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Postprint

This is the accepted version of a paper published in *International Journal of Rehabilitation Research*. This paper has been peer-reviewed but does not include the final publisher proof-corrections or journal pagination.

Citation for the original published paper (version of record):

Simmeborn Fleischer, A., Adolfsson, M., Granlund, M. (2013)
Students with disabilities in higher education – perceptions of support needs and received support: a pilot study.
International Journal of Rehabilitation Research, 36(4): 330-338
<http://dx.doi.org/10.1097/MRR.0b013e328362491c>

Access to the published version may require subscription.

N.B. When citing this work, cite the original published paper.

Permanent link to this version:

<http://urn.kb.se/resolve?urn=urn:nbn:se:hj:diva-20981>

Students with Disabilities in Higher Education – perceptions of support needs and received support: a pilot study

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Received 3 December 2013 Accepted 14 April 2013

International Journal of Rehabilitation Research

Abstract

Students with disabilities in higher education frequently need support to succeed in their studies. Perceived problems in managing studies and everyday life may be the same for students with different disabilities although the reasons for support may vary between them. In this pilot study, a questionnaire aimed to survey everyday functioning in students with disabilities was tested. Thirty-four students with Asperger syndrome (AS), motor disabilities or deafness/hearing impairments were asked 55 close- and open-ended questions regarding participation restrictions and available support programmes. One aim was to test the usefulness of the questionnaire. Another aim was to identify students' perceptions of their everyday student-life and the support they are offered, with a special focus on comparing perceptions of needs and support between student with AS and the other student groups. The results indicate the need to plan recruitment of participants carefully and that the questionnaire was useful. The descriptive analyses conducted, indicated that the groups primarily reported the same difficulties, but the open-ended comments indicated that the reasons for the problems vary between the groups. It indicates that likert type responses to questions concerning perceived difficulties need to be supplemented by open-ended questions concerning perceived reasons to problems.

Keyword: Asperger Syndrome, Deafness, hard of hearing, everyday student-life, Higher Education, Motor disabilities, Pilot study

Introduction

In the last decade, both the number of students with disabilities attending higher education (HE) institutions and the number of research studies concerning these students have increased (Hadjikakou, Polycarpou, & Hadjilia, 2010; Madriaga & Goodley, 2010; Madriaga et al., 2010; Matshediso, 2010). Among these students, some need more support than others to succeed in their studies and to function successfully in daily student activities. Hadjikakou and Hartas (2008) suggest that an individualised approach is required to identify and provide appropriate support needs for students with disabilities rather than providing general support based on type of impairment. However, students perceiving the same type of problems may need different interventions due to different causes to their problems. Differences in support needs among students may be related to the student's specific impairment, to other individual characteristics, to the attitudes of society and/or to the characteristics of the support provided. Findings from a previous study in Sweden indicated that the support provided in HE institutions in Sweden is primarily structured and planned from the perspective of students with 'traditional disabilities' such as motor disabilities (MD) and hearing impairments (HD) (Simmeborn Fleischer, 2012a, 2012b) rather than from the perspective of cognitive impairments such as AS. AS is a health condition within the Autism Spectrum Disorder that includes cognitive impairment. According to the Diagnostic and Statistical Manual of Mental Disorders, version 4 (DSM-IV, 1994), one essential feature of AS is impairment in social interactions, which is a factor that may cause difficulties in educational settings. AS students may perceive difficulties managing both daily life and studies (Simmeborn Fleischer, 2012a, 2012b). Therefore they may need not only educational support but also support in managing their daily lives including activities focused on social network and on managing everyday routines. In a study by MacLeod and Green (2009), a service model for students with AS and Autism is presented. "It offers an individualized and holistic model of support, in keeping with the needs associated with Asperger syndrome" (p. 631), but the authors argue that the model is useful also for students with other disabilities. To study whether a service model works for all students, methods for collecting data on everyday functioning of students with disabilities in higher education that can separate generic from disability specific needs is required. The present pilot study evaluates methods for investigating functional problems in daily student life for students with disabilities with a specific focus on AS. The construct of 'everyday student- life' is divided into two categories, 'daily life' defined as routines and activities related to daily living, and 'student life' activities and routines related to performing studies in higher education. The purpose is also to investigate if students with AS seem to have specific difficulties or if difficulties vary more between individual students than between different disabilities. Based on the evaluation and preliminary results a larger survey study will be implemented.

