

Deutsches Studentenwerk (DSW), the German National Association for Student Affairs, is the umbrella organisation of the 58 Studentenwerke, the student service organisations in Germany. The Studentenwerke are non-profit service-providers for students and institutions of higher education. They ensure the social dimension of higher education in Germany. They promote the social, economic, financial, cultural, and health-related concerns of all students in higher education institutions. The Studentenwerke operate student residence halls and dining services, they provide social and psychological counselling, administrate federal financial aid (BAföG), and assist German and international students on an equal basis.

The Informations- und Beratungsstelle Studium und Behinderung (IBS) is the national center of competence for the inclusion of students with disabilities. It advocates the unimpeded access to higher education and equal rights in higher education for people with disabilities and chronic illnesses in Germany. It provides information and counselling services on the subject of higher education and disability. The IBS is therefore the national contact point for prospective students, students and counsellors in higher education institu tions, employment agencies, and student service organisations. It represents the interests of students with impairments in relation to government, administration and the general public. The IBS was established in 1982 at DSW upon a recommendation of the Standing Conference of the Ministers of Education an Cultural Affairs of the Länder in the Federal Republic of Germany. It is financed by the Federal Ministry of Education and Research (BMBF).



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Studying with Impairments

Special Survey on the Situation of Students with Disabilities and Chronic Diseases in Germany

- Key Results -

Special Survey Studying with Impairments

8% of the student population in higher education in Germany has a disability or chronic disease. Who are they? How does the disability affect their studies? How can the vision of a "university for all" be turned into reality? This new study provides (some of) the answers.

In the summer semester of 2011, approximately 16 000 students with health-related impairments that negatively affect their studies participated in an online survey by Deutsches Studentenwerk, DSW (German National Association for Student Affairs). The students were asked about their concerns regarding choosing their field of study, completing and financing their studies. The surveyed students are enrolled at about 160 German institutions of higher educa-

With the publication of "Studying with Impairments," Deutsches Studentenwerk presents for the first time reliable and representative data on the social situation of students with impairments and chronic diseases in Germany.

The survey was carried out by the Institute for Advanced Studies in Vienna and financed by the Federal Ministry of Education and Research in Berlin.

Due to their healthrelated impairments, many students in Germany struggle with time-related and formal constraints of their studies such as tight exam schedules, the rigid seguence of modules or mandatory attendance requirements. Academic staff often doesn't pay enough attention to impairment-related concerns, and necessary

assistance such as lecture

notes in an accessible

form is often lacking. Although counselling services and academic adjustments are helpful, they are often not used. For the most part, this is because students are either unaware of such programmes or refrain from revealing their impairment. Almost three-quarters of these students are faced with additional costs; 15% have massive problems in securing financial aid. Mobility or sensory impairments negatively affect the studies of 12% of participants in the study. The vast majority of them is suffering from psychological or chronic somatic diseases. 6% of those surveyed have dyslexia or another specific learning disorder. Almost two-thirds of respondents indicate that they face strong or very strong impairmentrelated obstacles during their studies.

Usually invisible

45% of the students who participated in the survey feel that psychological impairments have the greatest impact on their studies; 20% attribute this to chronic somatic diseases (e.g. allergies, rheumatism, tumours): 6% to specific learning disorders such as dyslexia; 5% to visual impairments; 4% to mobility impairments; and 3% to hearing or speech impairments. 13% of the surveyed students indicated equal levels of impact from multiple impairments. Female students suffer more frequently from psychological impairments and/or chronic somatic diseases, while male students are more likely to exhibit specific learning disorders. One out of four students surveyed indicated that the impairment negatively affecting their studies developed only during the course of their studies. Most impairments and chronic diseases are not visible to others: only 6% of the students have an impairment that is apparent at first sight.

Not enough time

The impairment had a strong influence in choosing their field of study for almost 50% of students. The particular study conditions and career opportunities played the most important role in their decision-making. Almost 60% of the students indicated that the impairments had a strong or very strong impact on their studies, while 30% indicated a medium and 10% a mild impact. The difficulties arising during the course of studies are multifaceted: 70% of students mentioned time-related challenges in course and examination regulations; 61% mentioned organisational course challenges;

63% had difficulties in the organisation of lecture and exam situations; and 17% mentioned difficulties with work placements and excursions.

