which intends to generate more freedom of choice and better support for students with disabilities. Also, this legislation may represent a special challenge for persons diagnosed with AS, as their communication with others is disturbed in some way and this can lead to problems with knowing and expressing needs. This paradox may become particularly evident in higher education.

AS in relation to everyday student-life

Everyday student-life, as applied here, implies that the life of a student can be thought of as two-parted: everyday life and student-life (those aspects of life which are specific to being a student). For students with AS, some of the hallmarks of the impairments of persons with AS can generate difficulties in the everyday student-life. One of these hallmarks is that persons with AS usually early on develop a need for *routines*. This need for routines increases when meeting new people and in new surroundings (Attwood 1998; Ehlers and Gillberg 1994; Jackson 2003). Another such hallmark is *Special interests*. A student with AS may be very engaged in his/her special interest and can talk about it uninterruptedly. Sometimes this can become very tiresome for other people (Attwood 1998; Fleischer 2005; Frith 1991). But a special interest can also be an advantage if it coincides with academic subjects and areas. Persons with AS also have difficulties with focused *attention*, especially with paying attention to what other people are doing. It is usually hard to get persons with AS interested in topics outside of their own sphere of interest (Attwood 1998; Ehlers and Gillberg 1994). Specific over-selectiveness on details can lead to problems with generating a comprehensive view of a situation.

Persons with AS usually *interpret literally* what is said or written. This may mean that irony, puns and metaphors become incomprehensible, which additionally complicates relations with others (Attwood 1998; Frith 1991). They often have great difficulties understanding the intent behind other people's behaviour and can comprehend situations in a different way. Persons with AS can also have problems in interpreting body language, facial expressions and gestures, intonation and eye contact (Attwood 1998; Bogdashina 2005; Föreningen Autism 2007).

Students with disabilities in higher education

In Sweden, knowledge about students with AS in higher education is scarce. Hellberg (2007) has studied students at a college having a special program for persons with AS. The students described 'critical events in their lives' that occurred during their time in compulsory school, first, when they received their diagnosis, and second, when they started on the individually adjusted college program. During this program many students experienced success in their studies for the very first time (Skolporten 2008). Studies from the USA show that an increasing number of persons with AS enter institutions of higher education. Dillon (2007) reports that students with AS need support, otherwise they often fail. However, the support and services offered do not always benefit students with AS; many of them need more individualized support. Smith (2007), for example, reports that students with AS need unique and individually based accommodation. Lipka (2006) recommends that students with AS receive off-campus apartments and support; it seems there is a need 'to hold student's hands as they navigate college' (36), not only in academic matters but also in everyday life. A staff member decides the schedule, a spokesman and a therapist help the student with social and independent-living skills, homework and daily life.

A study of students with learning disorder and attention-deficit/hyperactivity disorder (AD/HD) showed that many such students 'who enroll in postsecondary institutions have difficulty with completing their programs' (Chiba and Low 2007, 40). One means to improve the success rate is to educate students about their difficulties in higher education. Chiba and Low (2007) discuss transition courses for students with AD/HD built on 10 essential strategies for a successful transition to college. One of the more important steps was to teach students about their disorder and about self-identifying. Comments from the students indicated that the course helped them: 'When I was first diagnosed, I had no inkling what my disability was' (50). The result showed that 'a course-based model can improve students' understanding and acceptance of their learning disorder' (51) and generate possibilities to be successful and complete graduation.

Different researchers present different pictures of how students with disability manage the transition to higher education. Wessel et al. (2009) showed that 'students with apparent and nonapparent disabilities' and 'students without disabilities' showed no difference in graduating from college. 'Many colleges and universities have a disability service office to help facilitate access to higher education and the academic success of students with disabilities, reducing the number of students with disabilities that drop out of college' (116). This study is focused on the support and disability services in Swedish universities.

Aim

The aim of the article is to describe the personal experiences of students with AS in relation to conditions of offered support. Another aim is to determine whether the support given by the university was experienced as facilitators or barriers for students' functioning in higher education. The article analyses the participating students' (from here on the participant student's will be referred to as the 'students') own stories, with a focus on investigating how they perceived their everyday life as a student in relation to the past and the future and the formal and informal support they are offered.

