This is the published version of a paper published in *International Journal of Inclusive Education*.

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


https://doi.org/10.1080/13603116.2018.1445303

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To cite this article: Kerstin Winberg, Hanna Bertilsdotter Rosqvist & David Rosenberg (2019) Inclusive spaces in post-secondary education – exploring the experience of educational supports for people with a neuropsychiatric disability, International Journal of Inclusive Education, 23:12, 1263-1276, DOI: 10.1080/13603116.2018.1445303

To link to this article: https://doi.org/10.1080/13603116.2018.1445303

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Published online: 07 Mar 2018.

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Inclusive spaces in post-secondary education – exploring the experience of educational supports for people with a neuropsychiatric disability

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ABSTRACT
The purpose of this study was to investigate the experiences of studying among people with a neuropsychiatric disability who received support from a Supported Education (SEd) programme, and people who did not receive this support. The research employed a narrative approach, where 14 participants with a neuropsychiatric diagnosis were asked to write a short reflective narrative about their experience of studying, with/without support from a SEd intervention. The results show that the persons without support from the model relied on their family as their primary support, and that support from formal support providers was not available prior to receiving a formal diagnosis. Those who received services from SEd were generally satisfied with the support they received, and did not emphasise the family as support givers in the same way. The study points to the importance of developing neurodiverse spaces, which can serve as transitional environments and that can help supported education models adapt to the needs of this group.

ARTICLE HISTORY
Received 24 January 2017
Accepted 21 February 2018

KEYWORDS
Supported Education; higher education; support; autism; ADHD; neuropsychiatric disability

Introduction
Supported Education (SEd) is commonly defined as the provision of individualised, practical support to assist people with psychiatric disabilities to achieve their educational goals, and has been used successfully to assist them to complete post-secondary education (Rogers et al. 2010; Eklund and Bejerholm 2014). Support is ideally provided to the individual within the regular education system, for example, directly at the university. SEd programmes are delivered based on principles related to availability and accessibility, self-determination, individualisation, flexibility, coordination and a focus on strengths and hope for socially valued roles as community members (Unger and Pardee 2002). In Sweden, SEd is one of the National Board of Health’s national recommendations for psycho-social interventions in schizophrenia (National Board of Health 2011), although the literature supporting its effectiveness is often based on studies with a wider variety of psychiatric
There is no recommendation as to whether to use the model for people with a neuropsychiatric disability (NPD) (this includes autism spectrum disorder, ADHD, dyslexia or OCD), but there are some local activities and projects that are working in line with the model in Sweden, aimed at people with NPD. The aim of the current study was to explore the experiences of educational support among two groups of adult students with NPD; individuals with experiences of an SEd-inspired programme focused on the educational needs of people with NPD, as well as those without such experiences. This research was part of a wider study (Winberg 2016) aimed at exploring experiences of support in higher education among adult students with an NPD diagnosis.

**Educational support aimed at people with NPD**

In Sweden, the first nine years of elementary education are compulsory for all children (Education Act, 2010:800, 7:12). Schools are required to adapt to the needs of all students, and students with NPD, if they do not have other severe developmental disabilities, are not eligible for special schools. Unless the schools make adequate adaptations, however, people with NPD tend to have difficulties, often resulting in poor attendance (Skolverket 2010, 74). Without the right support, individuals with NPD may not choose to or feel able to continue studying when school, following the compulsory years, becomes a voluntary choice. A lack of educational opportunities is clearly connected to increased vulnerability, to reduced social capital, to exclusion from participating fully in the society and in turn to worsened mental health (WHO 2012; Olin and Jansson 2009). Adult elementary education in Sweden includes Municipal adult (Komvux) and Special adult (Särvux) education. Within Municipal adult education, there are both vocational and special education tracks available. Komvux and Särvux are targeted to adults from the age of 20, who want to complete their elementary education, develop knowledge and skills, or perhaps change jobs. These are voluntary forms of education, intended to support growth based on individual needs and conditions, and are directed to prioritise those with the least education (Skolverket 2016).

Around every individual there are various supporting actors, including the individual’s social network, which can consist of family, partners and friends (Pillay and Suniti Bhat 2012), often referred to as informal support actors. An informal support actor has no officially assigned role to support particular vulnerable groups such as people with NPD. Other supporting actors are the so-called formal support actors. These are, for example, people who encounter a vulnerable individual in their profession and have a support responsibility (Pillay and Suniti Bhat 2012).