Background data

Support to students with disabilities in Sweden is regulated by both general and specific acts. There are 52 universities with 316 386 students (Swedish National Agency for Higher Education, 2011b). During 2011, 8 455 students with a disability visited a disability coordinator at the university. An increasing number of students with cognitive difficulties is reported, whereas the number of students with MD and students with HD is unchanged. In 2011 the number of students in higher education reported to have cognitive disabilities was 1694 (Stockholm University, 2012a). Type of cognitive disability was not registered.

The general right to be supported by society in Sweden is regulated in the Social Services Act (SoL) (SoS, 2009). This law includes all persons in the municipality, with two of the paragraphs focused on persons with disabilities. Because the law is general, an additional Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) was developed in the 1990s (Law 1993: 387, 2011). The LSS contains provisions relating to measures of special support and special services for three different groups of impairments. One of the groups consists of those who have an intellectual disability, are autistic or have a condition resembling autism (AS is included in autism). Thus students with AS in higher education may receive support to manage everyday life through LSS.

Specific support to students in Swedish universities is regulated by the Discrimination Act (Ministry of Employment, 2008). To be eligible for support through a coordinator, the student must have a diagnosis. The law gives students with disabilities the right to support, such as educational pedagogical support and access to a coordinator or similar professional, from the universities and HE institutions. However, each university and/or coordinator determines what support is to be provided and no guidelines for how to assess needs are provided. The coordinator, together with the student, decides what support is most functional and appropriate given the student's needs. (Stockholm University, 2011). The most frequently offered services are accessibility inside and outside the buildings, alternative examination forms, additional teaching and tuition assistance, IT-support, literature adjusted to medium, mentors and note-taking assistance (Stockholm University, 2012b). These types of support seem to be primarily designed for students with traditional disabilities such as MD (accessibility), HD (literature adjusted to medium) and vision impairments (note taking and mentors). How these services is perceived to facilitate everyday functioning is not known.

Aim

The first aim of the study was to develop and evaluate a questionnaire designed to investigate how students with disabilities in higher education perceive their everyday student-life, as well as how they view the support they are offered by the university and the municipality. Another aim was to conduct a pilot trial on surveying disability general and disability specific needs addressing the following research questions:

- What participation restrictions do students with AS, MD and HD perceive in their everyday student-life as a student?
- What support needs do students with AS, MD and HD perceive in their everyday student-life as a student?
- What support have students been offered?
- How do students with AS perceive their everyday student-life compared with students with MD and HD?

Methodological approach

The pilot study has a mixed approach using small groups of respondents providing both qualitative and quantitative answers in the evaluation part. In the part designed to compare perceptions of students in higher education with three types of disabilities, AS, MD and HD; descriptive statistics and content analysis were used.

Questionnaire

The selection of item-content for the questionnaire was based on a review of four sources; 1) findings from two previous studies and a literature review of studies concerning students with AS and other disabilities in HE, 2) the pedagogic support offered to students with disabilities in HE as documented by the universities (Swedish National Agency for Higher Education, 2012), 3) regulations about support in HE established by the Discrimination Act (Ministry of Employment, 2008) and the Swedish Higher Education Ordinance (SFS 1993:100; chapter 1, § 11), and 4) regulations about social support offered by the municipality regulated by SoL (SoS, 2009) and LSS (Law 1993: 387, 2011). The studies generated information regarding the difficulties, needs of support and strategies reported by the students with AS, relatives and coordinators (Simmeborn Fleischer, 2012a, 2012b) as well as information on the support (Hadjikakou & Hartas, 2008; Madriaga & Goodley, 2010) in HE. The other three sources provided information on the support system and available support options in higher education. A special focus was directed to students with AS.

