

## **Disability and higher education – what are the barriers to participation?**

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Higher education is generally regarded as of importance for young people, and it can be argued that this applies in particular to people with impairments. Norwegian research, for example, suggests that labour market participation is strongly associated with education. However, participation in higher education appears to be low. This can be due to barriers within the higher education system itself, or in the everyday life as a student. The purpose of this study is to explore the everyday life of students with impairments, and to describe the barriers disabled students are facing, and how disability and gender interact in Norwegian university/college education. A time geographic method, in-depth interviews and focus groups is employed. The approach is inspired by grounded theory. The paper discusses experiences of students with impairments in higher education with a main focus on participation. What obstacles are found, and what are the consequences for the studies, for making one's own choices and for participation in student life? What strategies do disabled students use to minimize the impact of existing barriers? The presentation relates to current policy on higher education and disability in Norway, and in that context, discusses the understanding of the concept of participation.

Keywords: higher education, disability, participation

This presentation will draw attention to the everyday life of disabled students in higher education in Norway, with the intention of elucidating some of the obstacles they can meet to achieving equal participation. A focus will be set on the encounter with service systems, and the findings I'm presenting belong to an ongoing PhD-project.

During the last 25 years equality and participation has been the main political goal concerning disabled people's situation in Norway. Despite this paramount objective, the Governmental Action plans have showed minor initiative concerning higher education. During the last five years there has been a shift in focus, as more attention has been put on environmental barriers.

Higher education is generally regarded as important for young people, and for disabled persons it is seen as one of the most important strategies to increase participation. For those that have higher education, employment increases

between two and three times (Bliksvær og Hanssen 2006), and to reach the governmental aim of an equal right to higher education, there are political agreements on the necessity of increasing accessibility.

At the same time the government put into action a reform to increase the quality of higher education, to stimulate students to work more effectively, and to study full time. (The universities are expected to make a closer follow-up of each student, to incorporate flexible learning, teaching and assessments, and to stimulate students to study abroad.)

What do we know then, about disabled students in higher education? We know that they end their studies earlier than non-disabled, and there are fewer impaired students continuing to a master and a PhD degree (Bliksvær og Hanssen 2006). The barriers they meet are about lacking practical adjustments (Brandt 2005, Sørheim 1998, Brattström 1998, Norges handikapforbund 2000), and they are met with a general attitude of ignorance, and the service system lacks knowledge on how to organise and coordinate to meet their needs (Brattström 1998, Sørheim 1998).

We have less knowledge about their everyday life, as to what degree they take part in students' activities, make new friends and socialise, or how they manage living by themselves, and to organise their everyday life. Being a student often means moving to live by oneself for the first time, often to another part of the country. For the majority of students handling food preparation, household care and economy for the first time can be quite a challenge, in addition to handling new expectations in studying and learning.

The intention of this study is to explore and describe the everyday life of disabled students in Norway. What obstacles are found, and what are the consequences for their studies, for making their own choices and for

participation in a student life? What strategies do disabled students use to minimise the impact of existing barriers?

### **Participants, data collection and analysing**

Until now I have met 12 students', 9 women and 3 men, aged 22 to 43, who are studying different subjects in social sciences, art, architectural design, information technology, health and social work or engineering. They come from different parts of Norway, but are now living and studying in the same city. Seven of them have invisible impairments (like epilepsy, rheumatoid arthritis, ADHD and dyslexia), one is hard of hearing, two are partially sighted and two have mobility difficulties and are wheelchair users. One of them has a personal assistant.

In cooperation with counsellors for disabled students at the university invitation letters were sent to students they knew. Request to participate also was put at the home page of the university and some organisations for disabled.

Data collection consists of a time-geographic diary, in-depth interviews and focus groups. Inspired by the grounded theory and method (Charmaz 1995, 2000), data collection and analysing is an ongoing process, trying to construct meaning of the emerging data.

### **Results**

During analysing, several codes and categories have emerged.

The categories I have selected to talk about today are:

- "Organising must be in place"
- "When support is experienced as a threat or as suspiciousness"
- "To be met gives energy"

### ***Organising must be in place***

This category is about all the work that has to be done to make the everyday life function. First of all it is a job to learn what your possibilities for support are. When different contracts and arrangements are made you have to collaborate in making adjustments and changes along the way. Berit was 22 years old. She had a chronic disease and used a wheelchair. She had to organise appointments with the nurses coming in the morning, with the physiotherapist, the social support, the hospital for frequent blood tests, the home help, her driving teacher, the student assistant and the daily transport to and from the university. She told me she had become quite a good organiser, but that she still had some challenges. Often the home help, that should clean her flat every fortnight, called and told her they had to change schedule, or they did not show up at all. She had experienced them as tactless and with barely any flexibility in discussions of appointment times. She put off taking contact with them trying to communicate, and due to this her flat had not been cleaned for several weeks

