

The importance of self-advocacy skills: 'This is what I can do, and these are the adjustments I require'

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Introduction

Since 2010 we have been following the transition experience of 80 young people with vision impairment (VI) as they have left compulsory education and made transitions into Further Education, Higher Education (HE), apprenticeships and the labour market. The purpose of the study is to identify any enablers or barriers which impact upon the participants' experience at these transition points and to develop a better understanding of how best to prepare and support these young people for adulthood.

In keeping with previous research literature, a consistent theme in our research findings is the importance of young people with VI being equipped with self-advocacy and social skills (e.g. Crudden, 2012). There have been many contexts in which the participants have benefited from, or been restricted by, self-advocacy skills. This includes when: negotiating support packages as part of 'Disabled Student Allowance' for university; negotiating support arrangements in higher and further education; explaining adjustments needed in the workplace; and challenging a lack of reasonable adjustments. We have also observed the importance of the young people having the confidence to establish whose responsibility it is to take action, and being able to articulate this position (for example, Douglas and Hewett, 2014). Self-advocacy skills are an example of a skill which specialist teachers of children and young people with visual impairments help develop through the 'additional curriculum' - the term used in the UK to describe all areas which would not typically be taught in schools as part of the core curriculum (see, for example the review by Douglas et al., 2009). In the US, the term 'expanded core curriculum' (ECC) is used in a similar way (e.g. Hatlen, 1996).

In this paper we focus specifically on the experiences of those participants who transitioned into HE. We explore the different situations where it was necessary for them to self-advocate, whether they were equipped to do so, and what experiences had helped in preparing them.

Background to the study

In 2010 over 80 young people being supported by Local Authority Vision Impairment Education Support Services and specialist schools in the midlands

regions of England and Wales were recruited into a longitudinal qualitative study. The entry requirements for the study were that participants were aged 14-16, and that they were able to complete a questionnaire independently. The participants recruited have a wide spectrum of VI, ranging from those with a mild impairment (not considered significant enough for formal registration as sight impaired in accordance to UK criteria for certification, RNIB, 2016), to those who do not have any light perception. However, in all cases the participant's VI was considered sufficient to warrant specialist support in school. At the time of writing we have been working with the participants for over 6 years, and 65 participants remain active in the research.

The purpose of a Longitudinal Qualitative Study is to observe change over time through a series of in-depth interviews with the same participants (Farrall, 2006). As we want to observe the participants' experiences of transition between settings which, after compulsory education, can occur rapidly, semi-structured interviews have been conducted with the participants at two key time points during each calendar year. These were typically the spring/summer prior to the young person making their next transition and in the autumn/winter a short time after they had made this transition. All interviews have been audio-recorded and transcribed verbatim. Participants have been compensated annually with a £10 gift voucher. The study received ethical approval from University of Birmingham Ethics Committee at each stage of data capture.

One of the most common transitions the participants have made is the transition into Higher Education (HE). By spring 2016 half of the remaining 65 participants in the study had chosen to go into HE, and more were intent on doing so. Table 1 gives an overview of some of the key characteristics of the 32 participants who had transitioned into HE by the academic year 2014-15.

Table 1: Overview of participants in HE (N=32)

Variable	Total (N)
Gender	
Male	18
Female	14
Registration type	
Sight impaired (partially sighted)	13
Severely sight impaired (blind)	11
Not registered	5
Participant does not know registration type	3
Preferred reading format	
Standard font size (up to pt 14)	4
Large print (Pt 16-22)	15
Very large print (Pt 24+)	4
Braille/Electronic	9

Type of secondary school education	
Mainstream school	19
Special school	11
Both mainstream and special school	2

These participants were interviewed at multiple stages of their transition into HE, including: at the time of initial application; prior to starting their course; in the first term of their new course; and at the end of their first academic year. The findings of these interviews are presented in Hewett et al (2015).

Self-advocacy in Higher Education

Interviews with these 32 participants identified several ways in which the young people were required to self-advocate in HE. We consider each of these in turn.

Negotiating support packages

UK-based students with disabilities in HE are able to apply for a non-means tested support package called 'Disabled Student Allowance' (DSA). This provides funding for specialist equipment, non-medical support, consumables like printer cartridges and where required, transportation. As part of the application process for DSA the student attends a needs assessment meeting where they discuss with a trained assessor the means by which they would like to participate on their course. For example, they may discuss options of working electronically, in braille or a combination of the two. They may wish to have a note-taker in lectures, or prefer to take their own notes but work with a support assistant after lectures. The purpose of the assessment is to put together a support package which can facilitate this. Whilst there were some variations from assessment to assessment, this package is normally devised by the assessor asking questions to the student about what type of support and equipment they had benefited from previously, and how they wanted to work in HE. This was challenging for several of the participants who did not have a clear idea of how they wanted to approach their studies. Some had limited understanding of what learning in HE would be like having only been in a classroom environment before, which offers much more directed learning. Others had limited knowledge of the specialist equipment available, having always worked using the same medium, and not having had the opportunity to experiment with different methods.

