Studying with impairments

The situation of students with disabilities and chronic conditions



11

Deutsches Studentenwerk

best2: The results at a glance

11% of the roughly 2.8 million students in Germany have a study-affecting impairment. What are the obstacles they face in studying? How are their difficulties compensated for? What has changed since the first survey in 2011? Nearly 21,000 students with impairments took part in the second "beeinträchtigt studieren – best2" survey among 153 higher education institutions in the winter semester of 2016/2017.

The group of students with study-affecting impairments is heterogeneous. Impairments can only be immediately recognised among 4% of these students, whereas well over two thirds (67%) never show any obvious signs of them. More than half of the students (53%) have a mental health condition that complicates studies, and this group has grown by eight percentage points since 2011. 20% face difficulties in studying because of chronic somatic conditions such as multiple sclerosis, rheumatism or epilepsy, 10% because of motor or sensory impairments, 4% because of dyslexia and other specific skill conditions, and 6% because of other impairments. 7% have several equally severe study-relevant impairments. Thus three out of five students with study-affecting impairments face considerable difficulties in studying (62%).

A multitude of obstacles

Nine out of ten students (89%) refer to impairment-related difficulties in organising and carrying out their studies and in exams and teaching situations. As was already the case in 2011, they arise most frequently through the high density of exams, compulsory attendance and deadlines for achievement. 7% experience difficulty owing to constructional obstacles, insufficiently equipped facilities or a lack of refuge spaces.

Difficulties studying: often hidden

Around 44% of students have impairment-related difficulty in social interaction that may trigger or amplify problems in studying. Fear of being rejected and stigmatisation as well as negative experiences with outing complicate communication with teachers, fellow students and administration. **89%** have difficulties conducting their studies: 65% in connection with tests and exams, 57% in the field of organising studies, teaching and learning, and 44% with contacts and communication at higher education institutions.

96% state that their impairment is not

directly perceptible

to others.

73% regard their approved academic adjustments as very helpful. **79%** would definitely choose their study programme a second time with regard to their impairment.

64% of them have impairment-related additional costs, while only 3% of them receive social security

benefits.

50% (also) take advantage of support from their family and friends to compensate for impairment-related difficulties in studying.

21,000 Participants

57% are familiar with the specialised counselling services available to students with disabilities and chronic illnesses.

Academic adjustments claimed too seldom

As in 2011, less than a third (29%) of the students claimed academic adjustments at least once and, most frequently, for concrete exams situations. 62% of the claims were accepted on average. Three out of four beneficiaries (73%) view the measures as helpful. Students forego benefits because the preconditions for claiming them are not straightforward, they have inhibitions, or they want no "special treatment".

Family support is provided

Three quarters of the students take advantage of self-organised measures to compensate for disability-related difficulties, the majority of them exclusively. Support by the surrounding family, physicians and therapists is of special importance in this context. Every third student is supported by his or her fellow students.

More awareness of counselling services

Nine out of ten students are familiar with at least one specialised counselling service of higher education institutions and the student services, and one third have made use of at least one of them – significantly more than in 2011. The chief topics are coping with one's own restrictions and applying for academic adjustments. Three out of five students have benefited from counselling. Needs-oriented support is seen as particularly important in entering studies.

Insecure financial support

Two thirds of the students have additional impairment-related maintenance and studying costs that represent a financial burden for them. Every sixth student has no secure maintenance.

www.best-umfrage.de

83% had their impairment before they started studying.

Studying? Works! Five encounters

Christian Opitz, 29 | History and Politics Degree/Public Administration at higher subject-related semester level | University of Potsdam | Impairment: Paraplegia

Ever since I had a serious bathing accident, I have been a paraplegic and needed a wheelchair. Of course this has had a huge impact on my day-today life as a student. Access to the university facilities and the distances between the university sites and buildings are particularly difficult for me. A faulty lift can mean that I have to miss a lecture.

The University of Potsdam provides me with a very good environment to study in. In particular, this includes a good support network within the university itself. The coordinator for students with disabilities, the examination office and also many of the faculties work together closely. Via various academic adjustments, I can largely make up for my impairments, for example by being given more time for written tests, which I need because my hands are partly paralysed, and through the option to withdraw from tests beyond the deadlines set. So operations or a worsening health condition do not automatically jeopardise my studies.