The research questions are:

- How do the students with AS perceive their everyday life as a student?
- What characterizes the interaction between the student and their student environment?
- Is the support provided by the university perceived as a facilitator or as a barrier?

Methods and procedures

A case study approach (Merriam 1998; Patton 2002) was used (Table 1). This approach is suited for analysing a phenomenon of some sort occurring in a bounded context (Miles and Huberman 1994, 25) When using case study as a methodology the researcher wants to make a 'holistic description and explanation'. Thus it is felt that a case study is well suited 'to situations in which it is impossible to separate the phenomenon's variables from their context' (Merriam 1998, 29). Persons with AS have difficulties understanding the intent behind other people's behaviour and they may comprehend situations in a different way than others (Attwood 1998; Bogdashina 2005; Föreningen Autism 2007). Using a case study methodology based on narratives therefore is a viable option in studying how support for students with AS is perceived as a facilitator or as a barrier in everyday student-life.

Interview about the life-experience of persons with AS

The choice of narratives as a method implies that I as a researcher focus on getting to know another person, to obtain knowledge about this person's experiences, feelings and expectations. In my research the focus is on their everyday student-life and their way through school to higher education. The fact that they have AS complicates telling their story.

When a narrative is circling around difficult life-experiences there is a need for space for the person to tell the story in his or her way, in an order that makes the person comfortable and safe. A narrative does not follow a strict order but rather travels back and forth between the past, now and the future. It means that the listener follows on a journey to the unknown and if the space allows it the person makes a weave and gives a rich and deep narrative. This can give the researcher new

Table 1. Presents the basic information of the three cases.

	Adam	Bert	Cesar
University size	Large	Small	Medium
University subject	Biotechnology	Teacher education	Technology
Age	27	32	22
Received diagnosis	23	22	14
Support for AS	Yes	No	No
Situation	Own apartment	Own apartment	Living with parents
Personal characteristic	Melancholy and reticent	Active and verbal	Withdrawn and quiet
Prompting	Yes	No	Yes

Table 2. Length of interviews and length of time between interviews.

	Adam	Bert	Cesar
Interview 1	3 h 2 min	3 h 47 min	3 h 15 min
Days between interviews 1 and 2	40 days	42 days	1 day
Interview 2	1 h 4 min	4 h 50 min	2 h 15 min
Days between interviews 2 and 3	162 days	144 days	33 day
Interview 3	1 h 22 min	2 h 35 min	2 h 8 min
In total	5 h 28 min	11 h 20 min	7 h 38 min

knowledge and also an understanding for new issue (Doecke, Brown, and Loughran 2000; Hydén and Brockmeier 2008; Johansson 2005; Skott 2004). For persons with AS the unstructured methodology of a typical narrative approach may cause difficulties in building up a coherent narrative. Thus, I used more follow-up questions and prompts to support the respondents in telling their story than what is common in using narratives. In this study the narrative was a base for the analysis.

Interview guide

In total, seven interview guides were used, one common for all students at the beginning of the study and then six interview guides, two for each student, individually based on the first conversation. Questions were not asked directly from the interview guides. Instead, they were used when necessary to pick up on what the students said in order to move the interview forward. The lengths of the interviews were dependent on and adapted to each student's interest and wish to verbally express himself. Table 2 shows the length of the interviews and the length of time between the interviews in the three different cases.

Data analysis

The following five steps were used for analysing the data (Figure 1).

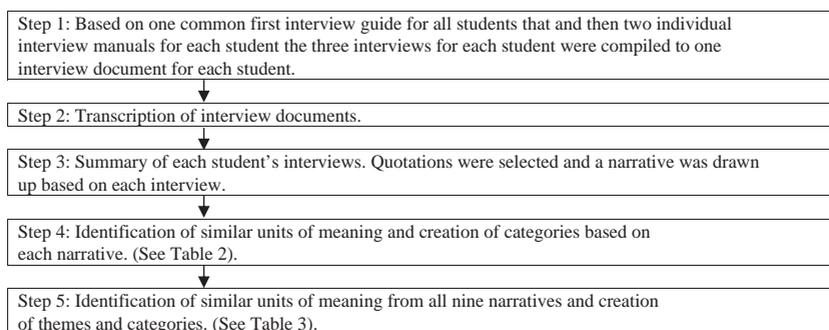


Figure 1. Steps in the data analysis process, modified model from Zakrirova-Engstrand and Granlund (2009).

