

Supported Education

1.2.6 Barriers to choosing, getting and keeping a study

The four ImpulSE project partners used the same research methods and procedures so the outcomes could be compared. We have conducted a literature review (both peer reviewed and gray publications), and have analyzed 30 questionnaires that were sent to experts in SEd and/or mental healthcare. In addition, we have organized focus group interviews with 27 people with mental health problems who want to go (back) to school. (For more details about the method and procedures, see Appendix).

Interestingly, in all four countries the answers to our questions about the barriers could roughly be divided into three categories: personal barriers, barriers in the educational environment, and barriers in the social environment. We have used these categories to organize our results. In Table 1 below, the most frequently mentioned barriers (in at least two countries) are summarized.¹

Table 1.1 Most frequently mentioned barriers in the four countries to choosing, getting and keeping a regular (vocational) education.

	Personal barriers	Barriers in educational environment	Barriers in social environment
Choose	<ul style="list-style-type: none"> - Earlier negative experiences with going to school - Lack of self-esteem - Fear of being stigmatized - Self-stigma Difficulties with choosing - Lack of financial means 	<ul style="list-style-type: none"> - Lack of support/clear information at the school - No match between educational offer and student's needs - Lack of information about support services - Unfamiliarity with support services among staff - Unclear and vague information about support services 	<ul style="list-style-type: none"> - Lack of financial, emotional and practical support from family - Lack of emotional and practical support from mental health professionals - Stigmatization by mental health professionals - Lack of cooperation among educational, medical and social services

¹ In the Appendices, you will find tables with all the barriers that were identified by the experts, focus groups and through the literature review in the four countries.

Get	<ul style="list-style-type: none"> - Presence of (residual) symptoms and side effects of medication - Fear of failure 	<ul style="list-style-type: none"> - Difficulties with application procedure - Several institutions involved and no communication between them 	<ul style="list-style-type: none"> - Fear of being stigmatized - Lack of knowledge about rights of people with psychiatric disabilities
Keep	<ul style="list-style-type: none"> - Direct consequences of psychiatric disability - Difficulties with executive functioning skills - Lack of self-esteem - Dilemma of disclosure - Feeling of stigmatization 	<ul style="list-style-type: none"> - Lack of support - Inflexible structure of the school system - Lack of understanding, expertise and empathy of staff 	<ul style="list-style-type: none"> - Little or no support from family - Little or no support from fellow students - Little or no support from mental health professionals - Stigmatization/ discrimination by fellow-students - Stigmatization/ discrimination by teachers

A. Barriers related to personal factors

In all four countries experts and (aspirant) students themselves frequently mentioned lack of self-esteem and fear of being stigmatized as barriers in choosing a study and also in choosing to go back to school in general. Regarding lack of self-esteem, one participant (NL) stated that her fear of failure hinders her in actually making a choice: “Am I able to do this?” Also, many experts mentioned that people with psychiatric disabilities are often convinced of the fact that ‘they just cannot do it’. Earlier negative experiences with going to school hinders people with psychiatric problems in their choice to go back to school. For some participants, these negative experiences originate from their time at elementary school. One participant said:

“At elementary school, the focus is on the future. But you don’t think about the future, you are trying to survive physically and mentally. At school, there is no attention or room for that. When you’re trying to survive, the future is not important at all. So, school is future oriented and if you put your achievements next to that, then you totally fail. The aversion I felt for school only disappeared after 21 years. So, now I am ready to think about going to school again.”

Self-stigma (that is, one starts to believe the negative stereotypes that exist about people with psychiatric disabilities and act upon them) was also seen as a barrier in choosing to go back to school: for instance, they believe that they are not intelligent and withdraw themselves from the school system. The (aspirant) students mentioned difficulties with choosing a study as another hindrance. There are too many studies that they like, or they do

not know what they want. Finally, lack of financial means is another barrier to choosing to back to school.