My advice to all those with impairments who are keen to study is to find out in advance about academic adjustments and the structures within the university. Get in touch with the counselling centre for students with impairments. A site or campus tour at the university of choice is particularly recommendable for students with physical impairments.

Inken Kanbach, 30 | Health Management Degree | 8th semester | Fulda University of Applied Sciences | Impairment: Chronic Inflammatory Bowel Disease

Since I was eleven years old, I have had Morbus Crohn, which occurs spasmodically. Many doctors' and clinic appointments, drugs and their side effects as well as severe abdominal pain and numerous infections have contributed to my not always being able to attend university events. So there is a lot I have to catch up on. My illness means that I often have to frequent the toilet. So academic adjustments, such as providing more time to cope with exams, written tests and seminar papers, is very important for me.

Despite my health condition, I opted for an internship at the University of Otago/New Zealand. That was a great experience, although my first thought was always to check out the sanitary facilities. I have received much support, in particular from the official responsible for international "Find out in advance about academic adjustments and the structures within the university."

— Christian Opitz





Top to bottom: Christian Opitz, Sabine K., Inken Kanbach

mobility and my department's programme coordinator. They have always had a sympathetic ear for me.

But things would hardly work without the strong backing given by my family, my friends and my partner. Communicating with others in a similar situation, my self-help association, is just as important, as is talking to people who do not have the same illness. However, I would like to experience more open communication with teachers, so that they can get a better idea of my situation. I would recommend others to never give up, because studying really is worthwhile!

Sabine K., 27 | Bachelor degree at higher subject-related semester level | Technische Universität Ilmenau | Impairment: Manic-depressive Disorder

My illness involves mood and concentration swings. It is particularly difficult for me to concentrate in a noisy environment. I have had several longer clinic stays to get my medication re-adjusted. I can work effectively but need more rest and regular regeneration periods. I have learnt how to reduce the pressure I put myself under. A study plan specially attuned to my needs and academic adjustments, such as more time and smaller rooms for written tests, help me cope with my studies, as does the support provided by university and student service staff. My reliable network of family members, friends, my psychologist and my neurologist is just as important.

When I started studying, more information for students with disabilities would have been helpful, since I would then not have had to out myself as someone with a health impairment. And what is very important to me is having more sensitive students and staff at the university who don't look at students solely as individuals with an impairment.

My advice to all students in a similar situation is that if you are dreaming of studying, do your best and put your heart and soul into doing it! Make friends! And take care of yourself! This also means complying with medicine prescriptions. Only then can your studies and your life as a whole stabilise so that you will be able to successfully graduate.

Sonja Borowski, 25 | Masters degree in Research, Development and Management | 3rd semester | Kiel University of Applied Sciences | Impairment: Dyslexia

My dyslexia can be spotted in all the papers I write. I therefore have my text checked in terms of sentence structure, spelling and punctuation by several people in my environment. This requires good planning and much coordinating. It also takes me more time to read texts and answer questions in written tests.





— Jennifer Friedauer

Top to bottom: Sonja Borowski and Jennifer Friedauer • During my Bachelor studies, I was entitled to academic adjustments up to my fifth semester. I was given more time for written tests, and it was not allowed to give marks for spelling in my case. In addition, I was given an extra room to write my tests. From the sixth semester on, my applications were no longer approved to this extent. Unfortunately, neither I nor others can explain why this should be the case. I believe that in order to create equal opportunities in university studies, appropriate regulations have to be in place on academic adjustments – also for students with dyslexia.

So far, I have been able to master my studies thanks to my parents, who, in addition to providing personal support, also paid for expensive educational therapies, as well as the many "little correction helpers". The officer for social issues of the student union and the university's officer for diversity are other important supporters. But what has been most important to me is communication with others having the same impairment. The group of "Young Activists" of the Federal Association for Dyslexia and Dyscalculia creates an environment for many individuals in which, for the first time, they feel that they and their way of living is understood and accepted.

Jennifer Friedauer, 27 | Masters Degree in Education Science and Social Science | 5th semester | Ruhr-Universität Bochum | Impairment: Visual impairment

As a severely visually impaired person, I do a lot of my work through hearing, also when taking notes in lectures. Teachers and fellow students support me and take into consideration that I require written material in large print and reading takes me more time. The biggest effort for me is to read the large number of texts outside the lectures and seminars. As a rule, to prepare and process contents, I use one of the eight specially equipped PCs at the Inclusion Counselling Centre (BZI) of the AKAFÖ (the student service organisation in Bochum). Unfortunately, these workplaces are not always available because other students with impairments need them too – for example for written tests. Early and central information on closing and engaged times and a reliable usable alternative would be a big help for me.