The content of the questionnaire was validated by two sequential trials performed by students in HE. The first trial included 25 students without disabilities attending two HE courses in special needs education who were asked to respond to the questionnaire as well as to questions about the form and content of the questionnaire. Respondents' comments as well as response patterns for the group were

investigated. After this first trial, three questions were modified to enhance clarity. In addition, some response options were altered to match students with MD, for example adapted technical support and students with HD, for example hearing loop. The second trial included six students with disabilities: two with AS, MD and HD respectively. They were asked to fill in the questionnaire while “thinking aloud” (Berth Danermark, 2003) followed by cognitive interviewing about the questionnaire (Statistics Sweden, 2001). As a consequence of this trial four questions were modified. Finally, the Regional Ethical Review Board (2011) at Linköping University required a modification of the phrasing of two questions to avoid stigmatizing respondents.

After the test trials, the questionnaire comprised 55 open- and close-ended questions, of which some had several response options. The questions covered seven areas: 1) demographic data (age, sex and disabilities), 2) area of study and study problems (programme or courses, drop course or completion of the studies), 3) daily life (experiences and support), 4) society and friendships (frequency of social contacts with society and relatives), 5) support mechanisms at the university (types of and experiences with support systems), 6) support outside of the university (types of and experiences with support systems), and 7) impairment factors (strategies coping with and experiences as a result of the impairment). See appendix for questionnaire.

Participants

To recruit participants, a letter was sent to all coordinators who provide pedagogic support to students with disabilities at the 52 Swedish universities, according to information provided by the Swedish National Agency for Higher Education (2011a). *Approximately 2 600* students with AS, MD and HD were, *in theory*, available as possible participants. In total, 62 coordinators at 52 universities were asked to collaborate: seven universities reported that they did not have any students with disabilities and 12 universities (15 coordinators) consented to identify students with disabilities and inform them about the project. Thus, coordinators at 33 universities did not give their consent when being approached by letter. All direct contacts with the students were made via the coordinators. The final sample consisted of 34 students who had been diagnosed with AS (16), MD (11) or HD (7) and were enrolled in HE and who had applied for pedagogic support from coordinators at 12 Swedish universities. The ages of the responding students ranged from 22 to 52 years; eight were males, and 26 were females. The involved universities represented both the major and the oldest ($n=3$) and the minor ($n=9$) Swedish universities. Most students in all groups attended programmes aimed at specific professional careers (32 in total). Five of the students, attended both a programme and freestanding courses.

Data collection

The participants were sent paper questionnaires and information about a specific website where they could also access the questionnaire. Thus, students could choose to respond to the questionnaire using a paper version or a web version. The researcher's email address and phone number were included to allow students to request for support or assistance in completing the questionnaire. Since only the coordinator knew which students were participate in the study, it was only through the coordinator the student could be reminded. Five coordinators has stated that they have sent reminders.

Data analyses

A descriptive analysis based on cross-tabulation was used. The first five questions in the questionnaire addressed age, sex, university, programme or subject, diagnosis and experienced difficulties. In addition, some basic questions about the student's educational level, programme or freestanding courses were included. Other questions asked whether the student wanted support and/or was currently receiving support in daily student life. Two final open-ended questions asked about positive and negative experiences of being a student.

For 15 close-ended questions on the questionnaire with response options, the student was given the opportunity to write comments. Comments to questions were assembled according to diagnostic group. Accordingly, these 15 questions were used for cross-tabulations based on the diagnostic category.

Finally, an analysis of the two aspects, ‘daily life’ and ‘student life’, was conducted based on the data from the cross-tabulation. The three questions used for this analysis included what the students perceived as difficulties, what they perceived as needs and what support they had been offered in daily life in one table and what they had been provided in student life in another table.

Ethical considerations

The study was reviewed and approved by the Regional Ethical Review Board (2012) at Linköping University (Dnr: 2011/227-31). As there are no descriptions on what university, programme or freestanding courses the students attend, the confidentiality of students, coordinators and universities was assumed guaranteed.

Result

In the results section the analysis of the usefulness of questionnaire items will be presented first followed by a presentation of the preliminary findings concerning disability general and disability specific needs among students with disability in higher education. These findings will be presented in two separate tables, ‘daily life’ and ‘student life’ in which the information necessary to respond to the three research questions concerning restrictions, needs and support are merged. In these tables findings concerning difficulties in everyday student-life, i.e. participation restrictions are matched with findings about perceived support to provide an overview of the everyday student-life. In a final analysis data concerning restrictions, needs and support are merged with explanations to difficulties provided by respondents to illustrate if and how perceived difficulties generated different kinds of support dependent on perceived explanations to problems.

