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Students and graduates with autism: perceptions of support when preparing for transition from university to work

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ABSTRACT
Despite the steps taken to improve support in universities, many students and graduates with autism face a substantial employment gap when completing university as compared to any other student group with disabilities. The literature shows that often students with autism do not have appropriate support to prepare them for entering the workforce. Therefore, it is imperative that this under-researched topic be studied. Utilising a participatory approach, in this article, we sought to investigate perceptions of students and graduates with autism about the employment support they received when preparing for university-to-work transition. The study involved semi-structured interviews with 30 university students and graduates with autism from Finland, France, the Netherlands, and the UK. Data were analysed using an inductive content analysis approach. Findings indicate that organisational enablers consisting of career-focused support and internships and practicums facilitated preparation for employment. Supportive and caring relationships emerged as forms of support that included mentors, committed and caring academics, and family members. Further, the findings indicated the aspiration for individualisation that consists of improving work and academic support, and awareness and understanding. These findings have also important practical implications.

KEYWORDS
Autism; university; transition; employment; support; participatory; qualitative research

Introduction

Autism is a developmental condition that is characterised by impairments in social understanding and communication, involving restricted patterns of cognition or behaviour, and may be further accompanied by sensory-perceptual difficulties (American Psychiatric Association 2013). However, autism itself is not an indicator of academic ability and individuals with autism are entering higher education at an increasing and unprecedented rate (HESA 2018; Jackson, Hart, and Volkmar 2018). Welcoming a diverse range of students at the point of entry is part of the general widening participation agenda in higher education (Weedon and Riddell 2016; EC 2018). Further, the higher education institutions have an obligation to implement reasonable accommodation (UN Convention...
autism and support at university

Since the number of university students with autism has increased, the transition into university and the social and academic challenges encountered during the study have been the subject of research for over a decade (e.g. Accardo et al. 2019; Anderson et al. 2019; Cox et al. 2017; Elias and White 2018; Gurbuz, Hanley, and Riby 2018; Hillier et al. 2018; Kuder and Accardo 2018; Lambe et al. 2019; Ward and Webster 2018). These studies showed that there are significant differences in support and adjustment practices between universities, and that poor autism awareness is common. For example, Zeedyk, Bolourian, and Blacher (2019) found that students with autism received less support from universities than had been implied, that campus disability services were geared more to the needs of those with physical disabilities, and that academic staff often lacked awareness of how to meet the needs of students with autism. Furthermore, Anderson et al. (2019) reported that non-academic issues such as challenges in social participation have proved to be more difficult to navigate than dealing with academic issues.

Whilst the transition into university and the time at university have been explored, little research related to the transition from university into employment has been undertaken. This period often causes anxiety for those with autism, but it can also be perceived as a positive departure and a moment for identity development when entering adulthood (Vincent 2019). A systematic review by Cashin (2018) found four studies that consisted of a
case study, discussion papers, and one UK-based study (Van Hees, Moyson, and Roeyers 2015; MacLeod and Green 2009; Martin 2006, 2007). These studies reported on the importance of individualised support prior, during and beyond the transition from university to the workforce. A recent study by Vincent (2020) recognised the potential that career advisors and academic staff could have to help students’ transition into employment, as the students reported that support was often too general and was not aimed at those with autism.

Students with autism often face challenges in goal-directed behaviours that are related to difficulties in executive functioning (Barkley 2012), which can lead them to struggle at university with the demand for having to be a self-directed learner in order to access the necessary support (Bell et al. 2017). Research further highlights that both personal and environmental characteristics need to be taken into account when deciding on and implementing individualised support for those with autism (e.g. reasonable accommodation, career services, teaching employability skills) (Jansen et al. 2017). Although individualised help is fundamental, employment and transition programme research highlights the importance of caring support people (e.g. mentors) (e.g. Hedley et al. 2018). Moreover, such people often have accepting attitudes towards diversity that can support students’ wellbeing and motivation (Pesonen 2016). However, while transition from university to employment has been explored, the current and limited research base has mainly focused on investigating students’ general experiences related to accessing employment when exiting higher education. Thus, research on students’ perceptions about employment support whilst at university to prepare them for the transition to the workforce is scarce.

