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Transition from secondary to higher education: an evaluation of a pre-entry transition programme for students on the autistic spectrum

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Abstract

For many individuals on the autistic spectrum making the transition from secondary into higher education can be particularly challenging and evidence shows that planning and coordinating this change effectively is extremely important for a positive experience. This paper outlines an evaluation of a pre-entry transition programme at one university in the North of England for first year undergraduate students on the autistic spectrum. By engaging with the perspectives of students, parents and practitioners it aims to uncover the value of the programme but also to understand more clearly where it might be improved. Its findings detail the practical, social and emotional outcomes of the programme for the different stakeholders and reveal the potential for informal networks of support to develop among both parents and students.

Introduction

This paper outlines an evaluation of a pre-entry transition programme at one university in the North—of England for students on the autistic spectrum. By engaging with the perspectives of students, parents and practitioners it aims to uncover the value of the programme but also to understand more clearly where it might be improved.

Transition is frequently portrayed by researchers as ‘a complex and often difficult period of a young student’s life’ (Krause and Coates 2008:499) with responses to it bounded by one’s capability to navigate change (Gale and Parker, 2014) . This characterisation has been confirmed by a large number of studies from the UK that indicate that the transition into higher education can be a particularly challenging and stressful process. Notably Lowe and Cook (2003) identify the abrupt shift from a family and learning environment that is often tightly controlled to one in which students are expected to accept personal responsibility for both academic and social aspects of their lives as precipitating increased levels of anxiety and distress. Students find this process of social integration and identity formation particularly challenging in the first weeks of higher education (Hughes and Smail, 2015; Warin and Dempster, 2007) and express considerable concerns about the academic demands involved (Gourlay, 2009). It has been suggested that these experiences are particularly pronounced for students from ‘diverse’ backgrounds, including disabled students (Kift 2009), and a number of studies have identified that the transition from secondary to higher education can be especially challenging for students on the autistic spectrum (Mitchell and Beresford, 2014; Van Hees et al 2014; Beresford et al 2013; Cooper, 2013; Rydzewska, 2012; Chown and Beavan, 2010; Adreon and Durocher, 2007; Martin, 2006; Breakey, 2006). This has particular import given that the number of students with a diagnosis of autistic spectrum conditions disclosing on entry to UK higher education institutions has significantly increased in recent years (Equality Challenge Unit, 2013).

Autism is a lifelong developmental disability, which affects how an individual communicates and relates to others, processes information, and makes ‘sense of the world’ (NAS, 2014). However, many individuals on the autistic spectrum experience these differences in a range of ways and to varying degrees, which accords with the concept of an autistic spectrum (Wing and Gould, 1979). Some autistic advocates such as Williams (1996), Robertson (2009), and Milton (2014) prefer a neurodiversity model as a means of describing the neurology and personhood of autistic people, to restrictive diagnostic criteria. Within this framework autistic individuals possess a blend of cognitive strengths and difficulties across a range of core domains, including those outlined above. Van Hees et al (2014:1684) identify strengths that for autistic students include, their different way of processing information also gives rise to some exceptional skills and talents, such as a strong memory, focus precision and an eye for detail, dedication, the ability of putting one’s mind to a subject, analytical skills, remarkable powers of observation etc.

According to Robertson (2009), a neurodiversity model assumes that strengths and difficulties are contextual and frequently the result of the interaction between an ableist society and individual differences or impairments. Thus, there is an impetus to understand more fully the diverse ways in which autistic students experience university, and especially transition, in order to identify aspects of practice that could be improved.

Transition to higher education for students with autistic spectrum conditions

In recent years many higher education institutions (HEI) have taken active steps to establish appropriate adjustments to support the successful transition for autistic learners (Barnhill, 2014; Mitchell and Beresford, 2014; Cooper, 2013; Pillay and Bhat, 2012; Zager

and Alpern, 2010; Camarena and Sarigiani, 2009) and in the United States transition programmes for young people on the autistic spectrum have been identified as a priority for research (Interagency Autism Coordinating Committee, 2012). Evidence suggests that getting a robust support package, which includes social, emotional, practical and academic provisions in place from the beginning is important for students' success (Mitchell and Beresford, 2014; Cooper, 2013; Zager & Alpern, 2010; Madriaga and Goodley, 2010; Martin, 2006). According to Beresford et al. (2013:3), where this does not happen and there is a lack of information, planning and coordination, this can have major implications beyond the immediate. They contend, A 'poor transition' is likely to lead to reduced support and unmet needs which may have prolonged and cumulative consequences for the young people's education attainment, health and welfare.