The usefulness of questionnaire items

The usefulness of the questionnaire items was investigated by analysing if all response options were used on likert scale items related to perceptions of restrictions, needs and support as well as the number of respondents providing responses to open ended questions. The following sections of the questionnaire were investigated: 1) daily life (experiences and support), 2) society and friendships (frequency of social contacts with society and relatives), 3) support mechanisms at the university (types of and experiences with support systems, 4) support outside of the university (types of and experiences with support systems), and 5) impairment factors (strategies coping with and experiences as a result of the impairment). The analysis revealed that for all items concerned with daily life and society and friendships all response options were used by at least one respondent except for the question about paying bills that no one of the respondents reported as a difficulty. Concerning support mechanism at the university and support outside the university respondents used all response alternatives for a large majority of the questions. For some questions concerning available support all respondents answered that they had not been offered this support or had not asked for the support respectively. For the questions focused on impairment factors, i.e. strategies used to cope with impairment, at least one respondent answered yes on all suggested strategies. Concerning the open-ended questions the number of students responding to these questions varied between 4 and 18 out of 34.

Restrictions, needs and support in everyday student-life

Table 1 presents the responses categorised as daily life according to student groups. The left columns show the six response options regarding perceived difficulties to participate and the number of students who perceived difficulties. The right columns show 12 response options regarding how many students that perceived a need for support and the extent to which necessary support had been offered.

Table 1. Students’ perceptions of difficulties and the need for support in everyday student-life related to the support they had been offered by the municipality

Participation restrictions				Support						
Response options	Perceived difficulties n=34			Response options	Perceived needs n=32			Support offered n=11		
	AS	MD	HD		AS	MD	HD	AS	MD	HD

	n=16	n=11	n=7		n=14	n=11	n=7	n=5	n=5	n=1
Household chores	7	4	4	Find way to complete chores	6	4	1	1		
				Get started	5	3	2			
				Clean house	3	2	3	2	3	1
				Do the dishes	2	1	1	1	3	1
				Change the sheets	3	1	1	1	3	
				Wash	5	1	2	1	2	1
				Iron	1	1	1		3	1
Food	7	3	5	Plan to buy food	2	2	3		3	
				Buy food	1	2	1	2	3	1
				Decide what to eat	5		2			
				Cook	5		2	2	2	1
Leisure interests	9	6	6	Get away from home	2	3	1		1	
Seeing family	10	4	3							
Seeing friends	9	8	6							
Resting	8	7	6							
Relaxing										

All students reported participation restrictions in their daily lives and of these, 32 also reported perceived needs for support. One student with AS and two students with MD wanted support but did not receive it. The students with AS and MD, to a higher extent than students with HD, reported that they had a need for support to successfully complete tasks and chores, but only one student was supported. Eleven students had been offered support from the municipality. A small difference emerged among the student groups regarding the type of support received. Proportionally, more students with MD received support.

Students with AS and MD described in open comments the need for support. One student with AS stated “My boyfriend is helping me, and we share the responsibility. I have help with grocery shopping, cleaning, changing the bed sheets, washing and ironing. It feels good to not be alone in taking care of a household”. Another student commented that “I am not [taking care of a household by myself] during the semester”. A student with MD commented “It's hard to summarise all the help I get”. The results indicated only minor differences between the groups, both according to reported need of support in daily life and the support offered by coordinators.

Table 2 presents the responses from the questionnaire regarding student life. The left columns show the ten response options regarding participation restrictions in student life and the number of students who perceived difficulties. The right columns show 17 response options about pedagogic support, the number of students who perceived a need for support and the extent to which the pedagogic support had been offered by the university.