One participant identified how her lack of knowledge of the specialist equipment available limited how well she could advocate for the technology she required in the assessment meeting:

"I could have done with more information about what technology is out there. Because I had issues with it, I got the wrong Dictaphone to start with...And, my scanner as well, I am aware now that there are scanners out there that are lot more portable, and a lot more..." (Severely sight impaired, braille/electronic user)

Another participant who had attended both specialist and mainstream school settings described how this had enabled her to develop an understanding of the way in which she preferred to work, and why:

"And that was one good thing about being in mainstream sixth form was I kind of started figuring out what was necessary and what support I had as a matter of course... When I then transitioned to college afterwards, I went there and was like 'I need this and I need this, I need this format' and I knew what I needed. That's why in college it worked because I knew what I needed and I could explain that myself." (Severely sight impaired, braille/electronic user)

Negotiating support arrangements

After a student who has disclosed a disability is accepted onto a course at an HE institution, they are usually invited to meet with the institutions disability support office to draw up a support plan outlining the support and adjustments required for them to be able to participate on their course. The participants identified several ways in which it was necessary for them to outline a case for these adjustments:

"And then, I had to do a lot of advocating in the first year, of actually explaining what I needed, and how I wanted it to go... I had to do my own research in terms of talking to other people, and talking to other students, stuff like that to give them suggestions of how to do things." (Sight impaired, print user)

One participant described how whilst he felt he had a good understanding of the adjustments required, he struggled at times to articulate this, having never being required to do so previously:

"I think I was as prepared as I could be, but maybe because I was used to things being put in place automatically. Yeah, I didn't make everything explicitly clear, I thought they would just understand like first time round." (Severely sight impaired, print user)

Explaining visual impairment

It was also necessary for many of the participants to explain their VI: what they can see and how it affects them. This appears to have been most challenging for the participants who are sight impaired and read print as they found that the staff and students they met struggled to understand how someone who was able to read printed material could still face significant challenges in doing so. There was a tendency for these people to think of VI simply in terms of visual acuity rather than impairment to central or field vision for example. Very few of the participants recalled having received guidance to explain their VI to others, and several experienced problems when explaining their VI to lecturers and their peers:

"No, and it was actually harder than I thought to explain to someone. Because I was so used to being in a college where everyone knew what a visual impairment was. And now I am back into a place where no one

really knows. I think it took a good couple of months for even just my flat mates to start realising the nature of my sight" (Severely sight impaired, print user)

One participant felt there was a general lack of understanding of VI at her institution:

"They don't understand that there is a spectrum. Now for me because I am not completely blind, obviously they will think 'oh, she can see, that means that we don't have to do as much as for a blind person" (Sight impaired, print user)

Self advocating when things go wrong

After a student's support plan has been agreed, it is forwarded to their department to ensure that the adjustments are put into place, and that the student is able to participate fully. However, our research findings highlighted that these adjustments were often not met, leaving the participant facing situations where it was necessary for them to challenge their lecturers (or at least times where they would have benefited from doing so). For example, one participant's department consistently failed to meet the basic adjustments that had been agreed as part of her support plan, such as making notes available electronically in advance of lectures. Whilst she knew this was wrong as they had responsibility under the UK's Equality Act to make such adjustments, the student did not feel confident enough to challenge them:

"No, I think the expectation was I wouldn't get much challenge...I don't think I was prepared at all for that one... I think if maybe I had been told of subtle ways...If I couldn't tell a teacher outright, maybe being told other methods to use..." (Sight impaired, print user)

In contrast, another participant described how she had dealt with problems immediately once they arose. She explained how whilst growing up she had been encouraged by family to do so and how, despite it being intimidating, she felt able to challenge senior lecturers.

"I understand why some people can't because they may have never had an issue before and don't know what to do, or maybe feel self-conscious. There are times at uni where I have literally sat there and been like 'right, I am telling people who have 25 years of research experience, [...] degrees, Masters, some of them are Doctors and Professors, and yet I am sitting there and telling them what to do!' It can be a bit intimidating, but you kind of have to get past it, and if you have really good relationships with somebody it's ok." (Sight impaired, print user)

Discussion

In this article we have identified four different ways in which a young person with VI may need to self-advocate. Whilst we have focused specifically on the participant's experiences in HE, we can anticipate them facing similar scenarios in employment. For example when discussing at interviews the equipment and techniques they could use to fulfil the role they were being interviewed for,

when explaining to colleagues how their VI affects them, and when addressing challenges which prevent their participation in the workplace.

Several enablers have been identified in equipping the young people to be able to self-advocate. These include having had opportunities to self-advocate when younger (for example explaining adjustments to class teachers in school or college); having a good understanding of their VI and how it affects them; and having a good knowledge and understanding of available specialist equipment and support.

Our research findings highlight how important it is for young people with VI to feel empowered to self-advocate, for example, by being encouraged by parents and specialist teachers. However, the findings also illustrate how important it is for the young person to be confident about what they need to say. In the different scenarios, this proved a barrier to young people who had not had an opportunity to consider the response they would give when facing specific situation.

It is also important to consider the role of the specialist teacher for ensuring that young people with VI are equipped for such challenges. The participants' responses revealed that they would have been less open to someone *telling* them what they needed to say, and rather they would have preferred the opportunity to *think together* and to discuss these scenarios and how best to respond.

Finally, we consider the outcomes for these young people. In many cases the participants were able to learn from their experiences in the first year of their courses by adapting the way in which they communicated and by finding ways in which to respond positively. In recent interviews we have been asked these young people how prepared they now feel for self-advocating in the workplace, and many stated that they will be able to draw upon their experiences in HE. However, some participants gave evidence of ways in which their final grade was affected by their lack of confidence to self-advocate. A small number even felt unable to continue and chose instead to withdraw from their course. As a large proportion of young people with VI go straight from compulsory education into the labour market, these findings illustrate how important it is that they are equipped with skills to self-advocate prior to leaving school. As the study continues we will explore the participants' experiences of self-advocating in the workplace, and whether they were able to draw upon their time in HE to facilitate this.

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