After transcriptions were made, the interview document for each student was summarized into a logical narrative order for each case (Hydén and Brockmeier 2008). These narratives were based on quotations from the nine interviews and for

ease of reading some quotations have been rewritten and some word orders have been changed. Then all narratives were brought together based on the Units of Meaning from the narratives, and the categories were analysed once more. In Table 3 examples of units of meaning are provided.

The Units of Meaning formed two themes, *Alienation* and *Struggle*. In each of these, there are five categories (Table 4). Each category consists of a number of Units of Meaning. In Table 3, examples from Units of Meaning of six categories are exhibited.

Ethical considerations

Before the interviews were made, the students were informed of the aims of the study – that it was voluntary to participate and that they had the right to withdraw at any time without giving any reasons. Consent was obtained and the students were informed that the information given would be used exclusively for the present study.

The names of the students were changed when the transcribing started. In addition, names and any other information that can be linked to the students have been changed.

Background to the study

The author's background knowledge is in the medical, pedagogical and socio-psychological fields of persons with AS. Furthermore, one of the author's sons has AS, a diagnosis he received as an adult.

Table 3. Examples of units of meaning from each student interview, assessed into categories.

Units of meaning	Category
1. He is and wants to be very private and he says that it is strange to talk about himself and that he does not want to let anyone into his private sphere. He has a wish, as he says, not to be so 'bloody handicapped'; he just wants to fit in and he says that this is important for him.	Identity
2. Cesar remembers that when he got his diagnosis it felt 'okay, now I know why I am this way'. He considers his life to be restricted by the diagnosis: 'if you are bad at something then it restricts you'.	Diagnosis
3. Bert was bullied and harassed through his entire childhood 'I was a terrible preschool child'. There were many conflicts and fights with other children and Bert thinks he 'was a bit tricky as a child'.	Bullying
4. In upper secondary school he started to smoke because 'then you could be with the others, so it became a social thing'. Even at upper secondary school it was difficult to be with friends and he says that he was not so good 'at the social side of things'.	Loneliness
5. He continues his story, telling how he learnt by observing others and he says that he is a 'people collector'. One of his special interests is pedagogy and he tries to understand how other people think and act. It is a way to become less isolated with regard to other human beings.	Special interests
6. When I asked 'if you had a dream or vision for the future, what would it involve you doing?', the answer was 'I don't know.' He has no plans or dreams for the future, but he wishes he had, as this would be much easier.	Future

Table 4. Summarizes the number of themes, categories and units of meaning from the three cases.

	Adam	Bert	Cesar	Common for all students
Alienation				
Identity	10	5	15	30
Diagnosis	11	12	20	43
Bullying	4	13	6	23
Loneliness	4	3	16	23
Spare time	2	8	7	17
Struggle				
Studies vs. everyday routine	15	28	24	67
Special interests	12	21	12	45
Support	14	11	25	50
Coping strategies	6	21	17	44
Future	8	9	10	27

An unpublished pilot study was made at a smaller university. Eight interviews were conducted with student counsellors and one focus group interview was performed with members of the student-health services. This first study provided information and knowledge about how support at universities is organized for students with disabilities, with a focus on AS. This pilot study indicated the problems for this group of students asking for and obtaining support (Simmeborn Fleischer 2005).

Limitations

This study involves only three male students. This limitation restricts the possibility for making theoretical generalizations.

The analysis must be interpreted based on the knowledge that two of the students’ narratives (see Table 1) to a certain extent are shaped by the alternatives provided by the interviewer through prompting. This relatively frequent prompting can be seen as a functional adaptation to the disability of the respondents. The prompting might violate the idea of narratives as a method and therefore it was necessary to verify the narratives (see Table 5).

Verification of narratives and themes

In the following results section, the narratives are presented for each category, which allows the reader to create their own opinion of the students’ description of their

Table 5. Research colleague verification.