The BZI made it a lot easier for me to start studying. There, I learnt how to handle my impairment and communicate with other students with impairments. I have become more aware of my strengths and weaknesses and now work as an academic assistant alongside my studies.

And now I also know how important communication is. What counts is that communicating about studying with impairments and the problems that arise in such a situation can only be performed with and by those affected themselves!

"Could **Stephen Hawking** have studied in Germany?"

What about equal opportunities for students with impairments at our higher education institutions? Prof. Dr. Barbara Welzel, Vice-rector for Diversity Management at TU Dortmund; Frieder Kurbjeweit, a student and activist in the University of Bremen's interest group "Interessengemeinschaft Handicap", and Sandra Mölter, Head of the Contact and Information Centre for Students with Disabilities and Chronic Illnesses at Julius-Maximilians University Würzburg, discuss the issue.

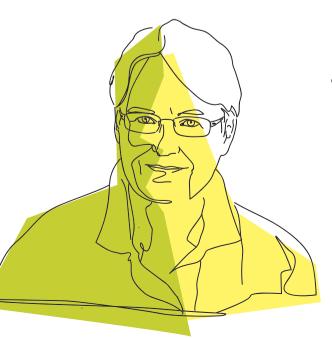
DSW: Has the UN Convention on the Rights of Persons with Disabilities (UNCPRD) of 2009 been implemented in higher education?

Frieder Kurbjeweit: No. I can't claim that the general goal of participation for persons with impairments has been achieved at the University of Bremen or elsewhere. Therefore, I would say that it's hardly known, not understood and not internalised, either!

Barbara Welzel: The Convention is extremely helpful for university management. We no longer need to discuss whether we intend to provide scope for participation and create accessibility. It's all about law in force that we have to comply with. Therefore all that I discuss is how we implement this law. **Sandra Mölter:** The UNCPRD has reached the University of Würzburg. Certain changes are perceptible throughout the country, too. But there are still considerable discrepancies regarding the level of implementation at individual universities.

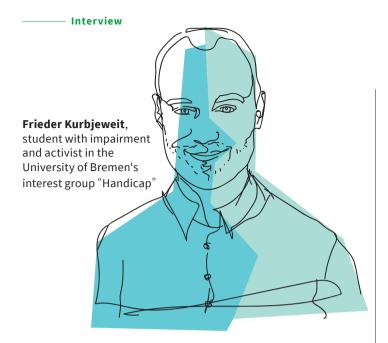
What kind of restrictions and obstacles do students with impairments face?

Kurbjeweit: Obstacles above all exist in the structures and in everything to do with the organisation of degree courses: inflexible study regulations, compulsory attendance, etc. The problem is that there are people with impairments and there is a structure that does not handle them well. Academic adjustments and accessibility is not enough. ►



"University management requires the support of the counselling centres, and it has to strengthen them."

Prof. Dr. Barbara Welzel, Vice-rector for Diversity Management at TU Dortmund



"Has the UN-BRK been implemented in universities? I'd have to say: it's barely known – neither understood nor internalised!"

> ► **Welzel:** We have to ask ourselves quite clearly: Could Stephen Hawking have studied at our universities? That's the standard we must talk about.

Academic adjustments ought to enable equal opportunities. Does this instrument work?

Kurbjeweit: What was really frightening about the first "best" Survey of 2011 was the considerable fear among students with non-visible impairments of being stigmatised. This is a reason many of them do not come to the counselling centre and don't even use academic adjustments as an instrument that could help them. But compensation alone will not lead to an inclusive university. This requires a different mind-set.

Mölter: There are clear, straightforward regulations for academic adjustments, and they have to be applied. However, some professors still believe that academic adjustments amount to an advantage. But it's about making up for a disadvantage, not about an advantage!

Kurbjeweit: We are always confronted with applications. Other people decide whether they are appropriate. I don't want to have to keep on justifying myself, and I don't want to be faced with scepticism, either. Of course you always get those who say: Well, are you sure that you really belong in a university?

Welzel: It is unacceptable that individual students should have to convince their professors of their right to academic adjustments. This communication has to be performed by the counselling centre, the respective university department and the legal department.