The Swedish disability reform from 1994 includes Support and Services for Certain Disabled People (LSS), focusing on cooperation between the various authorities to help people with disabilities to participate in society. The act targeted two main groups, people with intellectual disabilities and people with psychiatric disabilities. People with autism have been included within the group of people with intellectual disabilities, while people with ADHD were added later to the group of people with psychiatric disabilities. The Discrimination Act (2008: 567), 3:14 stipulates that universities should carry out targeted efforts to promote equal rights and opportunities for persons with disabilities who participate in, or are applying for an education. For people with intellectual or psychiatric disabilities, there is also special legislation and guidance for training or employment that the formal support
actors must adhere to. People with intellectual disabilities are entitled to a basic education in special schools focused on learning disabilities, secondary school and special education for adults under the Education Act (2010: 800). People with psychiatric disabilities are not entitled to such institutional educational support systems, but regulations in the Health Care Act (1982:763) 8a § and the Social Services Act 5:8 stress that local governments should work together to support this group.

Most programmes for people with intellectual disabilities focus on placing people in specific programmes with activities to support their training. For people with psychiatric disabilities, the primary aim is to support the coordination of formal services in order to rehabilitate the person in the community, with the goal of eventually participating in the regular employment market. A solution regarding people with high functioning autism (HFA), and which sometimes also includes more severely impaired people with ADHD, is a mix between support directed to either people with intellectual or psychiatric disabilities.

Several people with HFA, and some severely disabled people with ADHD, are being placed in special classes (Ljusberg 2011) and schools with limited enrolment (National Agency for Education 2014), both of which attempt to move the student from regular school activities, similar to the idea of special education aimed at people with intellectual disabilities. When entering higher education, several people with HFA encounter student support services with poor knowledge or resources to respond to and support people with HFA, although the number of students with HFA has increased (Pillay and Suniti Bhat 2012).

SEd is a model that is traditionally targeted to people with psychiatric disabilities to support their readiness for and participation in educational activities (National Board 2011). The purpose of the model is to support individuals as they make choices concerning their education, help them to begin their desired training and support them in maintaining their status as a student until their goal is achieved (Unger 2007). The ultimate goal is to improve their chances in the labour market by supporting vocational training (Mueser and Cook 2012). Although SEd programmes differ, most offer services including career and education planning, academic skills and basic competencies, time/stress management, developing social support, tutoring and mentoring services, outreach to relevant human service agencies, financial counselling, and information regarding rights and resources (Mowbray, Megivern, and Holter 2003). These services are delivered within a number of models and include: on-site support, mobile teams, educational experts based at mental health agencies and on-site campus-based services (Mowbray, Megivern, and Holter 2003; Unger and Pardee 2002). The majority of SEd models have been developed with a focus on supporting marginalised populations experiencing what is commonly referred to as serious mental illness, including schizophrenia but even serious depression and bipolar disorder. While these individuals, when active as students, may have access to student health services for example, those experiencing these more serious impairments (and sometimes in combination with NPD), have often dropped out of school or are seen as too ill to participate by on-campus services, so that SEd is more often included as part of mental health services.

Among the outcomes described in the research for SEd are increased the sense of empowerment and motivation among students who were able to choose their education (Bengs, Borg, and Liljeholm 2013, 58), increased social interaction, and that educational opportunities supported their development as individuals and a sense of moving on with their lives. Since SEd models also focus on environmental adaptations, it has been
demonstrated that the model has helped students to be included in society and take part in mainstream activities and resources (Morrison, Clift, and Stosz 2010, 84). Although several previous researchers have explored experiences of a diverse range of educational support interventions as well as spatial and social barriers to participation in higher education for people with HFA (see e.g. Madriaga 2010), no previous research has explored the particular experiences of SEd in relation to other forms of educational support among people with NPD. There has also been little focus on the particular environments in which these individuals might best utilise these supports.

Methodology

The study went through an internal ethical review process at the [Department at University], and it complied with standard ethical concerns related to anonymity, informed consent, safety, research process transparency and data security.