Heidi said: *I would like to be a part of the social life and make myself a network. But organising the everyday life takes all my time and energy.* Heidi was a woman aged 43. She was a wheelchair user, and together with a personal assistant she used two hours getting up in the morning, which was a challenge if she had lecturers staring at 8.15. She used an electric wheelchair which meant she had to go to university by a taxi with special equipment. Often she had to wait for the taxi, which was another part of the everyday challenges she had to plan for. Heidi lived by herself in a flat, and had personal assistants' working with her in daily activities, and a student assistant supporting her in studies. Weeks ahead she had to plan how to use the assistants working hours; when to do shopping, to do the floors and iron her blouses. She was concerned about their working situation, and of making it as predictable as possible. This also meant she had few chances of doing anything spontaneous. When spending long

hours at the university she had to bring a lift to get to the toilet during the day, which meant they had to plan extra time getting herself and the lift out of the house in the morning and extra space in the taxi. Heidi had learned to manage by her own, and it had been hard. She said: *I have a feeling of having to make the road I'm on by myself. I have spent my time trying to survive.* Her wishes for the years to come were to study for a semester in Australia, to get a job and to get a social network.

Other students talked about how they had struggled to put together a study program, so they could manage studying part time, and a quiet place to work at the university. Helga got her first epileptic outburst during an exam the first year she studied. She had to reduce her study progression, and got economical problems as she had to quit working part time. Her life was changed from one day to the next. Suddenly there were new challenges to keep up with and administer, and she often felt as if it would drown her. Getting to know her rights and the legislation influencing her study situation and medical situation was a challenge. She said: *Nobody told me about the support service at the university. I thought it was meant only for students that could not walk. One day I read about it in the university newspaper, and contacted them. They helped me getting extended time during exams and I got an office for myself where I can read and take the rest I need during the day.*

Kari was visually impaired. Because of a slow progression in getting the literature she needed, she had to do an extra year at the university college. When getting a study place late in July, and the study term starting in late August, she hardly got her books before exam at Christmas. She said: *I could buy a book in August, but it wasn't the right book.*

Managing to find the information needed, making applications and arrangements, keeping an overview and making changes when necessary, was an ongoing job for students in need for support. If the support did not function, their studies suffered, even if this had their highest priority.

**“When support is experienced as a threat or as suspiciousness”**

The intention of the Scandinavian welfare system is to compensate for extra costs or lacking resources to enable people to participate and take care of themselves on equal terms. For disabled students this can be economic support for extra costs in travelling, living and housing, a students’ assistance for taking notes or other kinds of back up. But support does not drop down as a gift when one think one needs it.

Helen was supported by the Norwegian Directorate of Labour and together with a counsellor an education plan had been made for her. Helen was satisfied with how they had cooperated in working out and reworked the education plan as she had progress or had periods of serious illness. She was studying to be a teacher, which was a profession she meant to be able to manage with the impairment she had. When I met her she had just got a new counsellor. Instead of continuing and finishing her studies he wanted to test her abilities at the labour market. Because of illness last semester, she had some essays left in order to complete her education. She was sad and irritated, and said: *“I do not look sick, instead I look quite well. If I had come there with crutches, it would have been different. ...I understood when I talked to him (the counsellor) that he did not trust me being sick. I think he believes I have fooled them. He asked me a lot of questions about why I was on rehabilitation, why I needed it.”* Helen felt that the counsellor threw suspicion on her, despite the fact that she was declared a 50 % level of disability. *“It seems like he had not bothered to look into my papers,*

*really sat down and read them, and then he gave more trust in his own observations than in what the papers could have told him.”*

Elisabeth also experienced mistrust from the counsellor supporting her in vocational rehabilitation. During her whole life Elisabeth had experienced professionals wanting to support her in ways they meant was the right for her. Now the counsellor thought that instead of studying she should get a job like other young women. She was resigned: *I tried to explain again and again why I can't do that now, and next you get the feeling of not being believed, that in the end they do not think that I am capable of completing my studies.”*

Elisabeth studied part time. She had a cerebral palsy and dyslexia, which meant that she had to spend extra time getting up in the morning, making her meals as well as reading and writing. She felt her everyday life was a struggle.

Kamilla was 22 years old. She had dyslexia and was studying chemistry. She contacted the faculty staff as soon as she entered the university college, in order to discuss the adjustment she needed. She knew that during exams she was entitled to sit in a room by herself, to get the examination questions orally, and be permitted to have headphones with music because that helped her concentrate. At the university college she was told that she could not expect to get what she required, they had tried that before, it cost a lot, and the institution did not feel this was the right thing to do for them. With help from the student support service things were settled. But still she felt that the person who had rejected her in the first place was distrustful to what she was listening to during the exam. *“I can understand why they have to be suspicious, because there is some cheating. But for me it all gave this negative impression. You are new in town and have to find your way around, and fix it all by yourself, and she was so negative.... I found it really stressing.”*

Vocational rehabilitation is meant to be a support, just as the modification of study and assessment situations. Support can also turn out to be a threat and a negative challenge. The students have, in different ways, experienced both how support systems can make their everyday life easier, and what a struggle it can be receiving it, and handling the feeling of not being worthy of the support.