Thus, effectively managing transitions is recognised as being crucial for autistic students' inclusion into higher education and wider society more generally.

However, given that these shifts in research and practice are relatively recent, current postsecondary transition interventions still remain sparse and their effects have yet to be empirically tested (Van Hees et al., 2014; Gelbar et al., 2014; Barnhill, 2014; Pinder-Amaker 2014; Costley et al, 2014). Barnhill's (2014) study, based on the provision of American colleges and universities, found that few institutions, only 7 out of 30 surveyed, offered pre-entry transition programmes for students on the autistic spectrum. Moreover, among her sample there was wide variation, from a 3-day orientation programme through to a 6-week intensive summer course. In the UK, there is also a paucity of empirical data available on specific pre-entry transition programmes offered by different HEIs. That notwithstanding, the small sample of studies that investigate transitions to higher education for students on the autistic spectrum identifies a number of features over two distinct stages: the planning stage and the induction stage (Martin, 2006; Cooper, 2013; Mitchell and Beresford, 2014).

Planning stage of pre-entry transition programme

Transition frequently begins many months before a student ever enters an HEI and for those on the autistic spectrum, information-gathering, decision-making and planning is extremely important (Cooper, 2013; Mitchell and Beresford, 2014). In the planning stage, transition programmes may include establishing early contact with the student and parents and planning the 'critical juncture' together (Cooper, 2013; Martin, 2006). Offering visit and taster days to the university, opportunities to meet members of teaching staff, and attending practice classes are identified as useful, particularly where students are able to experience settings 'in action' (Mitchell and Beresford, 2014; Camarena and Sarigiani, 2009; Chown & Beavan, 2010). Much of this stage will involve making contact with the HEI's disability service, identifying specific support needs and organising adjustments.

Parents are often a vital resource at the planning stage as some students with autistic spectrum conditions find initiating conversations with strangers challenging and 'find it difficult dealing with unexpected questions in a formal verbal environment' (Hastwell et al, 2012:59). Others may struggle with organisation, working memory and initiating action (Hill, 2004; Van Hees et al 2014), which can make arranging the various meetings, completing the necessary paperwork, and liaising with the disability advisors a rather onerous task. Evidence shows that parents also fulfil an important emotional role, often acting as a sounding board, a source of advice and psychological support (Whitson & Keller, 2004; Beresford et al, 2013). However, HEI practitioners must approach parents' involvement with sensitivity, as some students may prefer to establish their package of support independently (Van Hees et al 2014; Madriaga et al, 2008).

Induction stage of pre-entry transition programme

As Barnhill's (2014) study suggests pre-entry transition programmes can vary widely; however, the induction stage tends to focus on the practical and academic issues associated with starting a new higher education course. Mitchell and Beresford (2014) suggest that expectations of increased independence, greater demands for self-directed learning, self-management of time, and less structured timetables, as well as new peer groups and social situations in post-secondary education can be challenging. This sense of being overwhelmed is reflected by a participant from Beardon and Edmonds' (2007:159) emancipatory study, 'I found it extremely hard to cope with any changes...the stress of being a student...writing essays... presentations... managing time...interacting with students and staff'. Thus, a large part of any pre-entry induction programme into higher education focuses on providing information on procedures, understanding academic conventions and gaining awareness of institutional norms (Kift, 2009; Gale and Parker, 2014). However, Van Hees et al (2014) argue that programmes for autistic students must go beyond a focus on the academic to include other aspects of the experience too.

Pre-entry transition induction programmes may also include orientation around the campus or ways of 'acclimatising' students (Van Hees et al, 2014) so that they feel confident with their surroundings and identify the places that may be more or less comfortable on sensory levels (Smith and Sharp, 2013). Some students may choose to move into their accommodation early; this may be a few days prior to the beginning of term or for extended induction periods of up to six weeks (Barnhill, 2014). Smith (2007) suggests that students on the autistic spectrum may require unique and individually based accommodation, specifically suited to the students' sensory and social needs and Lipka (2006) suggests that this is most effective when it is off-campus. Thus, having early access to accommodation before the beginning of term is identified as useful for allowing autistic students to manage the practical and emotional process of adjusting to their new surroundings without having to meet new people at the same time (Vincent et al, forthcoming). It also provides an opportunity for students to establish new routines and systems to manage independent living before the additional considerations of formal learning begins (Van Hees et al, 2014).