Participants for the study were recruited through a public service provider where the SEd model was offered specifically to the target group and through Facebook. All participants had a diagnosis of a NPD. Neuropsychiatric disabilities or NPD is a term used in some countries, among them Sweden, in order to collectively describe a variety of diagnoses related to cognitive functions and impairments. All participants were currently studying or had previously studied at a mainstream higher education institution (such as secondary school or university). Based on these general recruitment criteria, two types of participants were recruited: those with experience during their studies, of support that built upon the SEd model, and others who had studied without having access to such supports. In order to recruit participants from the first group, a public service provider providing SEd services was contacted by the first author (Kerstin). The staff at the service received information about the study and were asked to distribute information to all participants visiting the service regardless of whether they had an NPD diagnosis or not, during a four-day period. Based on this recruitment strategy, seven participants with an NPD diagnose were recruited to the study: three men and four women. The service was located on a campus where a number of higher education providers were active and all participants were living in the same community. In order to recruit participants for the second group, Facebook was used. Information about the study was shared through Kerstin’s facebook account and facebook-friends were asked to share the information in their groups and networks. The information was shared 33 times in total by other people on their Facebook walls as well as in some Facebook-groups. Based on this recruitment strategy, another seven participants were recruited to the study, one man and six women. Participants in this group lived in different communities and attended different higher education programmes throughout Sweden. In total, there were 14 participants, 7 from each group, with an age range of 22–40. All participants had self-identified as having an NPD diagnosis and some participants from both groups reported a co-occurring mental health issue. Most of the participants were living on their own, or in newly started families, only a few still lived at home with parents, and most described learning as well as social difficulties during elementary school.

The data are based on shorter narratives written by the participants (Blom and Nygren 2009, 110) who were asked to write about their experiences of studying. In the instructions for the narratives, the participants were asked to reflect, in approximately one page, upon
how they had been supported during their attempts to study throughout their lives. They were, therefore, free to describe issues related to elementary as well as higher education experiences. After completing the narrative, they were instructed to read through it and revise it if needed. Those who wanted to participate in the study but found it difficult to write were given the opportunity to record a 3–5 minute sound file and listen to it before sending it to Kerstin where it was then transcribed. One of the participants chose to do so. After being submitted, Kerstin removed all identifying information from the narratives, including the particular diagnosis of the participants. The narratives have been analysed according to principles of narrative analysis suggested by both Pentland (1999), who focus on the manifest and latent message of the text by identifying for example sequence in time, focal actor(s) or evaluative frames of reference, and Schiffrin (1996), who focus on the textual structure by identifying for example, the conclusion, complication(s) or codes. Kerstin identified and organised the material by using both Pentland’s and Schiffrin’s methods to gain a deeper understanding of the narratives. An introductory analysis resulted in the identification of different supporting actors, for example, the family, and the participant’s experiences of these.

Findings

In the following section, we will explore the participants’ narratives of their experiences of educational support with a focus on informal and formal support actors. During the analysis, the importance of space, as either enabling or disabling (Gleeson 1999), became clear as an important theme. In particular, the participants make distinctions between receiving support in what previous research has referred to as neurodiverse spaces (Bertilsdotter Rosqvist et al. 2013) in comparison with spaces dominated by ‘neurotypicals’ (people without NPD); NT spaces. Neurodiverse spaces can be defined as safe and inclusive spaces for people with NPD, where people with NPD are able to interact with each other and afforded the possibility to interact with NTs in a less stressful and more appropriate way (Bertilsdotter Rosqvist et al. 2013). NT space can be defined as ‘mainstream’ cultural spaces (Milner and Kelly 2009). Building upon the work of researchers within the field of disability geographies, NT spaces can be seen as socially produced to exclude people with NPD in two primary ways. NT spaces can include exclusionary practices that actively keep people with NPD ‘in their place’ (Kitchin 1998, 345), such as special, non-mainstream spaces for people with disabilities – for example, special schools or classes for people with autism. They can also include ‘social texts that convey to disabled people that they are “out of place”’ (Kitchin 1998, 345). Inaccessible social interaction for people with autism exemplifies this; joking among NTs, coffee breaks or work meetings at the work space dominated by NTs are situations where people with autism may not be enabled to take an active part due to lack of social accessibility (see Bertilsdotter Rosqvist 2012).

Differences and similarities among the participants regarding whether they had experiences of SEd or not will also be discussed. The participants who received support from SEd services and supports had been receiving these through an educational support programme – further referred to as the program – which worked after this model. Based on the narratives of the participants, the programme may not only be seen as a place with a specific set of services that support functioning as a bridge to developing abilities
to participate in NT spaces, but also as a particularly enabling, safe, neurodiverse space in itself.