Academic adjustments - for me, too?

Only 27% of the surveyed students have actually submitted at least one request for academic adjustment for impairment-related difficulties encountered during their studies, exams and/or when attending lectures. However, 75% of those requests were at least partially

successful, 43% of the students who did not apply for academic adjustments believed that they are not entitled to them: 44% did not want special treatment; and 33% did not want to reveal their impairment to others. The main reasons for rejecting applications are that academic staff is unwilling to adapt their teaching methods, the academic adjustment is not considered in line with study regulations or the impairment is not accepted as a justification.

44% do not want to reveal their impairment

Although 60% of the surveyed students indicate that they face strong or very strong impairment-related obstacles during their studies, only 24% have made use of a counselling service offered by the local Studentenwerk (student service organisation), universities or student government. 44% of students do not use counselling services because they do not want to reveal their impairment, 36% feel that the counselling services do not address their specific needs.

Accessible universities and student service organisations

13% of surveyed students are dependent on easy access to and usability of facilities at universities and student service organisations. Good acoustics, illumination and ventilation of the rooms are important for 38% of the students. One-quarter of the surveyed students expressed a desire for special rest areas at institutions of higher education. Affected students criticise infrastructural barriers that they encounter in lecture halls and seminar rooms. Students have needs like online access to documents in an accessible format, special terms for borrowing from libraries, texts in spoken form and study assistance such as readers or sign language interpreters. There is a particularly strong demand for supplementary services at psychological counselling centres and dining services that accommodate the concerns of chronically ill students. Assistance and supplemental services are inadequate in many cases.

Insufficient financial aid

71% of the students have to confront additional impairment-related costs. In

many cases, this involves special needs not related to their studies such as medical consultations, psychotherapy or medication. Additional costs to cover study-related special requirements – such as study or communication assistance and mobility or technical aids – have to be paid by 9% of surveyed students. Students with impairments use the same sources of funding as students without impairment, which is mainly family support and federal financial aid (BAföG). Slightly more than 2% receive additional

impairment-related social welfare benefits. although they should be available to them by law. 15% of the surveyed students indicate that they cannot cover their living expenses in an adequate way.

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www.best-umfrage.de

Full text and English abstract of the study

www.studentenwerke.de/behinderung Further information on students with disabilities in Germany

Overview of Important Data

16 000

students with impairments participated in the survey, making the results nationally reliable and representative

94 %

have an impairment that is not visible at first sight

25 %

developed their impairment only during the course of studies

6 %

have a special learning disorder such as dyslexia

8 %

have a disabled person's pass

47 %

indicate that the impairment played an important role when choosing their field of study

60 %

indicated strong or very strong impairment-related obstacles during their studies

44 %

face difficulties with tight class or exam schedules

48 %

face difficulties with mandatory attendance requirements

41 %

of granted academic adjustments were very helpful

45 %

know the counsellor for students with disabilities

13 %

require accessible buildings and infrastructure

25 %

would appreciate more rest areas in higher education institutions







My Life - My Studies - My Impairment



Patrick W.
I have to avoid putting my heart under heavy strain and exposing myself to stress. I get tired more guickly and need longer rest phases. Due to my blood pressure medication, I have to go to the toilet frequently: five times is not unusual for me during a longer seminar or exams. The frequent interruptions of my concentration were especially problematic in my law exams because having sufficient time is a prerequisite for a good exam in this subject.

Until about one year ago, I had not heard of academic adjustment. As strange as this may sound, I still don't consider myself to be chronically ill despite the above-mentioned effects. I pay more attention to my body now, but I don't believe that focussing on the disease is the right path to achieving a fulfilled life.

Many people discouraged me from applying for the disabled person's pass because this data is shared among all authorities and might significantly reduce job opportunities. I feel grateful to my amazing family doctor. I am doing much better today thanks to her. I am also thankful for my sense of humour, which still allows me a smile at the lecturer's behalf. But I am who I am and I am not the facial impression that says 'again?' when I am on my way to the toilet for the fifth time during the same class."