Table 2. Students’ perceptions of difficulties and needs for pedagogic support in student life related to the pedagogic support they had been offered by the university

Participation restrictions				Pedagogic support						
Response options	Perceived difficulties			Response options	Perceived needs			Support offered		
	n=34				n=34			n=11		
	AS	MD	HD		AS	MD	HD	AS	MD	HD
	n=16	n=11	n=7		n=16	n=11	n=7	n= 5	n=5	n=1
Read literature	7	2	2	Audio books				2		1

Integraedte knowlge	2	4		Note taking Study techniques	7 1	3	1	3	1
Too many students	1			Single room for study				1	
Organise studies	2		1	Plan studies	1	1		1	1
Complete studies in time	3	4	7						
Test accommodatio ns			3	Single room for study	1	2		1	
				Other design of tasks	3	1			
				Reading and writing assistance	1			1	
				Examination support	3	3		1	
				Extended time for examination	2	2		2	1
				Use of a computer during examination		2		1	1
Succeed on exams	3	2	5						
Stay current with studies	3	4		Language interpreter			1		
				Support from a special pedagogue					
				Specific technical aids					
				Hearing aids		1	3		
				Mentor	2	2		2	2
Reflect on knowledge	3	2							1
Group tasks and seminars	2	1	1	Individual task rather than group task			1		

All three students groups reported participation restrictions in student life and a need for pedagogic support. There was only a minor difference between students with AS and HD compared to students with MD on the close-ended questions. On the open-ended questions, students with AS described difficulties in more areas than did students with MD and HD. In several different environments, students with MD and HD more frequently described difficulties that focused on bodily aspects, such as pain, difficulties moving or sitting, or problems hearing.

Disability general and disability specific needs

With respect to the open-ended questions in the questionnaire, the comments about difficulties varied among the three students groups despite perceiving the same problems regarding student life.

Students with AS indicated that they were tired, had sleeping problems, had a low stress tolerance, had difficulties concentrating and had difficulties performing required activities, such as note taking and reading the literature. Comments from several of the students with AS also indicated difficulties to understand social interaction, namely “difficulties with social interaction”, “social problems”, “difficulties with social skills” and “difficulties in social situations”. In addition, students with AS reported difficulties with memory, cognition, and interpretation, and they found it difficult to structure their time, to make plans, to grasp the concept of time, and to start and stop engaging in activities within appropriate time parameters. For example, doing housework, such as cleaning, required

considerable effort. Similarly, addressing their personal hygiene was also an onerous task. One of the students described being “constantly tired, doing things slowly, thinking very concretely/logically, being extremely pedantic, having difficulty concentrating, experiencing restlessness, experiencing impulsivity, having difficulty with ‘small talk’, sticking to routines, and being sensitive when it comes to food”.

Students with MD commented that they had mobility problems because of their need for a wheelchair, had difficulties maintaining a sitting position for an appropriate length of time and had constant pain. They also reported that doing housework, such as cleaning and cooking were tiring and difficult to do. In fact, one student needed full-time, 24-hour assistance. In addition, several of the students with MD commented about tiredness and pain, stating that they had “difficulty with pain”, had “constant pain in the back”, had “difficulty writing”, and were “very tired” and “fatigued”.

Students with HD described problems with communication, feelings of being excluded and concerns about social limitations. They also reported feeling stressed, having difficulty hearing in noisy environments and having difficulties locating the origins of sounds. One of the students wrote “difficulty hearing in crowds, numbness and pain in the neck - because I need to turn my head so that I can hear all the time. Socially limited because I can easily feel like an outsider and am not always able to keep up in a normal conversation”. Some comments concerned hearing, such as “my hearing is reduced”, “I have difficulties with communication”, “I have difficulty hearing in noisy environments” and “I am hearing impaired and hear poorly”.

Table 3. Examples of expressions of difficulties

Difficulty	Expression	Student group	HE support	Form of support
Fatigue	Sleeplessness It takes longer time to do things	AS	No	Community support: Healthcare, through medication given by psychiatrist and psychologist.
	Pain Physical difficulties Takes energy to do things	MD	No	Support in the household or other support through aids or some form of training, provided by an occupational therapist, physiotherapist or similar.
	Linked to anxiety to hear	HD	Yes	HE support: Teachers receive microphone that connects to hearing loop and repeat what the other students ask and respond.