Mölter: Academic adjustments in the case of mental health conditions is a big topic. Dyslexia, or reading and writing disorders, is another one. Here, some universities offer academic adjustments, and others don't. This is an area where I can see a considerable need for action, and that means providing information.

Welzel: But in order to provide information, we urgently need the "Informations- und Beratungsstelle Studium und Behinderung" (IBS), the national centre of competence for the inclusion of students with disabilities, which also has an impact on the Rectors' Conference and the public at large.

What kind of support do teachers and university management require?

Welzel: Management needs expert support and has to strengthen the structures. Counselling centres and self-help groups have to work knowing that they are supported by management. This is the step that we have made throughout the country with the "Hochschule für Alle" (University for All) campaign.

Mölter: Expertise and training programmes are important. They are already being provided by the IBS or by various universities. Many also run further education measures on didactics free of barriers or address the topic in the context of general seminars.

Welzel: A medium-sized university can provide a lot, but a small University of Applied Science is already unable to achieve this because it simply doesn't have the staff. Centres could be created to provide certain services for others as well. This is where politicians have to take action.

Kurbjeweit: It is not enough to appoint someone who then works with students with disabilities. For example, we are asked how things can be built free of obstacles. I know a little about this and can say what is really bad, but that's not expertise.

How can I demonstrate to students with impairments that the university is there for them?

Mölter: For instance, teachers could point out at the beginning of a lecture or seminar that there are services for students with impairments. They can show that they can be contacted.

Kurbjeweit: Such announcements in lectures and seminars have to be obligatory. They're well worth the three minutes they take.

Welzel: If there are teachers with impairments, this can show students with impairments that the university offers them scope and perspectives. In addition to concrete support, that has always been the biggest motivation that I have experienced.

Can you make use of the "best" data in your work?

Welzel: Data certainly provides a good reference point to build up a case. We lose a lot of information if we only have major surveys that do not show the details. That's why I think the best survey is so important. **Kurbjeweit:** At last the facts are plain to see. The survey demonstrates where the biggest problems are.

Mölter: The results help us develop our programmes.

Does diversity management strengthen efforts towards inclusion?

Welzel: There is a chance for us to move away from a supposed homogeneity. Diversity or heterogeneity is the normal case that a university needs to develop.

Mölter: That sounds good, but it does bear a certain risk. An officer for diversity does not have the expertise for all departments; she cannot be a substitute for a coordinator for students with disabilities or a counselling centre for students with impairments.

"Some professors still believe that academic adjustments are an advantage."



Sandra Mölter, Head of the Contact and Information Centre for Students with Disabilities at Julius-Maximilians University Würzburg ▶ Welzel: For instance, she cannot replace an equal opportunities officer. A Vice-rector or an administrative department for diversity management can strengthen efforts, support them and make them more visible. DoBuS, our extremely successful centre for disability and studying, is doing the same work as it always has, but knowing now that it is desired and does not have to be fought for.

What should a welcome culture for students with impairments look like?

Welzel: We are presently experimenting with a welcome culture that addresses everyone and asks no-one to out herself or himself. After all, students want to start their studies in the lecture hall, not at the counselling centre.

Kurbjeweit: To me, a welcome culture would be one that already gives me the feeling before I apply of being fully accepted despite my impairment and will not experience an additional burden through obstacles in studying. Unfortunately, I am currently still often asking myself whether universities really are designed with the needs of people in mind.

Welzel: We need universities as places where everyone can study in dignity, and without being humiliated. We are now spending a lot of energy on not merely perceiving the frustration that a problem causes but also the solution. It ought to be remembered more strongly and give others strength.

University for all 3 Supporters

Statements

Prof. Dr. Peter-André Alt President of the German Rectors' Conference

Equal participation of students with disabilities in a "University for All" represents a challenging task of key importance for higher education institutions that they seek to address with due responsibility. With the German Rectors' Conference recommendations on studying with a disability/chronic illness, universities already expressed their determined resolve to promote equal opportunities for students with impairments in 2009.



This endeavour has not lost any of its topicality. Rather, a more and more heterogeneous student body has brought it even more into focus. Therefore, it is important for the measures to eliminate and overcome obstacles to integrate all instruments available to universities, including curricula, academic adjustments and constructional modifications. Universities have repeatedly committed themselves to this and will continue to pursue the ambitious goal of a "University for All" with the tenacity required for such a task.

www.hrk.de

"That is inclusion!"