To fill this research gap, our aim in this study was to examine perceptions of students and graduates with autism about support related to the university-to-work transition. Thirty university students and graduates with autism from Finland, France, the Netherlands, and the UK were interviewed about their perceptions of employment support intended to help and prepare them for employment, to answer the following questions: (1) What are the perceived supporting factors about employment for university students and graduates with autism? And (2) What can universities do to support students and graduates with autism in preparation for employment? By examining what students and graduates with autism have to say, the findings have the potential to improve current practices in higher education, and to increase the employability prospects of those with autism, as well as increase autism awareness in universities.

Methods
Participants

Thirty participants (10 female and 20 male) from Finland, France, the Netherlands, and the UK participated in the study. The data were part of a European research project focusing on improving the employability of university graduates with autism (see http://www.imageautism.com). Inclusion criteria for the study included (1) participants had received a formal diagnosis of Autism Spectrum Disorder (ASD) or Asperger’s Syndrome from an educational or health professional; and (2) they were either currently studying at university or (3) they had been university students or had graduated within the last 10 years.
The participants’ ages ranged from 20 to 52 (mean age = 27.87, SD = 6.85). Of the 30 participants, 17 were students (8 bachelor’s degree, 5 master’s degree and 2 PhD) of which two were first-year students, five were in the midst of their studies and eight were due to graduate with a university degree within 12 months. Two participants had terminated their studies. Of the sample, 13 were graduates (4 bachelor’s degree, 8 master’s and 1 PhD). Detailed participant descriptions are outlined in Table 1.

Participants were recruited purposively using snowball sampling. The researchers distributed the project website and information about the research to their professional networks who further disseminated the information via social media, Internet forums, or via email in each of the participating countries in 2018. All the participants studied at European universities that follow the Bologna process with regard to supporting students’ transition to work, yet the participants’ universities were in four European nations that have different regulations in approaching the students’ university-to-work transition support (EC 2018). In Finland and in the UK (England), universities are encouraged to support university-to-work transition for the university students through incentives, whereas in France, the institutions are required to provide transition support, and in the Netherlands, there are no obligations or incentives (EC 2018).

**Procedure**

Ethics approval for this research was obtained from the ethics committee and written informed consent was obtained from all participants prior to data collection. Participation was voluntary.

Researchers developed the interview protocol in collaboration with students and graduates with autism. Firstly, the researchers had a meeting in which they drafted interview questions. Then, two official co-design meetings were organised with the students and graduates. The drafted interview questions were used as a starting point for discussions and for the iterative process of creating the interview protocol. The design cycle also included receiving feedback from the wider autism community after the first co-design meeting. Based on this feedback, the interview protocol was further developed during a second meeting. Next, the protocol was trialled in a pilot interview, which was followed by receiving feedback from the pilot interviewee with autism. Finally, the protocol was finalised. The interview questions covered support factors at university to facilitate employment and expectations about improvement (e.g. ‘What employment support did you have whilst at university?’, ‘How did you access the support?’, ‘What challenges did you face?, ‘What help would you have appreciated?’, etc.). Further, prompts and probes were used throughout the interviews (e.g. ‘Can you further explain what you mean?’).

Prior to their interviews, participants completed a pre-interview questionnaire that collected background information and to ensure that interview conditions met interviewees’ individual needs, (e.g. interview place, room lightning, bringing support person). Researchers conducted individual, semi-structured interviews in distraction-free environments, either at the university or at a location of the participant’s preference. All interviews were audio-recorded. The duration of interviews ranged from 35 to 75 minutes. In each country, the researchers used the same protocol in each interview situation.
<table>
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<th>Degree country</th>
<th>Age</th>
<th>Sex</th>
<th>Diagnosis**</th>
<th>Year of diagnosis</th>
<th>Field of study/degree</th>
<th>Student</th>
<th>Graduation year</th>
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<td>2018</td>
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</table>

*The participant background information was collected via pre-interview survey and confirmed during the interview.