Discussion

This study was the first trial to investigate the perceived study situation of three groups of students with different impairments in higher education in Sweden, with a special focus on students with AS. The questionnaire seemed to be useful based on the pilot tests and the variance in the respondents use of different response alternatives in items and a large proportion of respondents providing responses to open-ended questions. Regarding the survey of disability general and disability specific difficulties and needs the small sample excludes generalizations. However, it is an interesting trend that the groups compared tend to describe similar patterns of difficulties both in daily life and student life. This trend indicates that the questionnaire is valid for surveying disability general difficulties but might need to be extended with likert type items concerning impairment based explanations to difficulties.

The similarities in perceived participation restrictions may indicate that the difficulties are defined by role expectations on being a student with disability rather than by the type of impairment. However, perceiving the same restrictions does not necessarily mean that the same types of support need to be provided to all students. The responses to the open-ended questions indicated that there may be different explanations for the perceived restrictions that are partly specific to the type of impairment of each student, i.e. equifinality. Students with AS, MD, and HD seem to share perceptions of difficulties, however, there rationales for having difficulties varies. For example, fatigue could be deduced to sleeplessness for the students with AS but to pain for students with MD. Also the form of support and

the provider could differ (Table 5). The results indicated that an individualized assessment of the whole everyday student - life situation, not only of perceived difficulties but also of possible causes to difficulties is needed.

Impairment specific characteristics may also have a higher or lesser goodness of fit with the service system requirements. Explanations to participation restrictions provided by students with AS frequently concerned problems with social interactions that pervade the student's life. Accomplishing educational goals, such as reading the requisite literature and reflecting on knowledge, very often demanded interactions with other students and teachers. It is difficult to ask for support and help with studies if the student has not been included in the classroom activities. At the same time some students with AS may express less motivation for being included thus making it more difficult to express needs for support to the coordinator or teachers. These difficulties with expressing needs might be more common for AS students and are extra challenging if the support system (as in Sweden) requires the students themselves to express their needs and request support.

The results of this study showed that to succeed in higher education, students with AS, MD and HD need support in both their daily life activities and their student life. The lack of clear links between type of disability and perceived restrictions indicate that support probably need to be individualised according to each student's difficulties rather than from the starting point of a specific impairment or prefabricated list of supports. Those who provide support must consider each student, ask for the relevant information, encourage the students to talk about their specific difficulties and, most importantly, discuss how the difficulties affect their daily lives as well as their student lives. To support students to cope with and be successful in their university studies, collaboration between different services and experts is probably necessary.

Inclusion is one of the issues most often discussed in the research about students with disabilities and higher education throughout the world (Aleshina & Pleve, 2010; Cefai & Cooper, 2010; Claiborne, Cornforth, Gibson, & Smith, 2011; Fuwa, 2009; Hanafin, Shevlin, Kenny, & Neela, 2007; Khudorenko, 2011; Konur, 2007; Madriaga, Hanson, Kay, & Walker, 2011; Matshedisho, 2010; Mattson & Hansen, 2009; Messiou, 2006; Moswela & Mukhopadhyay, 2011; C. Smith, P., 2007; M. Smith, 2010). When a student is not included in the daily and/or student activities, the student may be a victim of stigmatisation, which has no connection to a specific diagnosis but is instead, more about the attitudes of others and role expectations. Such negative attitudes are based on perceptions of actions and behaviour, the risk of stigmatisation is probably higher for persons who have difficulty interacting with others or to participate in social activities. All interventions require environmental adaptations. The contribution of impairments and the fact that the same functional problem in different individuals can be dependent on different patterns of influences must be taken into consideration by coordinators and other providers of support. Inclusion likely requires individualised solutions based not only on a survey of perceived problems but also on a discussion of the possible explanations and all aspects of impairment.

Methodological issues

The fact that only 34 students answered the questionnaire means that the results only can be seen as indications. It highlights the importance of the recruitment methods to be used in a larger survey study. One reason for the small number of participants in this study was that coordinators chose not to consent. At a common meeting for coordinators from all HE institutions in Sweden, this study was the focus of a discussion. Some of the coordinators did not assess the study as important, stating that the coordinators' role is to provide pedagogic support and that they have no time to participate in research projects. These somewhat unexpected views indicate the importance of providing an in-depth concrete and explicit rationale of the study to key-persons distributing questionnaires. If possible it is recommended that the researcher participate in meetings where decisions or recommendations about participation is taken. A written rationale and streamed lectures providing a rationale can be distributed to possible coordinators before these meetings. Another option for future research can be to use the questionnaire in a case study where approximately five major universities constitute the cases. With

such a design, coordinators could be asked collaborate personally and a rationale could be developed in dialogue between researchers and coordinators.