Methodology

This section will outline one pre-entry transition programme for students on the autistic spectrum based at a university in the North of England, before detailing the research methods utilised to gather and analyse the data.

Case study: Early Start Programme

The Early Start Programme was established in 2013 and is managed and facilitated by the University's Learning Support Team with input from academic staff and other agencies. Over the last two years, 24 undergraduate students who had disclosed a diagnosis of an autistic spectrum condition to the institution have been through the programme. Of these all were between the ages of 18-21 with 15 male and 9 female. Like many pre-entry transition programmes for students on the autistic spectrum, it can be understood as having two distinct stages: the planning stage and the induction stage. The planning stage began by establishing communication with students at the point at which they identified the institution as their preferred place of study. An invitation was then sent to the student to come for an individual visit day where they would have the opportunity to look around the facilities, individually or accompanied with parents, discuss their support needs with a disability

advisor and meet with members of the academic staff from the degree programme on which they intend to study.

The induction stage began following receipt of exam results, once the students were able to confirm their place at the institution for that academic year. The students were sent an autism-friendly guidance pack on life at the university, including information about the city, campus, facilities, accommodation options, disability support and a specific autism social group. Students were invited to two days of induction, the Early Start Programme, at the university prior to Freshers' Week. This included moving into their student accommodation up to two days before other students with parents frequently accompanying them on this first day to assist with the move into their new flat or room. The programme proper began with a welcome lunch at the University; this offered students and parents the opportunity to meet one another as well as for members of the staff team to introduce themselves. During the two day programme students enrolled early, had their library induction and took a tour of the campus to identify 'quiet' areas that might be useful for studying or relaxing. Students also took part in a range of activities to support their academic and social transition, including a time management workshop, a cookery class and walking tour of the city. Students were introduced to members of the wider Student Advice Team and had opportunities to ask current students, who are also on the autistic spectrum, questions about their experience of studying and university. Finally, the Early Start Programme had staffed evening social events during the two days of induction as well throughout the Freshers' Week that followed.

Methods

As stated above, this case study considers the perspectives of students, parents and practitioners in evaluating a pre-entry transition programme for students on the autistic spectrum. It largely drew on qualitative data in the form of surveys among students and parents and one focus group among practitioners involved in delivering the programme (Punch, 2013). In doing so, it aims to understand more clearly about how the different stakeholders encountered the programme (Pring, 2000) and identify the areas that are considered most useful for meeting the students' transition needs.

Data collection and analysis

An anonymous student survey was developed by the author in 2013 and a similar postal version was developed for the parents the following year. Following Cohen et al (2007:381), who suggest that surveys among small samples should include open and "word-based" questions, both surveys had 4 main parts and sought mostly qualitative data. In order to measure whether the programme had met the needs of the students and parents, participants were given the opportunity to describe in depth their own experiences of the transition programme and to outline what was successful or where it might have been more effective. A focus group was chosen as the method of investigating practitioner perspectives on the value of the programme. Whilst a focus group may be limited in the number of questions that it can address in the time available, Patton (2002) sees the focus group interview as a highly efficient qualitative data collection technique as those involved are able to develop ideas collectively and counter false or extreme views. The focus group for this study took place some months after the last transition programme but at the planning stage for the next one, so although practitioners were required to reflect on past events, the structure and content of the programme was at the forefront of their minds. A thematic approach (Flick, 2014) was used to analyse the qualitative data drawn from the surveys and focus group interview; this involved reading and re-reading the student and

parent responses as well as the transcript from the practitioner focus group, developing codes to make sense of the data and from these identifying broad themes.

Sample

The available sample included 24 students over two years. Only those who had disclosed their diagnosis of an autistic spectrum condition to the institution were included in the sample. In 2013, a total of 11 students took part in the transition programme (7 male and 4 female) and in 2014 a total of 13 students (8 male and 5 female) participated. Of this sample, thirteen surveys were returned over the two years, 8 returned in 2013 and 5 returned in 2014. On both occasions, the surveys were distributed to the students at the end of the programme; however, as some were emotionally overwhelmed by the whole transition experience and could not attend every session, not all were available to participate. In total only 7 postal surveys were returned from parents, however these were only distributed in 2014 and not all students were accompanied by family members for the programme or involved them in the broader transition process. From among the practitioners, three were invited to participate in a focus group, including the Disability Advice Team Leader, one Disability Advisor and one Specialist Tutor responsible for academic support for autistic students; this group reflected those chiefly involved in designing and facilitating the programme and offered a significant level of insight. Thus, the sample involved in evaluating the Early Start Programme is $n=23$. It is acknowledged that one of the limitations of this sample is that it does not offer the perspectives of all the stakeholders involved and therefore may not be representative of all the students, parents or practitioners who participated.