Katrin E.

I have relatively frequent MS episodes that cause me to miss time during my studies. Due to medication and side effects. I am often required to stay home. The medication sometimes has a very strong effect on my concentration, which is why I had to postpone my last three oral exams. I already have to be so disciplined just to manage my everyday life. My studies also require a great deal of discipline and perseverance on top of that. The disease is a constant up and down. for people in wheelchairs are mounted I take full advantage of the good days. During the semester, I could only attend two or three lectures or seminars because the preparation and follow-up was too strenuous and exhausting for me. Sometimes I think that I cannot move one single step forward because my legs are so heavy. The disease is associated with many medical consultations, stays in hospital, physical therapy, ergo-therapy, etc. Sometimes this feels like a part-time job that I need to take care of.

It has never occurred to me to quit my studies because of my disease. That would mean allowing the illness to completely determine my life and make decisions on my illness. Some problems only arise during the course of studies. Then I need to look for support and seek the right contact person to find creative solutions. This quality of finding creative solutions and being flexible will definitely be helpful in my later professional



Michaela K.

I depend on an electric wheelchair and can't climb any stairs. My biggest problem are buildings: Lecture halls, seminar rooms, administrative offices and counselling centres often do not provide easy access despite existing building codes. Or the wheelchair access is not indicated. I can't even open the doors in renovated buildings due to their weight and they don't have any electric door openers. Sometimes doorbells at pedestrian height, which makes them inaccessible when seated. The new elevators don't have automated floor announcements. There still seems to be a severe information deficit at the universities.

It is mostly my parents who support me emotionally and financially. The social welfare office also significantly contributes to the success of my studies by assuming the costs for my study assistance needs. It would not be possible for me to pursue my studies without this safety net. The support 适 from my private environment is unparalleled. Despite setbacks, it is precisely this encouragement that allows me to continue believing that people with impairments will be accepted by society someday to such a degree that I can eliminate the guestion 'Do you have easy access to your office and how can I find it?' from my vocabulary for good."



Katrin D.
I depend on assistance in order to manage my studies. The assistants who work for me right now do as much as they can. However, they also have a limited capacity to help because they also need to complete their own studies. Furthermore, I am unable to study without technical aids such as a Braille Note device, hearing aids and micro port equipment which I currently do not

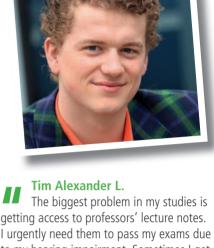
The biggest problem is convincing the teachers to provide necessary materials in a digital form in due time, pass on my microphone, or to let me participate in the courses in the first place. It should no longer be the case that every single student with impairment is forced to petition every lecturer in order to specify and assert his or her needs. If a few professors would demonstrate a little more flexibility and goodwill and the overall conditions at the university would be somewhat friendlier for disabled persons, there wouldn't be so many difficulties for students affected by impairments.

A few provisions, legal regulations, and academic adjustments already exist but unfortunately they are not thoroughly implemented. Students with impairments must obviously do their share, but it is hard for them to find the right words when facing a lecturer who refuses to help. This is humiliating and discriminating. I am at a loss for words each time. At least this is how I feel."



Anna S.
The particular problem with my anxiety disorder was and still is that although there are contact points for psychologically ill people on campus obviously, they can only help students if they contact the counsellors themselves. If this is not possible, these students are completely on their own. With about 40 000 students, such individual hardships simply get lost in the shuffle. It is difficult to cope with the administrative requirements and organising studies when you have a mental illness — especially due to the tight corset of study regulations.