Regarding respondents, students with AS were the most represented of the three student groups, most likely because an interest group known as Attention (organisation for persons, relatives and professionals within Neuropsychiatric disorder) highlighted the questionnaire on Twitter (an online social networking service and micro-blogging service) and Facebook. Again, it is recommended that interest groups are approached for presenting a rationale for the study in social media and web-sites.

Regarding the questionnaire some of the items regarding support needs were not indicated as a need by any respondent. It may indicate that further testing of this questionnaire section is needed. In addition, this section as well as the section on supports offered is dependent on the support system and thus have to be designed based on nation specific prerequisites.

Conflicts of interest

The research has been supported by Sunnderdahls disability fund (dnr 38/12)

References

- Aleshina, M. V., & Pleve, I. R. (2010). Social Lift or Social Exclusion? *Russian Education & Society*, 52(8), 34-43. doi: 10.2753/res1060-9393520803
- Cefai, Carmel, & Cooper, Paul. (2010). Students without Voices: The Unheard Accounts of Secondary School Students with Social, Emotional and Behaviour Difficulties. *European Journal of Special Needs Education*, 25(2), 183-198.
- Claiborne, Lise Bird, Cornforth, Sue, Gibson, Ava, & Smith, Alexandra. (2011). Supporting students with impairments in higher education: social inclusion or cold comfort? *International Journal of Inclusive Education*, 15(5), 513-527. doi: 10.1080/13603110903131747
- DSM-IV. (1994). *Diagnostic and Statistical Manual of Mental Disorders* (4 ed.): American Psychiatric Association, APA.
- Fuwa, Kazuhiko. (2009). Is the expansion of higher education in Japan for young students only or for all? A critical analysis from a lifelong learning perspective. *International Journal of Lifelong Education*, 28(4), 459-471. doi: 10.1080/02601370903031306
- Hadjikakou, Kika, & Hartas, Dimitra. (2008). Higher education provision for students with disabilities in Cyprus. *Higher Education*, 55(1), 103-119. doi: 10.1007/s10734-007-9070-8
- Hadjikakou, Kika, Polycarpou, Vaso, & Hadjilia, Anna. (2010). The Experiences of Students with Mobility Disabilities in Cypriot Higher Education Institutions: Listening to their voices. *International Journal of Disability, Development & Education*, 57(4), 403-426. doi: 10.1080/1034912x.2010.524445
- Hanafin, Joan, Shevlin, Michael, Kenny, Mairin, & Neela, Eileen. (2007). Including young people with disabilities: Assessment challenges in higher education. *Higher Education*, 54(3), 435-448. doi: 10.1007/s10734-006-9005-9
- Khudorenko, E. A. (2011). Problems of the Education and Inclusion of People with Disabilities. *Russian Education & Society*, 53(12), 82-91.
- Konur, O. (2007). Computer-assisted teaching and assessment of disabled students in higher education: the interface between academic standards and disability rights. *Journal of Computer Assisted Learning*, 23(3), 207-219. doi: 10.1111/j.1365-2729.2006.00208.x