Findings and discussion

Fundamentally, there was a strong sense that the extra support afforded by the Early Start Programme was useful for students making the transition to higher education, which aligns with previous research (Barnhill, 2014; Van Hees et al, 2014; Mitchell and Beresford, 2014; Cooper, 2013; Pillay and Bhat, 2012; Zager and Alpern, 2010; Camarena and Sarigiani, 2009). In total four main themes were identified from among the qualitative data derived from student and parent surveys and the practitioner focus group, these include the importance of practical adjustments, social and emotional effects, parental transition and networks of support.

The importance of practical adjustments

All three groups identified the value of the practical aspects of the programme. Both students and parents identified moving into accommodation early, gaining familiarity with surroundings, early enrolment, and gaining advice on coping with independent living as valuable on a practical level. For some of the students these provisions successfully took “the stress out of the whole process” and allowed them both the physical and emotional space to make the adjustment to a new environment (Chown and Beavan, 2010; Camarena and Sarigiani, 2009). Parents specifically reported how the programme “allowed for a really positive start to university life” and “got over the issue of doing things for the first time”, referring to the emotional challenge of change for some. Moreover, they identified the value in being able to engage in many of the typical student activities (stay in their accommodation, navigate the campus, eat in the canteen etc.) in an environment where they did not need to contend with additional pressures. The three learning support practitioners identified “independent living skills”, which covers a range of aspects from “cooking, buying food, budgeting...and I think just learning to manage away from mum and dad in a new environment” as a significant area of need. Whilst accepting personal

responsibility apart from the family context is recognised as being a challenge for many students entering higher education (Lowe and Cook, 2003), Mitchell and Beresford's (2014:152) findings that suggest that the academic abilities of autistic students often mask their ability to integrate into the new setting, to develop social networks and to manage expectations of independence and self-reliance. One practitioner suggested that "it might not even be possible to separate the independent living from the study skills"; in both instances a positive transition is marked by students developing "routines that make them successful" (Boucher 2009).

Although much of the feedback from the evaluations was very positive, all three groups identified aspects of the programme that could be improved. Functional aspects were specifically recognized as requiring improvement, including more active delivery and increased opportunities to socialise. Practitioners reported the need to better align the Early Start Programme with the formal support for disabled students, in terms of a mentor or 1:1 specialist tutors, from the outset and include access to more information as "I think students have a lot of very practical questions they want answering and I don't think we fully answered them last year". One solution was to develop "a café idea, a bit like an open day, where [students] can go to different people and ask really specific questions, like to accommodation, to funding, to the student services team, to academic staff etc. I think that will be really useful." A joined up approach to support such as this accords with previous transition research (Beresford et al., 2013; Mitchell and Beresford, 2014; Cooper, 2013; Zager & Alpern, 2010; Madriaga and Goodley, 2010; Martin, 2006).

Social and emotional effects

There was a strong sense among all stakeholders that the Early Start Programme was worthwhile for students on social and emotional levels. Research shows that this can frequently be an area of specific need among this population (Hastwell et al, 2012; Martin, 2008) and was thus an area that the programme specifically sought to address. Whilst students acknowledged the social benefits of meeting new people in a "relaxed and fun" environment, parents and practitioners were much more explicit in terms of the positive outcomes and reported positive shifts in students' levels of self-confidence and sociability. Parents positively identified the benefit of meeting "like-minded friends in a relaxed atmosphere" and a broad and varied programme with evening activities, which "helped to 'fill in' time where otherwise students would have been on their own". They also described how the programme specifically impacted on their son or daughter's levels of self-confidence; one parent puts it well, My son's reaction. He was very nervous and anxious on the Friday morning but by Saturday eve a different young man, feeling confident.

These examples resonate powerfully with the neurodiversity model of autism that suggests that many of the impairments and difficulties experienced by students with ASC are contextual (Robertson, 2009; Milton, 2014) and where the environment, rather than the person, can be altered then this can have positive effects.