Regarding getting a study, there was only one barrier that came up in at least two of the four countries: the presence of (residual) symptoms and side effects of medication. As one Portuguese student stated: "...when I started to take medications I had my admission exam and I didn't do it so well. I wasn't able to follow the college of my first choice." A barrier that was mentioned by students in the Netherlands was fear of failure. According to some participants, it is of course possible to get all the information needed, it is not that difficult, but it touches a kind of vulnerability. As one participant puts it, "It's not difficult, that is the stupid thing. It's not difficult, but when you fail, another piece of your self-esteem is gone: it wasn't difficult, yet I failed." This fear of failure reduces the chance that people with psychiatric disabilities apply for a study.

The most frequently mentioned personal factor that hinders the participants in keeping their study, is the direct consequences of the psychiatric disability, such as problems with concentration ("I can read the same page more than 85 times, yet I don't actually read it, very frustrating"); fatigue ("Travelling from where I live to school and back is extremely tiring. So, a full time study will exhaust me. The longer I have to travel by bus, the less energy I've got); psychoses; apathy and (re)-hospitalization. Also side effects of medication are seen as a barrier: some students said that when they had an increase in medication, their academic results got worse: "medication made me slower, and I had difficulty in reading; when finally I reduced the medication, I got better results." This barrier was named in all countries. A related barrier that was also frequently mentioned was difficulty with executive functioning skills. They lack competencies such as planning or structuring, or they do not structure in the right way. An example: "People with a disability do know that structure is important. Many people know how to do it. I also have a structure for myself, a very clear structure. I just do not adapt my structure and planning to the situation. So many people know how to deal with structure, yet they do not do it in the right way." Lack of self-esteem is also indicated as a barrier in maintaining a study: "I thought I wouldn't make it."

Another difficulty faced by students is the dilemma of whether to disclose or hide their mental health problems at school. If they decide to disclose, there is a risk of being stigmatized; yet if they decide to hide their problems, there is a risk of not getting the support needed. The feeling of being stigmatized also makes it more difficult to keep on studying. Students do not seek professional help because of this feeling of stigmatization and try to solve their problems on their own. Oftentimes, this doesn't work and worsens the situation. Finally, lack of financial means was mentioned again: "Now that I am older than 21, I am facing extra barriers. I do not get financial support from the government anymore. That is a barrier"; and, "Well, you do have to fill the refrigerator."

B. Barriers related to the educational environment

Lack of support at school during the 'choose' phase was mentioned in all four countries by experts, participants of the focus groups and in the literature. There is little or no extra support for people with psychiatric disabilities in this phase; also, the information that is given about the different studies is often unclear. Most of the time, the information is given during an open door day; personal contact with staff members is often not possible. A second important factor that was frequently mentioned, is the fact that the educational offer doesn't match the student's needs. For instance, there are few studies that can be done part time or in one year. In the Netherlands, all participants of the focus group stated that lack of (or too little) information about available support services at school is a major barrier in choosing a study. Participants cannot find the information: "There is a lot of bureaucracy, they send you from pillar to post"; staff members are unfamiliar with existing support services at their school:

I asked the receptionist of a certain faculty the name of the staff member to whom students with psychiatric disabilities can go to with their questions. The answer was that such a person does not exist and I received a brochure about the general support service of the university. But each faculty is more or less obliged to have such a specialized staff member! Then I think, 'Okay, so I cannot take this service seriously because no one knows about it'.

Furthermore, the information that is available is oftentimes unclear and vague. All participants agree that clear information about available support services is crucially important to make the right choice, as their choice depends on the expected chance of keeping the study. That chance of keeping the study largely depends on the available support at school. Another remarkable finding was that in Portugal alone the most stated educational factor that hindered people in making a choice was the high cost of tuition: "...if I didn't have financial aid, I wouldn't choose to go to college."

In terms of the question, 'what hindered you in getting a study?', the barrier that was mentioned in all four countries was the difficulty that the aspirant students experience with the application procedure. Examples that were given of these difficulties are no support with filling out difficult application forms and making the payment (Portugal); difficulties with getting accepted at a school because schools nowadays use strict selection procedures and more easily reject prospective students (NL); and problems with the form of assessment, as there was only one opportunity to sit the admission exam and there was no adaptation of the examination procedure (Czech Republic). In the Netherlands, the participants of the focus group mentioned that it hindered them that they had to go to several institutions to get the information they needed for applying for a school—"The course that I wanted to take was already over by the time we had all the information we needed"—and that these institutions (e.g., schools and governmental institutions) do not communicate and oftentimes contradict one another—"These institutions, yeah, they do not communicate for a bit."