That I was able to resume my studies after a three year involuntary break is thanks to my therapist. Together, we have developed a strategy with which I hope to find my way back into university activities in small steps which means without excessive demands on myself. I also recently joined a self-help group at the university. However, it is my fulfilled private life and the people in it that give me the courage for this second attempt. Who I am is no longer defined by whether or not I complete my studies."



getting access to professors' lecture notes. I urgently need them to pass my exams due to my hearing impairment. Sometimes I get lecture notes that are no longer up-to-date or very poorly structured, which makes them difficult to read and understand. When I started my studies, there was no department for students with impairments so I lacked counselling and support. In the meantime, I have become actively involved and head a department for equal treatment that also aims to be a contact point for international. homosexual, and feminist students. Fellow students give me support by sharing their notes, which helps me a great deal. The Federal Working Group for Disability and Higher Education provided me with information. I believe in myself. And this helps me to master my studies. I am inspired by the law of nature that has become my eccentric quiding principle: CREATE OR DIE!"



The biggest impairment of being dyslexic in my studies is the large amount of texts that I need to cope with. This sometimes really knocks me out. But this can be easily compensated with the right literature. I receive a great deal of support from fellow students who look over my texts and term papers or from the Office of the Dean of Students which supports me in compensating for my disadvantages."

There Is Usually No Simple Solution!

Interview with Dr. Maike Gattermann-Kasper, University of Hamburg, Office for Students with Disabilities or Chronic Diseases

Who is using your counselling services?

About one out of four people visiting my office are prospective students. They sometimes bring their parents or other reference persons. The other 75% are currently enrolled students. Employees from student advisory and examination offices, as well as academic staff, also approach me. The overall number of people seeking advice has continuously increased over the last years.

What kind of students come to your office for advice?



definition of disability, but they are certainly disabled in the legal sense. A significantly smaller portion of the people seeking advice is blind, hearing impaired or depends on a wheelchair.

What kind of questions do students frequently ask?

Above all, prospective students seek advice concerning hardship and academic adjustment provisions in the registration and admissions process. Students often have complex concerns regarding the flexible design of their course of studies and workload, as well as the adjustment of exam requirements. Frequently, this also involves questions of study financing. From my perspective, many students come here too late — when they have already encountered significant study-related problems that need to be taken care of immediately.

Do you always find a solution?

There is usually no simple solution. If this were to exist, my services would not be necessary. I see my mission as assisting students to find a suitable way to successfully complete their studies or — if this is not possible — at least find a feasible way. In many cases, reaching a sustainable solution

for the complex concerns of people seeking advice is only possible in cooperation with colleagues of other university departments or external organisations.

Would you advise every student with an impairment to make it public?

I think that this depends on to whom and for what purpose students reveal their situation. Counselling sessions are always confidential and their content may not be passed on to third parties under German data protection regulations. In this respect, I think that it makes sense when students at least reveal their impairment to us or other counselling centres and also seek preventive help. Within the scope of the counselling session, we can then consider whether it makes sense or not to reveal an invisible impairment to academic staff or fellow students. If students require adjusted study or exam conditions, there are no alternatives to reveal the situation. Yet, many students do not use these opportunities because they fear possible disadvantages. However, foregoing these opportunities may intensify the problems.

How do you raise awareness among students, academic staff, and administrative personnel for the topic of students with invisible impairments?

Even though these impairments are frequently imperceptible, we can still make this topic visible at institutions of higher education. For example, a specific service

Personal Details

Dr. Maike Gattermann-Kasper has worked at the Office for Students with Disabilities or Chronic Diseases at the University of Hamburg since 1998. Since then, she has been the coordinator for students with disabilities or chronic diseases. She is also involved in voluntary work as the head of the working group for higher education policy at the German Association of Blind and Visually Impaired People in Higher Education and Profession (DVBS e.V.).

Dr. Maike Gattermann-Kasper



for psychologically ill students called HOPES (Help and Orientation for Psychologically Ill Students) has been in place for more than ten years at the University of Hamburg in the area of psychological counselling. This service has significantly increased the acceptance of psychologically ill students and therefore fights stigmatisation. Furthermore, we were able to implement coaching and training programmes that strengthen the perception and competencies with regard to diversity, promoting inclusion as a result.

What must be changed?