The SEd programme which the participants were involved with emphasised accessibility and openness as essential components. They aimed to develop an open and accepting environment, in contrast to the study environments which many of the students had experienced as institutional and exclusionary. At the same time, they were located at an educational campus, where many parallel educational activities aimed at adults were located, in order to reduce stigma related to, or which can arise from, isolating individuals experiencing these types of disabilities.

**Enabling and disabling NT spaces**

In the following section, we will explore experiences of both enabling and disabling NT spaces among the participants who did not have an experience of participating in the SEd programme. Initially, we will explore meanings of support within private NT spaces, such as within a family or at home with a partner. Among informal support actors, the family and partners were frequently described as an important support among participants without experiences of SEd. One of the participants stressed the family as both their most important support and as a driving force both in studies and in everyday life. Another stressed the importance of support from their partner – for example, reminders to take breaks during long study hours, suggestions for organising their work, as well as help with household chores and supports that were helpful to their study-related executive functions. Parents are also described as important advocates for the participants' rights to formal support, although these are sometimes described with ambivalence. One participant described a parent as an important support when it comes to receiving the right kind of support during childhood, for example fighting for the participant’s right to education within a mainstream educational setting. On the other hand, another participant described how the parents had tried to protect him/her against experiences of failure by encouraging them to take more basic courses than what the participant themselves believed they could accomplish, thereby discouraging them from challenging her/himself by taking more advanced courses – cautionary advice which the participant eventually gave in to.

In a manner similar to these ambivalent experiences of support within private NT spaces, descriptions of support within semi-public NT spaces, such as the university, varied between enabling and disabling experiences which impacted access to potential support actors. For example, difficulties in getting to know other fellow students (and therefore be able to develop opportunities for social and academic exchange) due to frequent changes in the composition of the class at a university course, or expressions of lack of understanding and knowledge about diagnoses among fellow students. A participant described how fellow students were making statements about this diagnosis as a social construction and therefore not real. This caused the participant to refrain from disclosing her/his diagnose for any of her/his fellow students. They also avoided applying for formal supports from the university, since they were afraid this might lead to other students believing s/he had an unfair advantage (c.f. MacLeod et al. 2017).

Most narratives regarding formal support actors at semi-public NT spaces such as school centred around difficult social and spatial encounters. Difficulties in school
varied between a general sense of always finding it hard in school but never understanding why, or to receiving barely passing grades, to more specific narratives of difficult situations in socially and academically disabling environments. One participant described how s/he always found the dining situation at lunch time very difficult because it was such a socially vulnerable situation. S/he, therefore, discontinued having school lunch. Another participant described how the school had tried to improve the situation in the classroom by allowing s/he and a small group of other pupils with difficulties, to leave the classroom and have lessons separately, something s/he found problematic. Similar narratives describing the meaning of space include a participant who described how they had difficulties with social interaction at school, as they were bullied and ostracised. The class was lively and the participant, who was quiet and unobtrusive, was often placed among the unruly pupils to have a calming effect on them, an action which only made her/his study situation worse.

All participants emphasised one or two particular teachers from primary and upper secondary school as either good or bad. The good teachers were primarily described as supporting them in their studies, being flexible and making efforts to try to understand the way the student was thinking and experiencing school. These teachers had inspired them and paved the way to further studies, but perhaps most importantly, they had been experienced as personally engaged in the pupil.

In contrast to the good teachers, the bad teachers were repeatedly described as unfair, inflexible and non-pedagogical, not believing in or understanding the support needs of the participant, but rather believing them to be unruly pupils and for example, sending them out of the classroom. As an illustration, a participant described how s/he used to sit with ear phones during the lessons and turn off the music when the teacher was talking. Most of the teachers allowed this since s/he still performed well, but a specific teacher thought s/he was possibly cheating. For the participant, the headphones and music were a strategy to be able to concentrate, but this particular teacher interpreted it as a sign of the participant not being present during the lesson, and therefore penalised the student, despite the good work. One participant described how s/he was ‘too efficient’ in some subjects, which led to the teacher examining her directly in these subjects or sending her to a parallel class to act as an extra teacher, instead of challenging the participant with more advanced tasks in the subject.

In the narratives describing support at the university and general experiences of higher education, the teachers and student health office were included. Narratives describing the overall experience stressed environmental challenges/barriers, often different kinds of spatial changes or a new educational environment and a new everyday living situation, all of them resulting in stress and worries about not being able to manage their studies. On the other hand, beginning to study at the university was experienced positively since they now had the ability to choose the courses they wanted to take, based on their personal interests.