Interview	Author’s narratives of each interview	Author’s themes and categories
Adam’s interview 1 (check)	Adam’s narrative 1 (check)	Adam’s narrative (check)
Adam’s interview 2	Adam’s narrative 2 (check)	
Adam’s interview 3	Adam’s narrative 3 (check)	

everyday student-life. The students' statements have been verified through interviews with relatives and coordinators at the universities. These are separate interviews and will be presented in a forthcoming article.

The students themselves have also verified the material by reading and commenting on their narratives. All of them gave their approval of the interpretations that have been made. They also read the final article prior to submission and had the opportunity to comment on it.

Findings and discussion

Goffman's theory stigma is useful when studying phenomena such as identification, communication and interaction. According to Goffman's theory (Goffman 1963, 1990; Månson 1995) of stigma his use of a dramaturgical model of explanation, stigmatized persons are not allowed to or dare not stand on the stage, they are neither actors nor spectators. Persons who do not share the symbols of the society and are not fully involved in social interaction, may have to play the role of anomaly, they become alienated persons and are thus stigmatized. Bauman (1993) uses another term, 'ante portas' (171–5), which has the same implication as Goffman's 'stigma' (Goffman 1963). All societies have their own set of strangers who are denied participation in society (Bauman 1993; Månsson 2005). The main way to break such alienation is through communication and the use of commonly shared codes. In the present study, the students have a disability affecting their methods of communicating and interpreting interactions and hence taking part in a language-based community.

Struggle as a concept is closely related to moral philosophical and social psychological theories. Such theories (Honneth 1995) have been transmitted to the field of disability studies, for example, struggling for societal recognition (Honneth 1995; Houston and Dolan 2008) Recognition is important in order to experience autonomy and self-confidence. The struggle of the students in the present study was on the everyday level, but still concerns the feeling of belonging to a community and at the same instance self-confidence in being 'odd'.

Alienation

The data analysis gave rise to five categories within this theme: identity, diagnosis, bullying, loneliness and spare time.

Identity

Questions about identity and fitting into society to a large degree characterized the students' everyday lives. As Adam says, even in elementary school other pupils thought 'that you are a little odd'. Bert spent one high-school semester in the USA and he says 'there you are allowed to be a bit more openhearted, able to be yourself and show your Asperger-ness' [. . .] 'they are more pragmatic'. Cesar says that instead of socializing with classmates of his own age 'I was always socializing with the adults who worked at the schools I attended'. All three students have more or less actively tried to hide the fact that they have a disability. Adam wishes that he was not so 'bloody handicapped'; he wants to 'fit in' and expresses that is important to him.

Diagnosis

The students' hardships and difficulties have existed in their entire lives, but have become more obvious with age. Two of the students received their diagnosis after contact with a psychiatrist and the third student after contact with a psychologist. After Adam received his diagnosis, his life did not change. He says, 'I am what I am.' He 'does not really think about it' and he does not spend too much time considering his diagnosis and the effect it has on his life.

Bert revealed that there are others in his family who has a diagnosis within the Autism Spectrum. He himself received his diagnosis in connection with depression. As a child, Bert says that his 'mother trained me to appear normal'. If she had not, he probably would have received his diagnosis earlier. Bert did not admit the limitations he had, and the doctors he met concluded that he had ADHD as a child, which transitioned into AS when he became an adult. He views his disability as a disadvantage and believes that most people do not know what AS is, nor are they aware of the everyday troubles it implies.

Cesar got his diagnosis after an incident in compulsory school. He had to see a psychologist after that incident and it was decided to initiate an assessment process. After different tests and a brain scan, thinking his problem was connected to a brain injury, the doctor set the diagnosis of AS. Talking about his everyday student-life Cesar concludes that he has not had 'any great benefit from' having received his diagnosis. Also, he does not really want to talk about his diagnosis, because 'it doesn't feel particularly good (to get or receive a diagnosis, author's amendment), whether it is needed or not'.

All students regard their diagnosis as stigmatizing, and they prefer not to talk about it, nor has it had a positive impact on their ability to complete their university studies.

Bullying

Bullying occurred throughout their elementary school years for all students. Adam thinks he has learnt one lesson in particular from being bullied in elementary school, that is that peers always find flaws in him, and thus it is best to stay away from them, to be on your own.