- Law 1993: 387. (2011). <http://www.socialstyrelsen.se/publikationer2010/2010-6-21/stillunequal-summary>. Retrieved 25 May, 2011, from <http://www.socialstyrelsen.se/publikationer2010/2010-6-21/stillunequal-summary>
- MacLeod, Andrea, & Green, Sue. (2009). Beyond the books: case study of a collaborative and holistic support model for university students with Asperger syndrome. *Studies in Higher Education*, 34(6), 631-646. doi: 10.1080/03075070802590643
- Madriaga, Manuel, & Goodley, Dan. (2010). Moving beyond the minimum: socially just pedagogies and Asperger's syndrome in UK higher education. *International Journal of Inclusive Education*, 14(2), 115-131. doi: 10.1080/13603110802504168
- Madriaga, Manuel, Hanson, Katie, Heaton, Caroline, Kay, Helen, Newitt, Sarah, & Walker, Ann. (2010). Confronting similar challenges? Disabled and non-disabled students' learning and assessment experiences. *Studies in Higher Education*, 35(6), 647-658. doi: 10.1080/03075070903222633
- Madriaga, Manuel, Hanson, Katie, Kay, Helen, & Walker, Ann. (2011). Marking-out normalcy and disability in higher education. *British Journal of Sociology of Education*, 32(6), 901-920. doi: 10.1080/01425692.2011.596380
- Matshedisho, K., R. (2010). Experiences of Disabled Students in South Africa: Extending the Thinking behind Disability Support. *South African Journal of Higher Education*, 24(5), 730-744.
- Mattson, Eva Heimdahl, & Hansen, Audrey Malmgren. (2009). Inclusive and Exclusive Education in Sweden: Principals' Opinions and Experiences. *European Journal of Special Needs Education*, 24(4), 465-472.
- Messiou, Kyriaki. (2006). Conversations with Children: Making Sense of Marginalization in Primary School Settings. *European Journal of Special Needs Education*, 21(1), 39-54.
- Ministry of Employment. (2008). Discrimination Act (SFS 2008:567). Retrieved 5 july, 2012, from http://www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Lag-20011286-om-likabehandl_sfs-2001-1286/
- Moswela, Emmanuel, & Mukhopadhyay, Sourav. (2011). Asking for Too Much? The Voices of Students with Disabilities in Botswana. *Disability & Society*, 26(3), 307-319.
- Regional Ethical Review Board. (2012). Vetting the ethics of research involving humans. Retrieved 4 april, 2012, from <http://www.epn.se/start/startpage.aspx>
- Simmeborn Fleischer, Ann. (2012a). Alienation and struggle: everyday student-life of three male students with Asperger Syndrome. *Scandinavian Journal of Disability Research*, 14(2), 177-194. doi: 10.1080/15017419.2011.558236
- Simmeborn Fleischer, Ann. (2012b). The Support to students with Asperger Syndrome in Higher Education - the perspectives of three relatives and three coordinators *International Journal of Rehabilitation Research*, 35(1), 54-61. doi: 10.1097/MRR.0b013e32834f4d3b
- Smith, Caroline, P. (2007). Support Services for Students with Asperger's Syndrome in Higher Education. *College Student Journal*, 41(3), 515-531.
- Smith, Maria. (2010). Lecturers' Attitudes to Inclusive Teaching Practice at a UK University: Will Staff "Resistance" Hinder Implementation? *Tertiary Education and Management*, 16(3), 211-227.
- SoS. (2009). http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/8407/2009-126-188_2009126188.pdf. Retrieved 30 january, 2012, from http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/8407/2009-126-188_2009126188.pdf
- Stockholm University. (2011). Students with disabilities. Retrieved 10 Maj 2011, from <http://www.su.se/english/study/current-students/studying-with-a-disability>

- Stockholm University. (2012a). Statistics. Retrieved 22 Mars, 2012, from <http://www.studeramedfunktionshinder.nu/english/statistics.htm>
- Stockholm University. (2012b). Studentinfo. Retrieved 12 september, 2012, from <http://www.studeramedfunktionshinder.nu/english/studentinfo.htm>
- Swedish National Agency for Higher Education. (2011a). Adresses to Universities. Retrieved 10 january, 2012, from <http://www.hsv.se/densvenskahogskolan/universitetchogskolor/adresslistaibokstavsordning.4.539a949110f3d5914ec800062390.html>
- Swedish National Agency for Higher Education. (2011b). Höskoleverkets årsrapport 2011. Retrieved 10 January, from <http://www.hsv.se/download/18.64c5e8ee1325cbb0e518000532/1108R-tabellbilaga-universitet-hogskolor-arsrapport-2011.pdf>
- Swedish National Agency for Higher Education. (2012). Higher Education in Sweden. Retrieved 15 January, 2013, from <http://www.hsv.se/highereducationinsweden.4.28afa2dc11bdcdc557480002000.html>