In a manner similar to the way in which primary and upper secondary school teachers had been described, particular teachers at the university were described as either educational enablers or disablers. Good teachers were similarly described as supportive and flexible, with a knowledge and understanding of diagnosis as well of the difficulties that may arise from these. For example, a participant described how even before her/his diagnosis was established, when asking about the possibility of doing a verbal presentation in a more private space, they were allowed to do so without question. A participant described how s/he strategically started to apply for courses within departments and courses where
they would meet these ‘positive’ teachers, having previously experienced many bad teachers at the programme.

The participant who did not dare to disclose their diagnosis to her/his fellow students, did not dare to with her/his teachers as well. They were afraid that the teachers would consider, in the same way as the other students, the diagnosis as a social construction and were therefore also afraid of being discriminated against and having other demands placed on them. Another mentioned experiences of teachers who had suspected that they had a diagnosis and had confronted them with this in a way that the participant felt was inappropriate. In addition, in trying to push the participant to disclose in this problematic manner, the participant described how these teachers failed them on examinations and how they were finally forced to take a study break. When s/he resumed their studies, they fought to have access to other teachers and were, therefore, able to continue successfully with their education.

All participants stress both the positive and negative impact of their contacts with the student health office. Central to this is the meaning of a formal diagnosis in order to have their needs for support acknowledged and subsequently become eligible to receive support. Several described frustration related to being not taken seriously when seeking services without a formal diagnosis. One participant described how they, despite having applied for support as soon as s/he started to study, was not seen as having a credible need. It also took a long time to initiate services since several certificates confirming the diagnosis were required. Most participants thought, however, that the support they received following this initiation process was positive and helpful. Those who had been waiting for a long-time expressed relief when they finally received services, which also enabled them to keep deadlines for the first time.

Some participants had chosen not to apply for support for a variety of reasons, considering possible support to be disabling rather than enabling, for example, a fear of being stigmatised by fellow students and teachers. They also described having learned to manage their difficulties alone and that it felt harder to apply for the support than to keep managing the difficulties on their own. They also experienced the available support services as inadequate and therefore potentially disabling.

**Enabling neurodiverse spaces**

Narratives from the group of participants who had not received SEd included both positive and negative experiences of a variety of both informal and formal support actors as well as different educational spaces. Unlike that group, the narratives from the group of participants who had received SEd primarily concerned experiences centred around the SEd programme itself. Among the few participants mentioning other support actors, these were brief, retrospective and primarily negative narratives. Only one participant described experiences from the school in greater detail. In that narrative, primary school went well and the participant was academically successful, although it was clear s/he was different. In high school, s/he was bullied by the other pupils which led to a downward spiral with destructive behaviours.

I have always been really eager to explore my possibilities and curious about the world …. In junior high school I was bullied, and as a defense, I became best at being the worst.
Support services available from other formal support actors, beyond the SEd programme, were presented as disabling and insufficient to meet their needs. However, they were sometimes also a link, or path into the SEd programme. For example, one participant described how her/his counsellor had suggested her/him to turn to the programme when the counsellor noticed how meaningless the participant experienced what they were doing during the day. Another participant described their dissatisfaction with several formal support actors since s/he experienced their support as both insufficient and based on an underlying derogatory view of her/his abilities, disabling her/his sense of self.

I’ve experienced many national and local government services as unbearable since there is an underlying disparagement of me as an individual, and how that can hurt my self-esteem. And what do I get in return? Yeah, for example a cleaning schedule I don’t need ….

In all the narratives describing the programme, the participants stressed how it felt to go there, they described and reflected about the atmosphere at the space. Several stressed a sense of meaningfulness attached to attending the programme and that they felt they were part of a context. The atmosphere was described as open, warm, familiar, safe and energising. Feeling normal, being part of a place where you can grow and develop, getting to know others, being seen and heard, feeling accepted and accepting others, and always feeling welcome were some of the experiences that participants stressed. Two of the participants also described a sense of permissiveness and freedom. To illustrate, one of them wrote:

I don’t get rid of my energy or tension by sitting still, following codes for behavior, I feel more free just knowing that this is a place where others have disabilities or knowledge about it.