Parental transition

Previous research (Van Hees et al, 2014; Mitchell and Beresford, 2014) shows that parental involvement is a significant factor in the success of induction programmes and this was the case for the Early Start Programme. Although not all students chose to involve their parents in the process, those that did tended to have a high level of input throughout the planning stage of the process and were considered a vital resource by practitioners. Frequently they were responsible for liaising with the University and offering emotional support to the students throughout the process, which is also affirmed in other studies

(Mitchell and Beresford, 2014; Whitson & Keller, 2004). However, this study identified that many of the parents themselves found the process of their son or daughter's transition emotionally challenging (Newsome, 2000). One practitioner noted, I think quite often with the parents, it's a massive transition for them because they are letting go of the person they have kind of been looking after for the last eighteen or maybe even more years...and so if we are able to give them some confidence then that feeds back to the students.

A clear relationship is identified between how the parents feel about the transition process and its impact on the students; where parents feel reassured that their son or daughter will be well-supported this seems to enhance the experience of transition. The approachability of the practitioners facilitating the programme was identified as a significant reassuring factor, for example, parents reported "knowing that help is available and meeting the staff who can provide it" and having the "chance to chat to staff" as important. Moreover, parents valued how "as a team you really 'get' Asperger's from the point of view of both student and parent", indicating the importance of understanding the specific needs of the students and the parents during this transitional stage. Many parents also reported feeling relieved that they could see their son or daughter engaging in activities, growing in confidence and feeling happy as the statements above suggest.

Networks of support

Practitioners reported that one of the strengths of the Early Start Programme was that it created networks of support; these were formal and informal and supported both the students and their parents. The value of formal support networks for some students was in terms of getting them "linked in" with a disability advisor, 1:1 tutor support, or a mentor was highlighted. To exemplify this, one practitioner offers the example, We've had two [students] that I can think of that before they came in we were really, really concerned that they would possibly not be able to cope whatsoever but they are coping really well, very well. I think that has to be down to the amount of that was put in at the beginning and the ongoing support. However, some of the support is also informal and is characterised by students "looking out for each other". It was acknowledged that these supportive relationships and friendships frequently occurred organically "without our intervention" and in the "in-between" moments of the programme but were nonetheless clear signs of its impact. I think you can see how successful [the Early Start Programme] has been just from the friendship networks that developed that we can actually see and when you meet up with a particular student they will often refer to another student and there is that – I mean – sense of really caring about each other, for example they might tell you that they are a bit worried about so and so and it's kind of nice to see that.

Interestingly, just as many of the parents appeared to exhibit their own transition needs, there was also evidence that informal networks of support were important for them too, as one practitioner observed, I had a chat with the parents on their own and the best thing really was afterwards when I came out, I noticed they were sitting there chatting and supporting each other and I think if they feel supported and are talking to each other then they feel more confident and that will go on to the youngsters as well...that was unexpected but another moment.

In this sense this group support each other through the process of their own transition from parents of a dependent child to parents of an increasingly independent young adult.

The formation of informal networks of support among the parents and students respectively was one of the unexpected but very positive outcomes of the programme. For both groups, the shared experience established at the Early Start Programme, enabled them to engage

on personal levels in expressing challenges and identifying needs. Where practitioners only observed this taking place during the two-day programme among the parents, they reported that for students this informal support network was still significant for some well into the first year of study.

Conclusions

In conclusion, care must be taken when identifying wider implications due to the limited scale and localised context of this study, moreover, it must be acknowledged that the data was broadly derived from 'satisfied' respondents and consequently does not include the voices of *all* the students and parents. In the future, it would be illuminative to seek to include the perspectives of a wider range of students, parents and practitioners, including those for whom the transition to higher education was not successful in order to extend the findings outlined here.

However, the available data from this evaluation does demonstrate that the Early Start Programme at this one university in the North of England was positively received and offered significant benefits to students on the autistic spectrum and their parents. The range of practical adjustments put in place for students, including early access to accommodation; campus familiarisation; early enrolment; and workshops and activities on independent living and academic skills were all considered useful. Opportunities to develop social relationships and networks of support were also identified as being positive, both for students and their parents. Furthermore, the emotional reassurance that was offered through a programme staffed by practitioners who clearly understand the strengths and needs of individuals on the autistic spectrum was acknowledged as valuable. However, whilst this study signals significant benefits, there remains a clear demand for more robust evidence in order to determine what is most effective in terms of pre-entry transition programmes to university for students on the autistic spectrum.

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