** AS = Asperger Syndrome; ASD = Autism Spectrum Disorder.

*** Although the participants are studying towards master's degree, they are at the bachelor level in their studies. In Finnish universities, it is typical that students are admitted to master's degree program at point of acceptance to the university.
Data analysis

We used an inductive approach for analysing the qualitative interview data, which is effective in addressing specific research objectives and questions (Hedley et al. 2018; Thomas 2006). The inductive content analysis by Thomas (2006) consists of five steps. First, the data are prepared for analysis, which is followed by familiarisation with the data. Then coding and categorising the raw data takes place, from which key themes are identified. This leads to identifying a thematic framework based on these key themes and identified processes. Finally, during the fifth step, as a result of revision and refinement of the emerged themes, the framework should produce three to eight summary categories. More than eight major themes can be considered to be incomplete inductive coding (Thomas 2006). Furthermore, we followed the ‘consolidated criteria for reporting qualitative research’ (COREQ) 32-item checklist to ensure comprehensive qualitative data reporting (Tong, Sainbury, and Craig 2007, 352).

First, interviews were transcribed verbatim, anonymised and those that required it were translated into English, taking great care to preserve meaning (van Nes et al. 2010). The transcriptions and translations were checked for accuracy by at least one researcher in each country who was fluent in both languages. Capabilities of Microsoft Word (highlighting and commenting) and Excel (e.g. grouping coded items) were used for analysing. In the analysis of the raw data, the research questions were initially utilised in categorising the data and in identifying thematic framework. Two authors first independently analysed the data, and then met to discuss the emerging themes (e.g. enablers in the organisational structurers, respondents’ experienced barriers, caring academics, aspiration for support, etc.), which was followed by a discussion with another author. This was followed by the first author analysing the data independently during which the refinement of the category system led to three summary categories (Thomas 2006). These were discussed with a co-author until consensus was reached. Throughout the analysis, the authors referred to the raw data and compared against the notes they had been making during the research process. Additionally, all authors discussed emerging themes throughout the research process. Additionally, peer debriefing was used to discuss the main themes and subthemes as they emerged.

Results

Analysis of the interviews resulted in three main themes with seven subthemes. These are presented in Figure 1. Data extracts are identified using participants’ codes outlined in Table 1.

Organisational enablers

Academic career-focused support

Factors, including career services, information lectures and career-focused activities, emerged as factors perceived as being supportive. For example, the interviewees discussed information lectures that consisted of career services ‘Coming into one of the lectures’ (UK3), ‘someone [career services] said that practice interviews can be arranged with them’ (FI2), or ‘something was said about LinkedIn, and something about what
should be put in a job application’ (FI3). However, the students mentioned that these lectures were not well advertised, and they could not really recall even having attended one. For example, one student stated: ‘Maybe there was this kind of, I have a hazy recollection, that there was this kind of lecture … ’ (FI1). Although career services advertised their support during the information lectures, yet participants reported that they were unaware that such career guidance existed at university. As one said: ‘I’ve never heard of them.’ (NE12). Some students also feared that they would be judged: ‘ … I know it was an option to go to the career services at my university, but I never did. Because I felt like they would judge me for my resume, so I just didn’t go.’ (NE5). These perceptions identify important issues related to the advertising, visibility and inclusivity of the career services. These type of issues with the accessibility were also identified by other participants; for example:

I just do not remember at all that there would have been this careers’ advice. Pretty much, maybe, through fellow students I heard about many things, what kind of jobs they have, what kind of career fields. That way really [I heard about careers etc.]. (FI1)

From the previous extract in particular, it appears that career services could advertise their support more. Further, one major barrier that specifically emerged was a demand for being self-directed in order to access the support; for example:
I have had to go there myself to get some actual support … And the only real support they’ve given me is just kind of tips for writing a CV … interviews and employment …. But other than that, there’s not really been any support in finding a job, I’ve had to find a job myself, so I kind of have to look for the jobs myself and apply for them myself …. (UK3)

Some university degree programmes included career-focused activities, such as interview practice, CV sessions and visiting industry speakers during university lectures. Participant accounts revealed varied perceptions related to career-focused activities; for example: ‘… [this]module, course … We were practising interviews, it’s preparing us for the actual interviews …’ (FR1), ‘In the last year of the bachelor’s [programme], we had a specific course … in which we were trained in interview skills and how to build up your CV, and networking.” (NE2), and ‘Six full-day courses. That was for careers in teaching or in research.’ (FR5).