Bert was bullied and harassed throughout his childhood: 'I was a terrible preschool child.' There were many conflicts and fights with other children and Bert thinks he 'was a bit tricky as a child'. His secondary school years, Bert says, were hopeless. He had lots of problems and did therefore not attend his secondary school as often as he should, and had to take some courses over and over again. He felt left out: 'my classmates called me "the invisible man"'.

Cesar says that he has always had difficulties making friends and that this has continued into adulthood. At both primary and secondary school he would spend time with teachers and not with classmates of his own age.

Loneliness

The depiction of loneliness is somewhat ambivalent. On one hand, the students want to be alone and have a great need for this. On the other, they want to be part of a context and to have friends. Adam does not meet many people and he is quite lonely.

He meets regularly with his family but he does not go out much and does not want to spend time with anyone else either. He has never moved anywhere far away and he lives alone in his family's old apartment. He thinks that it would probably sometimes be fun to have someone to spend time with.

Bert states that during his compulsory schooling he was quite isolated and lonely. At the same time, it was important to be alone with his thoughts in his room with a closed door when he was home after school. His experience of loneliness was two-fold: there is the feeling that it is pleasant and positive to be alone but at the same time it is negative and lonely.

Cesar feels a duality to being alone. He needs and wants to be alone sometimes but not all the time. He did not have very many friends when he was growing up and in upper secondary school he started smoking because 'you could fit in, it was a social thing'. At the same time, he likes it 'when it is calm, this means I am often alone' and he prefers to be alone a lot. Now and then he visits an uncle who has a dog. He takes the dog for walks and sees the dog as his friend, 'we are like the same person', and he thinks this is adequate company for the most part.

The students describe it as important for them to be able to control the conditions of their social relations. This can cause problems with formal studies, as well as with the more informal social activities which are usually a prerequisite for success in higher education.

Spare time

Adam does not meet many people and he thinks the amount of spare time he has is 'too much' and that he has nothing to fill it with. At the same time, he says he is satisfied with his spare time, he is at home a lot and he partly enjoys the solitude: 'I want it like that.' His meeting group at the Student Union generates some social interaction with others. Adam has had contact with this group even when he was on a break from his studies, something positive since Adam says 'I am very bad maintaining contact with others so it feels good.'

Bert participates in role-play games: 'My social development has largely come from role-playing.' Through the game and through controlling the game 'I can figure out how it should be.' He has learnt how to socialize with other people. He also knows that he has a need for control over what he does and says, despite speaking a lot and openheartedly. He claims that he 'can turn on and off when I want to, I have practiced this a lot', which means that when daily life 'becomes too much' he can shut himself down in his own world for a little while.

Cesar spends much of his spare time at his computer with role-play and strategy games. He can play over long periods of time. He says, 'that's a bit why you play, to get away from reality', and he adds that he 'has no real reality'. Games simulate 'living in another world' where he can get away from daily life and he continues 'that's probably why I play for the most part'. It happens at times that he plays together with someone else through LAN and that they sit in the same room and this is 'fun at times'. Since Cesar has started municipal adult education he has been out with a few classmates to bars.

The category of spare time is also characterized by ambivalence. The need for a meaningful leisure pursuit with social contact is there, but at the same time the students restrict the social opportunities involved.

Struggle

The data analysis gave rise to five categories within this theme: studies versus everyday routine, special interest, support, strategies and the future.

Studies versus everyday routine

It was not always easy to get the everyday student-life to work properly. All three students experience difficulties in different ways. These difficulties are directly related to the diagnosis characteristics of AS and affect their possibilities of studying effectively. One phenomenon that emerges is that day-to-day activities take a lot of time, since it is hard to plan and structure the days. Also difficulties such as problems with food, sleep and anxiety are mentioned.

Adam's studies have had their ups and downs. He has not attended all course meetings, he has switched courses and taken study breaks. His daily life mostly consists of being at home, where the everyday structure is weak. He forgets to eat and has problems planning what he is going to do. It means he does not really 'pull it together and get studying done'. He has constantly slipped behind on his studies, had problems handling all the literature and been unable to do group assignments. Adam also has other problems with activities of daily living, such as washing and cleaning.