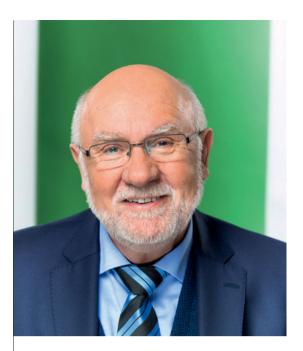
Jürgen Dusel

German Federal Government Commissioner for Matters relating to Persons with Disabilities

From my own experience, I know what it is like to graduate as a student with an impairment without much support. Fortunately, there have been some changes since the 1980s, and most universities have made significant progress since then. Nevertheless, efforts must not stop. Quite often, students with disabilities and chronic illnesses have to struggle to gain acceptance if their impairment is not visible. Therefore, a low threshold has to be established for academic adjustments, which must be awarded swiftly. This requires reliable and transparent information and support structures. Ultimately, all students benefit from it. That is inclusion.

www.behindertenbeauftragter.de





"The topic of academic adjustments ought to be addressed in every event for first-year students."

Prof. Dr. Rolf-Dieter Postlep President of Deutsches Studentenwerk, the German National Association for Student Affairs

Our "best2" survey is the crucial data base for improving the situation of students with disabilities or chronic illnesses. It provides important impulses for politicians, for student services and, last but not least, for the students concerned themselves. There is still a lot to do.

Academic adjustments are still not made enough use of. Especially in the introductory phase of studying, we have to offer students with impairments more support and even more information. The topic of academic adjustments ought to be addressed in every event for first-year students. Thanks to all those who participated in "best2". Let's get down to work!

www.studentenwerke.de

Glossary

Academic adjustments

Academic adjustments are to make up individually for disadvantages arising from impairments. Students with impairments that are relevant to their studies require academic adjustments regarding access to the university, in organising studies, in lectures and seminars, and in exams and tests, but also with respect to BAföG grants or in making use of university and student service facilities. Academic adjustments are a form of reasonable accommodation.

Accessibility

The physical environment, communication services and the design of spaces that people live in are accessible if all people have equal access to them and can use them without the help of others. The precondition for accessible study and exams conditions is the elimination of constructional, study-organisational, communicative and other obstacles.

С Chronic illnesses

Chronic illnesses are conditions for a longer period. They may also take a fluctuating course, such as in the case of chronic bowel diseases or epilepsy. If they result in restrictions in participating in society, they are legally referred to as a disability.

D **Disabilities**

People who have long-term physical, mental, intellectual or sensory impairments which in interaction with attitudinally and environmentally conditioned barriers may hinder their full and effective participation in society on an equal basis with others belong to the group of persons with disabilities, according to the UN Convention on the Rights of Persons with Disabilities. In other words, "individuals aren't disabled, but their environment disables them".

Ε

Equal opportunities and the prohibition of discrimination

Universities are required by law to ensure that students with disabilities are not disadvantaged in their studies and can enjoy the services of a university without needing the help of others.

Inclusion

Universities are inclusive if their members recognise the heterogeneity of students and teachers, value

diversity and create prerequisites for the self-determined and equal participation of all. Thus they follow the guiding notion that "it is normal to be different".

R

Reasonable accommodation

People with disabilities encounter a wide range of obstacles in their environment. That is why the UN Convention on the Rights of Persons with Disabilities contains the concept of "reasonable accommodation". It becomes necessary when access to and the conducting of studies is restricted owing to constructional, study-organisational, communicative and other obstacles. Appropriate accommodation is designed individually and in relation to situations.

S

Severe disability

If a level of disability (Grad der Behinderung – GdB) of at least 50 is officially established, the responsible authority will apply for a disabled person's pass. It is helpful for students in applying for inclusion assistance aid and in hardship applications in the context of university admissions procedures.

Realisation and Final Editing media*mondi*

Design and Art Direction muehlhausmoers

Deutsches Studentenwerk

Informations- und Beratungsstelle Studium und Behinderung (IBS)

Monbijouplatz 11, 10178 Berlin, Germany Phone: +49 (0) 30-297727-64 E-mail: studium-behinderung@studentenwerke.de

www.studentenwerke.de

The "best2" survey was conducted by the Deutsches Studentenwerk together with the German Centre for Higher Education Research and Science Studies in cooperation with the Institute for Advanced Studies Vienna. The project is funded by the German Federal Ministry of Education and Research.

Berlin, September 2018