Two of the participants described how they contacted the programme when they were facing major challenges in their education, and both felt some uncertainty as to whether they should seek support from the programme. One described how s/he was in a phase where they thought they ‘should’ be able to handle the tasks themselves. The other participant described how it initially seemed like cheating to go to the programme and get help with things which seemed easy for others. Both described how these feelings disappeared thanks both to the staff and the atmosphere:

It was actually that the program is a really open, pleasant warm environment that makes it seem a clear choice, even though you’re not sure you should be asking for support.

Similarly, the participants describing the physical environment stressed that it felt like being at a workplace where one could sit in an office if one wanted to, there were printers and computers for example, and that it was less messy and more comfortable than sitting in the library. They stressed that the location of the programme, adjacent to the university campus so one could seamlessly move between them, was a central and positive factor. Several participants found it was good to not have to sit at home and study, that they got more done when at the programme site. Some wrote about the value of being able to come to the programme even when they did not have the ability to study or were on sick leave. By coming to the programme, there was still a sense of belonging to a context. This was also described as a link to everyday life, for example by walking to the programme and having a coffee or doing needlework.
Among the particular supports the participants reported having received were concrete study support, support to sort out and understand instructions for tasks, support to create a daily structure, support during difficult courses, constructive criticism and advice, and even getting a call when they had been away for a while to ask how things were going. Support related to developing and maintaining contacts with various authorities, which often required complex paperwork was also considered central. To illustrate the importance of this support one participant wrote:

It’s important that my daily routines function so that I can use as much of my energy as possible to focus on my studies. I mean both at home in my apartment and the daily chores that have to be done there as well as food and daily rhythms around sleeping for example. I’ve worked on all this with the help of the staff at the program.

The support that was offered came in various types, quantity and varied over time depending on what support a participant needed at the moment. For example, one participant described how s/he was at the programme just a few hours per week, but thanks to this ‘little support’ s/he dared to take on a major challenge and was able to complete it much more successfully than s/he had expected to do without support. Another important support which respondents described was encouragement and counselling from the staff.

All participants described the importance of the support of the staff and described them as open, accommodating, stable, friendly, present, patient and responsive to the participants in a neutral and sympathetic way. They stressed that they felt seen and heard, rather than being seen as deviant. To illustrate, one participant wrote:

A big part that has been important for me is that even when the staff are really busy they notice me and there is a feeling of being seen, heard and listened to.

Several participants described how the staff had listened to them when they had both big and small problems, regardless of what these concerned, had been willing to discuss their problems and helped them to collect and organise their thoughts, thereby giving them energy. The staff were also described as challenging and encouraging the participant. For example, one participant described how s/he had to take a break from their previous studies, resulting in a sense of failure. It was only when s/he came to the programme and discussed study options with the staff and received encouragement that s/he dared to apply to start studying again.

There were also trained teachers at the programme, who were described more specifically in most of the narratives. Similarly to other staff, the teachers were described as responding to the participants with understanding and patience, something which several noted that they had not experienced from teachers before. They felt that they could discuss tasks and ask any questions without feeling stupid.

Social interaction with other students at the programme is also mentioned as important by most participants. They referred to both openness between the students and the opportunity to choose whether one wanted to socialise with others or not. While the programme was a place for educational support and a social meeting space, many mentioned that it also actively encouraged social interaction, for example by having painting or cooking evenings. Only one participant wanted to make the point that social interaction could sometimes be problematic since it could take too much energy.
Many participants stressed the importance of the programme in their personal developmental process. For example, one participant describes how s/he felt safer after receiving support from the programme. Another participant described how s/he had learned about and accepted her/his disability, how the support from the programme had increased her/his self-esteem and confidence, but also a sense of security with regard to a return to the labour market. Another participant stressed her/his sense of increased self-confidence and self-esteem as a result of being challenged and encouraged at the programme.

Conclusions

The results presented above suggest the potential of SEd models to contribute to opportunities for young adults with neuropsychiatric disabilities to continue with and complete their education and avoid the social exclusion and worsening mental health connected to low education, unemployment and marginalisation. Respondents describe the adaptation of environments and accommodating educational supports, which can help them participate successfully in what has been referred to here as Neurotypical spaces.