Bert's studies are close to an end and he will soon graduate. He has needed much more time to complete his assignments than other students. His everyday student-life has not always worked well because of his feelings of stress and anxiety. 'It takes an incredible amount of energy' to, for example, pay an invoice, and when he is finally ready to pay, the paperwork has gone missing. Bert says that he would work better if he did not have to clean and pay invoices, since it is hard to do different things at the same time. 'I need to focus on the task at hand much more' compared to people without AS. These days the university offers a calmer environment than before and his everyday student-life works better. He has studied 11 semesters and has had study breaks. From time to time, his finances have been at a point where he has lived on the edge of starvation. He has created a coping strategy: 'I tend to find alternate solutions for my problems. I am always looking for a solution that will work for me.' This means that despite his difficulties and disabilities, he can find ways to handle his everyday student-life.

Cesar entered the university for a one-year basic technical course but that did not work out very well. The course-work included some group assignments, which Cesar thought were reasonable, but he had difficulties with exams. There were a few others on the course that did not pass the exams either and one of them started on municipal adult education instead, and this other student suggested Cesar to try it as well. So after one term at university he started on municipal adult education and has completed all courses he has taken so far, and his goal is to apply to university again. Cesar lives at home and does not have to take much responsibility for cooking, cleaning or washing. Despite that, he has been able to see that his everyday student-life takes more time compared with that of other students. He has difficulties in planning and keeping to times. Furthermore, he needs help with structuring when it comes to his studies.

Prominent for all three students are planning difficulties which create further difficulties in getting the everyday student-life to work. Planning requires an ability to have a general overview of the situation, which the students seem to lack. This also

leads to difficulties with asking for support. Activities of daily living, for example, paying invoices and doing laundry, seem to require much more energy for these students than for others. The balance between daily life and studies therefore becomes disturbed. Tasks that are done routinely by people without AS become large, overshadowing projects for these students. They simply do not have enough energy to deal with studies on top of all the activities of daily living. Doing daily tasks also becomes a distraction from their studies, in such a way that if they cannot be done in the way the student intended, then all other activities stop as well. Cesar gives as an example: When he is waiting on someone to call, he cannot do other tasks, for example, study-related activities – at the same time.

Special interest

One of the diagnosis criteria for AS is having special interests, and all three students in the study have these. During the interviews, it became obvious that their special interests mean a lot to them. Their tone of voice changed, their body language became livelier and their statements became richer when they talked about their special interests. Consistently for all three students, their special interests have become a safe zone for them, a world where clear rules and limits exist, and a world where they do not get stressed. Their special interests have also partly impacted their choice of studies.

Adam disappears into a fantasy world, stimulated mostly by books. When he talks about this fantasy world, he states that it is positive since it is easy to understand, despite being dark and characterized by evil. His special interests also concern movies about imaginary wars, war robots and military strategies. These are easy to understand, and through following given military strategies, the result is easy to predict, which feels like a relief from the normal struggle of the unpredictable everyday life.

Bert has a special interest that has helped him a lot. He says he ‘people-watches’. He learns through watching others, and he tries to understand how others think. It has led to being less cut off from the outside world, as he has learnt to interact with other people, and not to be ‘odd’. Bert plays role-playing games and, in the same way as Adam, he slips away from the struggle of daily life through these role-play games. His special interest has an interesting side effect. The social imitation that role-play implies allows Bert to understand and to get into other people’s situations, something persons with AS normally have difficulties in doing.

In a similar way, Cesar is interested in computer games and computers in general. His special interest has taken up much of his time, and his mother has tried to limit the time he spends on these activities. What distinguishes the special interests, in all three cases, is that they become a safety valve to escape from the struggle of daily life. Common for all students is also that the use of this safety valve tends to become too extensive, thus occupying time that could be better allocated to other things.

Support

All three students have been offered various forms of support by their universities. This support has, however, been offered and accepted in different ways. All the students are uncertain about what the support offered is supposed to do for them.

When Adam, after diagnostic assessment, returned to his studies he asked for support through the university coordinator. He then received mentor support and reported that the mentor 'was generally nice, I guess it was pretty nice'. However, this support became a source of stress, since the person who became his mentor was a 'new' person for Adam. Hence the support became a catch-22 situation. The support required that Adam could tell (was based on Adam telling) his mentor what his needs were, and Adam says that 'I didn't know what kind of support it should be, how he was supposed to be able to help'. Adam says that probably not very many people know that he has AS, not that he is ashamed of it, but he prefers not to talk about it. The only support he accepts is activity compensation payments from the social insurance office. He does not have any thoughts about getting any other support either from the university or at home.