**Assessed internships and required practicums**
Participants considered assessed internships and required practicums, that were part of degree programs, useful in building self-confidence for embarking on their life in the workforce; for example: ‘I did an internship. During the internship, I gained a lot of self-confidence and I really had to learn to speak in groups. That is very important in the work I’m doing now, so I’m really happy about that.’ (NE10). Furthermore, the internships and practicums helped them to understand participants’ strengths, weaknesses and future directions; for example: ‘It helped me to realise what I am good at, and what I wanted to be good at, and what I absolutely did not want to be good at …’ (NE12), and ‘… I learned a lot from it and did that help me for employment …’ (FR6). However, participants also reported that what they experienced was different from a real work context with regard to having a safer environment in which one can make mistakes than in actual employment: ‘It was very different from real work. There is still protection then [in the degree practicum]. My lack of social skills was mentioned, but it was seen more as uncertainty that could be overlooked’ (NE9). Another student continued:

> As a trainee teacher you have a totally different job than when you are actually a teacher. Above everything else, the five hours that you teach as a trainee is totally different from the 20+ hours that you do it in practice. … (NE1)

These extracts portray that when practicums are different from the real-world work environments, the students might not be able to recognise their strengths and support needs in which they would need to be accommodated. Further, if the student recognised such support needs, solutions to support those could also be found during the practicum, which could be utilised later in the workforce.

**Supportive and caring relationships**

**Mentors**
The relationships with mentors refer to personal tutors and coaches, and staff from disability and mental health services. Such relationships were more than receiving general advice and touching the surface (e.g. career services), as they were caring and deeper, enabling students and graduates to receive more targeted support for employment.
Participants described various instances in which they received help in the job search from their tutor or coach: ‘I had appointments with a mentor for a year (twice per month) and that also helped … This person took me seriously and that was nice and supportive’ (NE9). Other participants continued:

Well, I have a coach … And that is life coaching. I’ll definitely go over it with her … I’ll discuss it with her about what do you think, what do you think might suit me? She knows me well. And maybe she has contacts. And so I’ll sort it out in that way …. (NE5)

… I have an appointment with her weekly and we can just discuss my work and current issues and stuff like that … she’s kind of helped me with a lot more with how to go about getting employed while on my degree. (UK3)

From the previous extracts, clearly these mentors outside university structures had close relationships with the students and were supporting them rather than just providing general guidance. Although it emerged that the students received support from tutors or coaches, yet others did not: such assigned tutors were not mentioned by the Finnish participants, even though there are tutors, yet students have to reach out to them independently (see e.g. Pesonen et al. Forthcoming).

The participants also recognised disability and mental health staff members as supporting factors, as well as showing an interest in their needs. Some participants described how they had received help from the disability and mental health services rather than elsewhere; for example:

They offered to help us with the paperwork if we had any difficulties. Also, [name] told me how to look for internships and write down in columns when I contacted someone, if I did get an answer … to keep the history of all this. (FR2)

However, unfortunately, students typically had to find out about these services independently, although there were also students who were explicitly told to go to disability or mental health services; for example: ‘… I was told that I had to go to the mental health service, otherwise I couldn’t continue with my course. I didn’t dare, but I acted like I had done it. They didn’t check’ (NE9).

**Committed and caring academics**

The interviews further indicated those holding university teaching and research positions provided support and advice to students. For example, lecturers might help with ‘application techniques’ (NE3). For some, academics helped to find employment through their own industry contacts and knowledge. For example, one student described a helpful professor:

[She] helped me with eye contact a lot and how to interact socially as a professional. So, she taught me how to act in job interviews and some things that maybe you should and shouldn’t say and when you should and shouldn’t say them in the work environment to your manager or your subordinates or things like that. (UK5)

Another student spoke about a support group that was organised on a voluntary basis by committed academic staff for struggling students: ‘Well this “have a grip on your studies” has been pretty good … and I hoped to take part in this group’ (FI4). Overall, participant accounts made a clear connection between committed and caring academics and its
implications for preparing students and graduates for employment whilst in university. It was also clear that this was not a systematic form of support, as the interviews indicated that some students and graduates had been more fortunate to encounter such committed academics than others.