The group that had not received support from the SEd programme experienced the family as the primary and most important provider of support. Family relationships are complex however, and can sometimes provide more stress than support (c.f. Klamas 2010). Family support also comes with certain risks, for example, that the parents and the person with NPD have different views on the person’s ability and thus different perspectives on the need for and nature of supports. Another risk is that the person may become dependent on this informal support and then be less prepared if they move away from their family. The natural support of the family then disappears, which may create major problems when the participant is to begin her/his studies (cf. Pillay and Suniti Bhat 2012).

The importance of flexibility and individually tailored support is raised by both groups. The group that did not receive the support from the SEd programme expressed more frustration with their studies at a higher level. The formal support actors were described as inflexible and that they had to wait for a long time to receive support. The importance of a school which is flexible and meets the individual needs of the students with NPD is stressed in several Swedish studies (The Swedish National Agency for Education, 2010; 2014). Since there is no specific legislation or guidelines for the group of people with NPD in Sweden, however, there is no requirement for the formal support actors to be flexible and provide individually tailored support to these students. The group that had received SEd services expressed frustration regarding the lack of flexibility among formal support actors too, but to a much lesser degree. They could instead turn to the programme for support when frustrated in contacts with the authorities. The lack of flexibility or guidelines may also be illustrative of a lack of a support vision, based on an understanding of differences between neurotypical and neurodiverse ways of functioning, and the importance of an inclusive space which can support their continued inclusion/participation rather than exclusion.

The participants emphasised the importance of professional support actors’ knowledge and understanding of the participants’ difficulties (c.f. Pillay and Suniti Bhat 2012). They additionally, however, pointed to a lack of focus on their strengths and abilities, as well as their impairments and deficits, when being assessed for services (c.f. Cosden et al. 2006).
The lack of flexibility is also connected to the link between diagnosis and support required by the formal support system (c.f. MacLeod et al. 2017). Participants who had not received SEd services described difficulties in maintaining their position as students. This lack of support while awaiting a formal diagnosis resulted in their not completing courses, taking breaks or dropping out, and even ending up on sick leave. The participants who received SEd describe how they have been supported in the choices that affected their education and how the programme also helped them to get into their desired education, and provided support during that education. Even when students had been on sick leave, the programme continued to provide the students with support, which meant that the participant could maintain their role as a student (c.f Bengs, Borg, and Liljeholm 2013).

The group with experiences of SEd described many aspects of the environment in which the programme occurred as extremely valuable. The environment that the students describe may be seen as a neurodiverse space, an open and flexible environment, in which their needs are accommodated, their strengths are recognised and valued, and where they are able to find support and acceptance rather than exclusion, and yet still maintain their identity and role as a student. By emphasising the importance of educational environments as neurodiverse and safe spaces, the SEd model may be enhanced for individuals with NPD while pursuing educational goals. The ‘ultimate’ goal, as expressed in SEd principles, is to accommodate people with disabilities within what we describe here as NT spaces, or commonly described as naturally existing educational environments. As an accommodation to the needs of people experiencing alternative cognitive functions (such as people with NPD), the immediate goal of maintaining people with NPD in a student role, while developing confidence and skills to move forward in their lives, is achieved in the particular neurodiverse space of the SEd intervention explored here.

Particularly worrisome in the results presented here is the fact that the importance of the environment itself and the particular relationships within it (with fellow students and teachers) is something many individuals (as represented by the first group here) are not even aware of. While the struggles of not receiving specific, relevant and flexible supports in the first group are clear, what is particularly striking is how the lack of opportunities and possibilities for experiencing themselves in such neurodiverse spaces can reinforce exclusion, a barrier to self-development and self-confidence, and ultimately lead to missed opportunities for developing a work life and becoming dependent on a disability pension (Storrie, Ahern, and Tuckett 2010). Recent research also suggests that an increasing number of students with autism are challenging university health systems and structure, in general, to be more aware of and responsive to the needs of students with autism’ needs (MacLeod et al. 2017). More inclusive and accommodating university structures and services, responsive to the needs of people with NPD, might reduce the number of individually oriented responses to individuals who have unnecessarily experienced failure and worsening psychiatric conditions. The research focused on how campuses and educational environments can themselves develop as neurodiverse spaces, building on some of the knowledge gained from SEd services, could contribute to such a socially inclusive vision.

If students with particular needs have access to environments that support their continued inclusion/participation, and that are not dependent on a diagnosis-related referral for specific individualised services, there is the potential for many students to not only maintain their educational involvement but to achieve their educational and vocational goals.
Disclosure statement

No potential conflict of interest was reported by the authors.

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