Bert considers it hard to ask for support and he says 'how can you get help when everything is moving so fast, my life feels as though it is flying past at 300 km/h'. At the university he told the coordinator and a teacher that he 'has trust in' his diagnosis. When he met the coordinator, he found out what kind of support was available and could make things easier for him, but he did not want a 'relationship where they have to spend time with me in exchange for money. That would have felt very weird so in the end I decided not to make use of it'. Things have, however, worked well with the teacher whom Bert trusts. He has, through the support of this teacher, been able to make progress in his studies.

When Cesar got his diagnosis, neither he nor his family received any help with understanding what the disability meant, and they were told nothing about available support. When Cesar realized that his studies were not going well he sought support through the university coordinator and was offered help with notes and to borrow a computer. However, help with notes from another person was not something he wanted, since 'I don't know how good that guy is at keeping quiet'. Cesar does not want anyone to know about his difficulties. He received no information, neither verbal nor written, about other kinds of support available and Cesar did not contact the coordinator again, nor did the coordinator offer any follow-up. Cesar never tried to get any support again: 'I did not know if that would help or anything'. He uses his cell phone as a calendar with reminders so that he will not forget times and meetings.

The support from the universities has not worked in any of the case studies. Support services are built upon the student's own ability to communicate their particular needs, and when they are unable to do so, the support fails. Support services are also general, and seem to be offered without the coordinator having assessed the needs of the individual student. The three students have different needs and they all lack the skills to ask for help, which, for instance, Bert confirms: 'I am really bad at asking for help'. The support that Bert wants from the university is 'an environment where Aspergers feel safe and have the opportunity to develop a good social competence'. A common theme is difficulties with everyday chores. Such problems are not matched with support focused only on the study situation.

Coping strategies

All three students use some form of coping strategy to handle their everyday student-life. Adam drinks quite a lot of coffee with lots of sugar, for it 'keeps me alert'. For him five lectures a week created too much anxiety. He does not have time to read all

the material for each lecture and at the same time be able to fulfil his need for some private sphere.

Adam's strategy is to avoid certain courses and he tries to get as much information as possible before the course starts because 'not to have full control over what is about to happen is hard'.

Bert is more outgoing in his strategies: 'I tend to find alternate solutions for my problems. I am always looking for a solution that will work for me'. This strategy almost always consists of social imitation. By observing how others act in given situations, and then by doing the same thing, he becomes aware of his own difficulties. His drive to get forward is irritation and anger: 'a strong engine of change is that I get pissed off and then a lot of things happen'. He uses this strategy 'to strive for the answer' and he has become 'aware that other people don't think in the same way'.

Cesar has no explicit strategies to handle his everyday student-life, apart from his stubbornness, and says that he is 'the man who does everything twice'. He partly uses anger, or possibly even powerlessness, as a driving force for getting a university education, to be able to show on paper that he actually knows things.

In one of the cases, the strategy of social imitation is enough to cope with everyday student-life. However, in the other two cases, embryos to strategies were reported, as to drink lots of coffee with sugar or do everything twice, to be able to handle everyday student-life, but these strategies were sufficient.

The future

It is not easy to maintain dreams about the future when you live in a world that is hard to handle. Daily activities are chaotic, and it is hard to make everyday life work. When it does not work, the students devote themselves to their special interests. These conditions mean that the students' dreams of the future become insignificant and unclear. They exist, but are not expressed in a clear and obvious way, and thus cannot be said to constitute actual goals.

Adam has never had dreams like others have about wanting 'to be a fireman or a doctor'. 'Long term planning is not my thing', but control of what is to come, Adam says, 'is important' and wishes he had more control over this. 'It would be easier then', with such control. He does, however, have some plans for the future. He will apply for some new courses at the university, but is considering part-time study. Adam does not really think about his everyday student-life other than 'I take every day as it comes'.