Parents, family and friends
The participants expressed how important support from people who are close to them had been whilst in university; for example: ‘To be honest I have more benefit from people that I know in employment matters [than from career services]’. (FI6), ‘… I do have the advantage that I have parents, and my friends who are somewhat older, or something. I think that, in five years from now, that will be done quite differently …’ (NE8), and ‘… we had courses, but really learned from my father who’s in that work field’ (FR4), as well as a British graduate stated on help provided by their partner: ‘… My wife … your partner has to bridge that gap and be able to both understand you and tell you when you’re being weird and don’t do that. She helps me translate neurotypical for me a lot. (UK5) These extracts demonstrate how the students received support from the people who are close to them, and such support potentially can relate to better employment opportunities.

Aspirations for individualisation
Individualised work and academic support
Although it was apparent that the participants had concerns related to the academic career-focused support, for instance: ‘I thought it was really bad. I could not take it seriously …’ (NE13), the interviews indicated that they hoped to improve the career-focused activities:

I think maybe what could have been done better is we could have gone to visit the agencies within one of my modules a lot more regularly than what we did. So, then I could get rid of the fear of the unknown once I’m actually approaching that time. (UK1)

Another student continued by stating:

Oh yeah, maybe we should also do something about the fact that the people who do this course cannot find a job. But that, yes, that is mainly in, indeed, according to me it was a block of seven weeks, with one hour per week. Yes, that kind of thing. (NE2)

Students also spoke about improving the support provided by career services. For example: ‘I would have liked to have lessons earlier on careers or applying, but what I did receive is adequate, I think. I tried to find out everything for myself.’ (NE3) and ‘… I would have hoped that there would have been more like this orientation to the workforce.’ (F11) and ‘… just like to have, like a checklist of what I’m supposed to do step by step.’ (NE6) Another participant continued:

I think that I needed an overview of what the companies are … in terms of possibilities … So I could form a picture of that, later I saw that I could have maybe made a choice for an internship that took that into account. That would have led to better insight. A clearer picture of where you could go. (NE11)

Furthermore, one of the areas that the participants also struggled with was related to lack of individualised support during the internships or practicums. For example:
Internship, I only think I did a month. And it was so horrible, like just being there every day was so exhausting and daunting. So, I just started calling in sick almost every day. And then I just disappeared. And then they started calling me. It was so stressful. (NE6)

The participants expressed their views about how to support during internships and practicums could be improved. These were related to earlier recognition of their autism and the impact it might have on career suitability, for example: “[I needed] someone who had convinced me that teaching was really not the right direction for me (NE1)” and ‘… someone who had recognised my autism, and could have then suggested that I do something else’ (NE1).

**Awareness and understanding**

The participants would have hoped to have more support and understanding of neurodiversity from the academics. For example:

I wish my lecturers … wish they’d got to know me better … and I just needed some understanding and guidance to help flourish with the work and the other point being it, that really I just wish I had had some better mentoring, guidance …. (UK4)

Participants also brought up hopes for ongoing support where they could go when they needed help in recognising daily problems related to work and study, free time, as well as trying to find solutions to them together. For instance: ‘… someone who could have helped me with separating work, study and relaxation’ (NE1) and:

Just someone who I can always go to at any time, when I have problems, like someone who’s sat next to me I guess in lectures and work, someone who I can ask who is trained in the course that I was on and my condition and, you know, someone who I could go to just to get maybe prompting or support on things … (UK3)

**Discussion**

This study examined employment support related to university-to-work transition for students and graduates with autism. Our study contributes to the existing literature related to post-secondary transition for individuals with autism (e.g. Cashin 2018; Elias and White 2018; Lambe et al. 2019; Vincent 2019, 2020) by widening the perspective to specifically include students’ and graduates’ perceptions about employment support related to the transition from university to work. We discovered that the support within university structures was not meeting students’ individual needs and that caring relationships were the most favourable supporting factors. Both these main themes shared a significant feature related to individualisation: participants had expectations of individualised support, which was also related to perceived supporting factors and shortcomings in those. Such lack of adjustment can lead to an unsuccessful transition consisting of poor employment outcomes, feelings of isolation, and jeopardising the overall quality of life (e.g. Hendricks and Wehman 2009; Moss, Mandy, and Howlin 2017; Pesonen 2016; Pesonen, Kontu, and Pirttimaa 2015; Rogge and Janssen 2019; Vincent 2020).