The topic of students with impairments is not just a subject of counselling. It should become standard procedure that representatives for students with impairments are involved in the development of all structures and processes that are relevant to this student group from the very beginning. I believe that this is the only way to achieve a "university for all" that was postulated in the recommendation of the German Rectors' Conference regarding higher education with disabilities and/or chronic illnesses.

At my university, for example, this works very well in the area of study and work placement. As a result, we have systematically embedded academic adjustments that are continuously revised from a legal and practical perspective for the benefit of student applicants and current students.

What is the biggest problem for people with impairments in mastering their studies?

An institution of higher education is a complex system with a wide range of offers, but it also comes with a variety of difficulties that are challenging for everyone. However, students with impairments are frequently asked to make additional organisational efforts in order to reconcile study-related and impairment-related requirements. This is why they need more flexibility or even additional time to complete their studies. Another factor is that institutions of higher education have very little or no influence on some basic conditions for students with impairments. This applies especially to the contradictions between everyday life at university and social and welfare laws.

Is it true that ...



... there are no students with impairments at many institutions of higher education?

Wrong assumption – many of those who are affected cannot be recognised as such. For example, just 6% of these students can be immediately identified as having a medical impairment since they are in a wheelchair or use a white cane. In contrast, about two-thirds of them – including many with chronic physical or psychological diseases – manage to remain invisible in the long term. Incidentally, the visibility of impairments does not indicate the amount of obstacles during their studies.

... academic adjustment is just another word for benefit?

No – the purpose of academic adjustment is to overcome existing barriers and impairment-related disadvantages in the admissions process, during studies and related to exams on an individual and situation-based level. Students with impairments are entitled to these adjustments by law. The design of such measures is developed in a dialogue with administrators at institutions of higher education, boards of examiners and academic staff. Binding regulations serve the transparency and verifiability of various measures.

... new facilities of higher education are always easily accessible?

This is incorrect – although they have ground level entrance, elevators and bathroom facilities for the disabled, this unfortunately does not remove all of the physical barriers. Depending on the impairment, missing electronic door openers, inadequate guidance systems for the blind, poor acoustic conditions or insufficient rest areas can represent obstacles for impaired students

... many students with impairments forego their rights?

This is correct – the right to academic adjustment is granted by the higher education acts of the German federal states. However, many students do not take advantage of academic adjustment either because they do not want special treatment due to fear of stigmatisation or because they are unaware of their eligibility. But many are also discouraged by the ignorance or negative attitude of academic and administrative staff.

... chronically ill students lack a contact point at institutions of higher education?

This is a misunderstanding – many students with chronic diseases do not consider themselves as being disabled and therefore do not feel that the respective counselling service addresses their needs. Coordinators for disability matters and counsellors for people with disabilities are not just contact points for students with physical and sensory impairments, but also for students with chronic somatic or mental health problems and those with dyslexia and other special learning disorders.

Comments



Prof. Dr. Horst HipplerPresident of the German Rectors' Conference

"The universities have declared their intention to do everything in their power so that a physical or health-related impairment does not get in the way of successfully completing studies at institutions of higher education in Germany. They have also expressed this with the German Rectors' Conference recommendation of a 'university for all'.

The challenge is to dismantle infrastructural obstacles on the one hand, but also to tune the study courses and teaching to the needs of students with impairments. The goal is to encourage students with impairments to

pursue higher education. And the university administration and staff must also be encouraged to increasingly deal with this topic and to consider the needs of these students in all their activities.

All this is indispensable, but not so easy when faced with the necessary efforts that must be mastered due to the sharp increase in student numbers."

www.hrk.de



Senator Ties Rabe
President of the Standing Conference of the
Ministers of Education and Cultural Affairs
of the Länder in the Federal Republic of
Germany

"The present study makes it very clear that structural barriers in facilities, funding problems, or the conception of degree programmes pose a particular challenge for students with impairments or chronic diseases and can negatively affect their studies. Academic adjustment provisions and quotas in the admissions process were important steps towards paying more attention to the special situation of these students in the past. Today, only degree programmes that are accessible for students with impairments or chronic diseases can obtain the necessary accreditation.