The most frequently mentioned barrier related to the educational environment in keeping the study is lack of support. Often because of a lack of means or expertise of the staff members there is too little time and support for people with psychiatric disabilities, whilst this is often the most crucial factor in successfully carrying on with a study and finishing it. The experts in the Czech Republic cited the lack of coordination and cooperation between, for instance, the educational consultant, tutor, school psychologist and the student as the main problem. The inflexible structure of the school system is another factor that was mentioned in all four countries as hindering students in completing their education. For instance, in the Netherlands nowadays, the education is focused on competencies. This kind of education has a less clear framework (i.e., students have to prove by building up a portfolio that they possess a certain competence), which can lead to problems for disabled students. Also, the difficulties with getting tailor-made exams are seen as a barrier. Examples of this inflexible structure of the school system were: "closed and streamlined system, unwelcoming of students with psychiatric disabilities"; a "rigid structure in faculties that doesn't allow for alternative forms of student assessment" (here referring to lack of alternatives to oral exams, presentations, and fieldtrips); "existing student services don't feel a responsibility for this group"; and "schools don't allow a reduced study progression to match the student's capacity." A final frequently mentioned barrier to keeping the study is the lack of understanding, expertise and empathy of staff. A student from the Czech Republic said: "When I wanted to explain my problems, nobody listened." Another example in this regard comes from a Dutch prospective student: "There was no involvement at all at my former school. Not even from my tutor. I'd already quit school for three months when my tutor found out.... There was no social awareness at all."

Participants also mentioned that sometimes staff members think that they know how to deal with persons with a certain disability because they've met a person with that kind of disability before. They then tend to ignore all distinctions between people with the same disability and behave in the same way towards them. This can lead to a misfit. One of the participants experienced this and had to quit his study. Some experts that were interviewed in the Netherlands stated that the lack of understanding, expertise and empathy of staff members is sometimes caused by the fact that these students with a psychiatric background do not disclose their problems, and therefore the staff members do not know about these problems.

C. Barriers related to the social environment

The lack of social support on a financial, practical and emotional level from family and mental health professionals is seen as the major barrier in the social environment of the prospective student in choosing a study. As a Dutch participant of the focus group puts it: "The belief of the people around you is important. The social network influences making a choice. Am I able to do this? Am I ready for it? Where am I in the process?" The social environment can influence the self-esteem of the prospective student in a positive or negative way, and self-esteem is needed to eventually choose a study. It was also

mentioned (in more countries) that parents sometimes discourage the prospective student because they under- or overestimate their child. The mental health practitioner is sometimes too much focused on medical treatment, and not so much on the participation of their client. A rather shocking factor that was mentioned in Norway and the Netherlands is the stigmatization by mental health professionals that is experienced by the prospective students as a barrier in actually choosing a study. Some of these students responded that their psychologist or psychiatrist actively warned against studies ('wait until you are well enough to start studying')—"They didn't realize that it was studying that made me well." In the Czech Republic, the lack of cooperation among different services was mentioned by the experts as an important barrier. Educational, medical and social services do not work together to manage individual cases; there is no networking.

Remarkably, not many factors in the social environment were mentioned as barriers to getting a study. In Portugal, prospective students mentioned the fear of being stigmatized/labelled as a hindrance in this phase. Experts from Norway cited lack of knowledge about the rights of people with psychiatric disabilities. This lack of knowledge (of staff members at schools or at social services/ student loan departments) can often result in the retraction of rights, either in the form of financial support or with respect to the length of support offered: "They showed no understanding that my illness made it difficult to make full progress."

Two factors seem to be major hindrances for students in keeping their study: little or no support from the family, co-students, and/or mental health professionals, and a related factor of stigmatization/discrimination by co-students and/or teachers. It was mentioned that family members often do not know much about (the content of) the study and sometimes underestimate or even discourage the student. Furthermore, sometimes mental health professionals do not provide support with, for instance, arranging adjustments and making agreements with the school. Regarding stigmatization and discrimination, one participant of the focus group in the Netherlands indicated that he has been terrorized because of his disability by his fellow students, which eventually led to a psychosis. Another participant said: "I felt alone. Shut out. I did not feel I was part of them."