Our findings showed that the participants were required to be self-directed in navigating the support intended to help them to gain necessary employability skills, as well as to build networks that might improve employment prospects. Some participants had even explicitly been directed to seek support services and even then, they did not necessarily
have the independence and courage to ask for the services. Such demands that they seek support independently can be especially challenging for those with autism due to the challenges around executive functioning that can prevent them from goal-oriented behaviours (e.g. Barkley 2012). Although often the mission of higher education is to promote independent and self-directed individuals, and generally students close to graduation are presumed to be more self-directed than those in the beginning of their studying (e.g. Harvey, Drew, and Smith 2006), yet this did not appear in our findings. Almost half of the participants were either graduates or close to graduation and struggled with the demands of self-direction.

These issues of self-direction, as well as the lack of personalised support expressed by the participants, may challenge the whole ethos of universities that aim to support students in becoming independent learners. Supporting and teaching someone to become a self-directed learner at university has been highlighted in earlier research (e.g. Bell et al. 2017; Harvey, Drew, and Smith 2006; Wilcox 1996). However, with the increase in number of students with autism, perhaps there is an even greater need for initiatives emphasising support from the student’s first year and beyond to become self-directed (e.g. Harvey, Drew, and Smith 2006; Wilcox 1996). Even starting to support such skills well before entering higher education could be considered (Bell et al. 2017). Perhaps this type of support would also have implications for students to become more independent job searchers.

The participants were from universities in four European countries, each seeking to obligate universities to provide transition to work support for students. For example, support is obligatory in France whereas it is not compulsory in the Netherlands (EC 2018), yet our findings showed that the lack of employment support appeared to be a Europe-wide issue. Further, it appeared to be ‘pure luck’ when students received more personalised support, which was often provided by committed academics, mentors or family members. Perhaps developing interventions to improve the employability of university graduates with autism within the European Union are needed to solve this existing dilemma. In such improvement of support, it should be accepted that it is not the sole responsibility of a university to take care of students with autism; liaison between universities and employers needs to be emphasised in the transition of students with autism to the workforce (see also Hedley et al. 2018). However, a cautionary note is needed here: when aiming for harmonisation of more inclusive services they should not be seen as being synonymous with standardisation, as services need to be individualised to meet the needs of neurodiverse students, and policies should recognise this, too. Overall, much work still needs to be accomplished on inclusive services and revising the policies to meet the needs of all (e.g. Moriña 2017; Zeedyk, Bolourian, and Blacher 2019).

Limitations and future research

This study has its limitations. Our sample is not representative of all university students and graduates with autism. Although interviewees represented several subject areas, our sample could have benefitted from a broader perspective on various subject areas, as some subjects may have specific career issues. Future studies should therefore consider this when seeking study participants. Further, although the international element is important and our main aim was not to examine the contextual disparities between
nations, focusing more on this would be important in future studies. For example, it would be interesting to study what government-mandated infrastructure for students with autism is available (e.g. existence of collaboration between the universities, workplace and possible independent third-party organisations) (see also Bühler et al. 2020). Furthermore, it would be also interesting to study the students’ possible demands of self-direction in job search and issues related to autism and executive functions. In future studies, the sample could also include both participants with and without autism in order to examine further what employment support issues are autism specific. Additionally, our sample contained fewer autistic females than males, although the male to female ratio in the current study is 3:1, which reflects the typical gender distribution in autism (Loomes, Hull, and Mandy 2017). It is possible that there are gender-specific employability enablers and barriers, and understanding these would be of benefit in the development of support services. Overall, future studies should also involve people with autism in all stages of the research (e.g. in data collection and analysis), as well as in evaluating the efficacy of the implementation of potential research-based practices.

Our study demonstrated that in order to improve employment outcomes for university students and graduates with autism, all identified enablers and need for individualised support need to be considered. This requires universities to train their staff continuously (Moriña 2017) and build bridges with potential employers. Although our findings suggest that employability issues for students with autism are Europe-wide, future studies are unquestionably needed to inquire into this. Such studies would also have the potential to lead the development of possible interventions to solve the underlying issues.

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