Although this is an encouraging development, the German federal states and institutions of higher education must continue to work together to promote the improvement of study conditions. For instance, the Standing Conference has reacted to student criticism of the Bologna reforms with comprehensively changing the structural guidelines in February 2010. At the same time, it encouraged institutions of higher education to use the flexibility in the

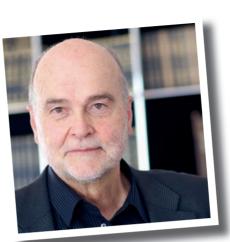
structural guidelines such as those related to the duration of a bachelor degree programme or the successful completion of study modules.

The focus for the evaluation of degree programmes continues to be the number of exams, the study curricula, the facilitation of study abroad, the ratio of compulsory and optional modules, the admission to other institutions of higher education and the transition to Master's degree programmes. The German federal states have either already modified their higher education laws or initiated measures for an effective implementation of the higher education reform. Many guidelines, guiding principles or orientation frameworks were also introduced at the institutions of higher education with the participation of students.

These intensive efforts of the federal states and institutions of higher education will also immediately benefit students with impairments or chronic illnesses."

www.kmk.org 를





Prof. Dr. Dieter TimmermannPresident of Deutsches Studentenwerk,
DSW (German National Association for
Student Affairs).

"First of all, this special survey has encouraged us at Deutsches Studentenwerk in our political advocacy work for students with impairments or chronic diseases and we are happy to have such detailed data available about their study situation.

The research provides a multitude of insights for the concrete work of the student service organisations in Germany. The portion of invisible impairments among students is very high, but many of them refrain from revealing their impairment. Disability and higher education — this still appears to be a taboo, even for those who are affected.

Counselling and academic adjustments are effective, but the affected students are still not familiar enough with them. This also means that far too many students with impairments are unaware of their rights. Insufficient study financing remains a central problem. This not only involves sign language interpreters and student assistants, but also additional expenses in the cost of living."

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Glossary

Studying with Impairments

Accessibility

Difficulties often arise for people with health-related impairments because the university environment is not accessible. This results in limited access and usability of services and facilities. The goal is to dismantle structural, communicative and didactic obstacles. Whenever barriers impede self-determined participation in higher education, individual academic adjustments must ensure equal study conditions.

Disability

According to the UN Convention on the Rights of Persons with Disabilities people belong to the group of persons with disabilities if they have a long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder their full, effective participation in society on an equal basis with others. In clear words, this means: "People are not impaired, but are being impaired."

Equal rights and the principle of non-discrimination

Federal and state legislation require institutions of higher education to ensure that students with disabilities are not disadvantaged in their studies and can study at institutions of higher education without the help of others as much as possible.

Chronic diseases

Chronic diseases may be longer-lasting illnesses or those with an episodic progression such as chronic bowel disease or epilepsy. If they lead to an impairment of social participation, they fall under the legal definition of disability in Germany.

Inclusion

Institutions of higher education are inclusive if their members accept the heterogeneity of students and academic staff, value diversity, and create the conditions for everyone to partici-

pate on a self-determined and equal basis. They follow the guiding principle of "it is normal to be different" in this process.

Disability-related additional requirements

Students often incur additional impairment-related costs. For example, they might need sign language interpreters or transport services. Additional costs may also result from increased expenses for accessible housing space, toiletries, medication, etc. Under certain conditions, social welfare providers cover these additional costs.

Academic adjustments/disability compensation

Academic adjustments aim to offset impairment-related disadvantages on an individual basis. Students with impairments need academic adjustments in the admission process to higher education institutions, during their studies, and when taking examinations, but also for federal financial aid (BAföG) or the use of facilities at the institutions of higher education and student service organisations.

Severe disability

If the degree of disability is officially determined to be at least 50, the responsible authority will issue a disabled person's pass upon request. This can be helpful to apply for integration assistance in higher education or academic adjustments in the higher education admissions process.

Integration assistance

Integration assistance for persons with disabilities is stipulated under the German federal law on social welfare assistance (Eingliederungshilfe, Sozialgesetzbuch SGB XII). For example, the Eingliederungshilfe pays for study and communication assistants, technical aids or additional transportation costs.