***‘To be met gives energy’***

This category is about good and bad experiences when meeting people that are of importance to you in handling the study situation. It concerns staff members, both the administrative and professional. It’s about the feeling of not being seriously met and seen, not being given the information you are promised, and the humiliating feeling when having to ask for what could be understood as a favour.

Bjørn dreaded having to outline his difficulties when asking the leader of the institute for support in discussions of future plans. But he knew he had to do it, in order to complete his studies. Former experiences had made him reserved, and he was afraid that the academic staff would treat him differently than other students.

Helen talked about the meaning of both positive and negative meetings with staff members. The positive experience, she pointed out, was meeting persons that made it easy for her to ask for help. She called them resource persons and said: *A resource person is good at seeing. I talked to one of them about the last paper that I had failed, and she said, “this is not a problem. You have to do what is the right thing for yourself, and tell me if you need me”. That was great for me. Meeting a person like that makes things a little bit easier, and that is one of the main reasons why I still am a student at that institute*” To be met was said to be important. *“Meeting kindness is central in how much energy you put into it.*

*It gives you vitality, and makes you want to pass. When people try to understand and make adjustments, it gives you a push and a help to put up with the challenges..... you can't continue at an institute, and you can't bear it if you know you will be met by a face telling you: "oh, is it you again. Oh, no, are you coming to make it even more complicated for us".*

For a long time Helga had no one to talk to when she got epilepsy. Her parents lived far away, her friends were too scared to be with her after they had seen her having an epileptic attack, and her doctor told her to get rid of the phobia of getting new attacks. Then she met the social advisor at the student health office. She was a real supporter. *"I could talk to her, she had experience, and she understood more than I did. She helped me finding ways to handle the situation."*

What these students told me was that every time they had to ask for help in one way or another, they were at risk of being turned away.

### **Strategies to participation**

Martin Molin (2004) shows how participation is dependent on both internal and external conditions. Internal conditions refer to individual factors, as willingness and capacity to participate. External conditions, on the other hand concerns the physical and social environment, rules and norms that enable participation, in addition to the opportunity given to the person. Participation then can be described as an interaction between the individual and her or his social and physical environment.

The students in this study all had some bodily restrictions or what in Molin's term can be called internal conditions due to impairment (paralysis, pain, fatigue and often the need for regular rest) which brought along knowledge of what they normally could manage and what activities to prioritise. Their willingness and

determination to accomplish the study they had planned can also be seen as a part of internal conditions. External conditions influencing participation was meeting the student in an inviting and accepting way, giving them an opportunity to co-operate and participate in finding solutions, and by that inspired them to continue studying. At the same time there were persons and situations that they perceived as the opposite. According to various White Papers, disabled students have equal rights to education, and legislation in higher education instructs the university to adjust the learning environment to the principles of universal design. Economic support is meant to reduce extra costs due to impairment. Meeting impolite, not flexible or mistrusting persons, lead to constant anxiety. For periods the handling of challenging situations was their main job, and not studying.

The strategies found to handle this, were individual and seemed to depend upon previous experiences. Helen and Heidi told me they had decided to continue study at the faculty where they had met an understanding attitude and accessible study situation. This meant that external conditions like attitude can decide what discipline to choose to work on.

The majority talked about the support and help they had received from their parents, to whom they turned to when the situation was experienced as too difficult.

Kamilla, Helga and Bjørn went for regular physical training or outdoor life, activities giving them new energy to manage concentrating or reducing pain. Bjørn also were free to come and talk at any time to a counsellor for disabled students at the university. For periods when he was unsure if he would be able to manage, he did that often. When meeting university staff at his faculty, Bjørn's strategy was to be as kind as possible. If he smiled and had a positive attitude he had experienced it easier to obtain the support he needed.

When meeting representatives of the officials, competence like knowing the legislation, also seemed to be a way of managing challenges. It seemed like the better they knew their jargon and rules, the easier co-operation turned out to be.

The extra challenges these students met, involved extra time spent in communication to and with official services and university staff. One consequence of this was less time and energy for studies and leisure activities. Often they had to prioritise between time for studies and time with friends, and for all except one student in the material, studies came first and especially friendship was suffering.

It seems like the external conditions necessary for being able to study are what is given the most difficult and worrying challenges. It concerns how people understand the experiences these students face, how disability is understood in our society, and how society define support and the process of reducing barriers. In order to increase their chances of participation these students had found individual strategies in order to be perceived as worthy of support.

Given the opportunity to participate does not come in an easy way, and it seems like their strong will and determination is keeping them 'on the road'. To make participation in higher education an equal right, listening to these students' voices and their ideas, I think is one of the main ways getting to know how to reduce barriers and develop a more inclusive society.