Bert says that the choice to start studies at a university was not very difficult since, as he says, the other alternatives that existed 'weren't very appealing'. Bert says with a longing in his voice that he would like to go back to the USA, and 'possibly even work there instead of here'. But no long-term plans exist; today it is all about getting his degree and finding an employer that wants to hire him.

When Cesar was about to graduate from upper secondary school a guidance counsellor told him to apply for a university education in engineering, and that 'job prospects are always good in that'. Cesar says that the future is 'hidden in darkness' and that he seldom thinks about it.

The students' views of the future seem limited partly because of an inability to visualize themselves in different situations. This inability has accompanied the students since childhood. Adam, for example, says 'I've never been able to check out the alternatives, never checked out the future'. Not be able to dream about the future,

and make long-term goals that are accurate enough to be motivating, may constitute obstacles in their studies, especially in terms of the low motivation.

Conclusion

Alienation and struggle are important subjects in all three students' narratives. Experiences of alienation are a continuous theme in their life, with a clear linkage to stigmatization. According to Goffman's theory (Goffman 1963, 1990; Månson 1995), persons who do not share the symbols of the society and are not fully involved in social interaction, may have to play the role of anomaly (i.e. being stigmatized); they become alienated persons. The results of this study partly confirm Goffman's theory but they also illustrate the importance of choice. The alienation expressed by the respondents is accepted as a state of life and self-reinforce, partly a struggle that they struggle to overcome. The respondents have a need to be alone, but at the same time they long for friends and fellowship with other students. Maybe Goffman's theory does not consider the influence of person characteristics and the struggle to define a role enough. The Goffman's theory is very much based on societal constructs but need to consider the role of the individual in creating his or hers everyday student-life, both in terms of actions and perceptions. Some people may actually see a certain value in perceptions of alienation and even act in a manner that reinforces processes of alienation.

The everyday student-life of the respondents consists of finding solutions to be able to handle activities which other students mostly do not have to spend any special amount of time and energy on. It also consists of a struggle to find time to be alone and having time for special interests. Thus, everyday student-life consists in large part of a struggle with spare time and day-to-day activities. The struggle is dual and paradoxical focusing both on being accepted in the role of student and on maintaining an identity as partly alienated. This takes a lot of energy, which leads to difficulties in concentrating on studies.

A common denominator university support is that all the respondents have difficulties in interacting with their student environments, and that they themselves feel that something is not working, but they lack the skills to define the problem. They do not know what support they need and the support that they have been offered becomes just another barrier.

The support they received was experienced in some cases as more negative than positive, and when their interaction with their counsellor did not work out, they did not go back to look for other means of support. They did not tell the counsellor that the support was not working nor did they explain their reasons for not accepting the given offers of support. The students experienced that the coordinators did not understand them and thus there was no point in going back and asking for something else. Freedom of choice is in fact no choice for these students: it is just one more complex issue for them to deal with. If freedom of choice requires that you know your needs and that you know what support to ask for, then it becomes a catch-22 situation if you cannot identify your needs and have difficulties knowing what to ask for.

Achieving functional everyday student-life is not only about obtaining support from the university focused on studies, it is also about managing everyday activities. The narratives reveal a shared situation for all three students: the support provided does not facilitate everyday student-life. In order to be effective, the support offered

needs to be coordinated and individualized, and to focus on managing both everyday life and studies. Chiba and Low (2007) described good effects on students' ability to manage higher education by participating in a course-based model to promote successful transition to college. The students were taught 10 essential strategies including self-advocacy, compensatory strategies, knowledge about laws and college-appropriate time lines, how to seek appropriate assistance and finally one very important strategy: 'teaching how to organize for learning and living' (41). Both Chiba and Low (2007) study and this study indicate that students with AS need training and support to learn and apply strategies to manage the everyday student-life that include both managing studies and managing everyday life routines.

There is an increasing number of persons with disabilities who are attending higher education. There is a lack of knowledge regarding how students with cognitive disabilities such as AS will be able to manage higher education. Especially important is research focusing on how students who have difficulties in understanding information and planning their life can effectively utilize existing support systems. If students with AS and cognitive disabilities are going to have the same opportunities as other students there is a need to modify the way of offering support. There is also a need for more collaboration between university authorities responsible for support and their support coordinators.

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