Conclusion

When we take a look at the barriers mentioned in the four countries, we can conclude that there are more similarities than differences. Notably, in Portugal the financial situation is more often mentioned as a hindrance in going (back) to school than in the other countries. In fact, in Norway this factor has not been mentioned at all. Nowadays, in Portugal, financial difficulties are a main problem and hindrance for many families that have to set priorities, and in numerous cases paying for college tuition becomes less important compared to more basic needs. Another noticeable difference is that in the Netherlands, lack of information about support services was mentioned more often than in the other countries. It seems that there are several support services available, but they are not available and visible enough for students with psychiatric disabilities.

Important barriers that were mentioned frequently across countries and across the phases of choosing, getting and keeping a study are fear of failure of the (prospective) student; stigmatization by staff members, mental health professionals and co-students; problems caused by the mental illness itself and medication; and lack of support (social, practical, financial) from family, co-students, staff members and mental health professionals. This brings us to the question of what helps (prospective) students with psychiatric disabilities choose, get and keep a study? The answers to this question will be discussed in part 1.2.7 of the toolkit.

Appendix

A. Literature review

Both peer reviewed and gray publications were used to get information about the hindrances that people with psychiatric problems encounter when going (back) to school. Publications were included when they described the situation in the specific country. Key terms including 'students with psychiatric disabilities', 'mental health problems and students', 'psychiatric disabilities and (higher) education', and 'students with special educational needs' were used in search engines for Google Scholar and several literature databases such as WorldCat and PsycINFO. As can be read in the four separate reports about the results of the research in the four countries, in the Czech Republic and Portugal especially very few publications were found. Of the four countries, the Netherlands is the country with most publications concerning our topic.

B. Questionnaires from experts in Supported Education/mental health care

Next, we were interested in what experts on Supported Education and/or on students with mental health problems consider to be barriers to going (back) to school for young people with psychiatric disabilities. Therefore, all partners sent the following two questions to several experts by e-mail/letter: "What hinders young people with psychiatric disabilities in going (back) to school?" and "What hinders young people with psychiatric disabilities in keeping their study?"

The experts all came from the social networks of the partners, and were all working in education or in mental health care. In total, 30 experts sent back their answers to the questions.

All partners used the same coding system to analyze the answers. For each question, all the answers were put together into one file. Next, all answers with more or less the same content were marked in the same color. For instance, all answers about 'lack of self-esteem' were coded in red. By coding the answers with colors, one can more easily distinguish categories in the answers.

C. Focus group interview with people with mental health problems wanting to go (back) to school

Besides asking experts in the field of Supported Education about the barriers people with a psychiatric background face when going (back) to school, we also asked people with a disability themselves about their experiences with going (returning) to school. We did this in a focus group meeting. A total of 27 participants joined the group interviews that were organized by the four partners. The participants were all part of the networks of the

partners—for instance, because they were participating in a course on SEd that was organized by the partner. The age of the participants ranged from 17 to 60 years. Of the participants, 13 were male and 14 female. All participants had dropped out of school once or twice before. Psychiatric diagnoses were, amongst others, depression, schizophrenia, PTSS, anxiety disorder and autism.

The procedure was roughly the same in the four partner countries. The interview was led by one or two interviewers (at least one partner working on the ImpulSE project took part in the interview). Before the interview began, the purpose and plan of the group meeting was discussed. We mentioned that the interview would be audio and/or videotaped and that the recordings would be destroyed after the analysis. Also, we guaranteed that the reporting about the group interview would be anonymous. Finally, we told the participants that we were going to ask them about what hinders and what helps them in choosing, getting and keeping a study. The actual interview lasted between 75 minutes and two hours. In general, the participants appreciated having the opportunity to tell about their problems related to studying. They felt heard.

The interviews were transcribed and the answers subsequently analyzed using the same color coding system as was used to analyze the answers of the experts. That is, answers with more or less the same content or meaning were given the same color: for instance, all answers about 'lack of information about available support services' were marked in blue. By coding the answers in different colors, one can more easily distinguish categories in the answers. After we finished the report about the focus group meeting, the report was sent to the participants for feedback.