

# **Transition to Adulthood**

## **The views and experiences of blind and partially sighted young people transitioning into adulthood in the UK**

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### **Introduction**

The Longitudinal Transition Study started in 2010 with the aim of understanding the experiences of young people with a visual impairment leaving compulsory education. We were particularly interested in the enablers and barriers experienced as the young people moved towards the labour market. Over 80 young people from England and Wales have taken part. This study has a longitudinal qualitative design, with the same participants being interviewed by telephone at regular intervals along their transition journeys. This short summary report highlights

some of the key findings from Phase 2 of the study which was funded by Nuffield Foundation and took place between April 2012 and November 2015.

## **Experiences and choices of transition**

### **Young people with visual impairment follow similar transition pathways to their sighted peers**

The participants have followed a number of different pathways since completing their GCSEs. For the majority (over 90%), this included further study in a sixth form or further education (FE) college as a first step, and about half of these participants continued onto higher education (HE) (with more intending to do so). Just four participants went straight from GCSEs into apprenticeships or employment, while a further third followed this pathway having completed courses in sixth form/FE. Another popular option for seven participants after completing their sixth form/FE courses was to take a 'gap year'.

### **Some people have been long-term NEET since leaving education**

Four participants since leaving FE have been long-term Not in Employment, Education or Training (NEET). Their stories vary. Three have not been actively seeking work, and demonstrate little confidence of finding employment. In contrast, one participant has been extremely active in seeking employment and on two occasions was offered positions only for the employer to change their mind, citing reasons related to his visual impairment.

They said that there wouldn't be anything they could do for me, yet they didn't even let me try.

### **Transitions are not always smooth and as intended**

For some young people their transition pathways have not been straightforward. Several participants spent longer in FE than originally intended, some could not secure apprenticeships as they hoped and five of those who started in HE did not complete the first year of their course. While the participants received some support to prepare for their next transition, this tended to take a narrow focus rather than taking a broader perspective of the potential routes they might take.

### **Some young people are 'churning' in the education system**

Over the course of the research, we have identified evidence of 'churning', particularly amongst participants in the FE sector (although this may be a feature of the current age of our participants). Churning is

characterised by the young people repeating years in college, or repeatedly taking courses at the same level (or even lower levels) and appearing not to make a positive progression. Similar findings were noted by researchers in other disciplines.

### **Transition into higher education can be extremely challenging for young people with visual impairments**

The transition into HE has proved very challenging to a large proportion of the 35 participants who made this transition. Very few of the participants received any specialist guidance to assist them in planning the type of support and equipment they may need, and in most cases they felt ill-equipped at different points of the transition process. Access to services like Disabled Student Allowance (DSA) and mobility support seemed problematic for many.

My mobility on campus is being paid by DSA, and my mobility off campus will be paid for by my social services. But there is a delay with that, because of issues with payment and funding.

In the UK, the Equality Act requires education providers to make anticipatory adjustments for students with disabilities to enable them to fully participate on their courses. However, the research highlighted several ways in which HE providers are failing to do this. Instead they commonly sought to make compensation through extensions. Of 35 participants in HE, five did not complete the first academic year, whilst several of those who did demonstrated real resilience.

### **Young people with visual impairments are leaving school with limited knowledge of employment services**

By the end of Phase Two of the project, eight participants were in long-term employment and five have been in apprenticeships. Those who have successfully transitioned into employment or apprenticeships at this stage tended to have less severe visual impairments and those with more severe visual impairments have tended to choose to stay on longer in education. There was little knowledge of, or engagement with, Access to Work (a grant available to disabled people to pay for practical support in helping them start or stay in work). Even when reminded of Access to Work, none of the participants investigated the scheme further.

## **Levels of Independence and Preparation**

### **Young people are not making use of low vision aids**

Twenty seven of the participants reported using low vision aids (LVA) for reading. The participants' perceptions of LVAs were mixed, with several describing difficulties in using them. It was noted that some participants who use large font sizes were not making use of them. There were concerns regarding who had given the young people their LVA and whether they were qualified to do so and were offering appropriate advice.

She tried to give me handheld CCTVs and magnifiers, and I said to her it's not working.

### **Braille is highly valued**

The experiences of the 20 young people who had learned braille differed according to the time of onset of their severe visual impairment (since birth or a very young age, or later in life). There was a group who described themselves as being considered 'borderline' as to whether they needed to learn braille or not (based upon the severity and progression of their visual impairment), which meant that they did not receive any tuition until later in their school careers; in three cases they felt this was insufficient to be of any practical use. The age at which the young people were taught braille seems to be a factor in the eventual success of the learning outcome. Use of braille was more common in an educational setting, and the participants noted having less opportunity to use it when at home. Those who had the greatest opportunity were the young people using refreshable braille displays. Whilst none of the participants used braille exclusively, most identified certain tasks which they prefer to do in braille, highlighting the importance of choice of medium when accessing information.

Braille is like my pen and paper.

### **Young people with visual impairments prefer to use accessible mainstream technology**

While all the participants reported using a computer to access information, relatively few of them used specialist software to use the computer, preferring to make some basic adjustments such as changing the resolution or font size.

Throughout the longitudinal study, we have noted a general movement by the participants towards the use of 'mainstream technology'.

I use an iPad in my placement for my notes. You can adjust the brightness and the darkness. Can enlarge things when they need

enlarging. You can do all kinds of things with it – it's the best thing I've ever had.

### **Using mainstream technology as assistive tools**

Well over half of the participants said they would use mainstream technology as an assistive tool to help them access information independently, in the same way they would use specialist assistive tools such as LVAs. Of concern are reports from participants that their Disabled Student Allowance (DSA) assessor informed them they were unable to use DSA to purchase equipment unless it was 'specialist'. Instead many of the young people chose to fund tablet computers themselves:

When I was first going into DSA and all that, they were saying that maybe we could get you a laptop, we wouldn't be able to get you an iPad or anything like that [...] but on balance, in terms of my visual impairment and accessing uni, the iPad has made a bigger impact to me, and made it easier to access things.

### **Many of the young people do not feel prepared to live independently**

The majority of participants aspired to live independently in the next few years, although they identified potential barriers to this, eg, finding a suitable job and having the available money. More immediate barriers were also identified including having the necessary skills to live independently and restrictions from family members who they felt did not facilitate them in striving to become independent.

If I moved to a new place that I didn't know, I would find it hard to find shops.

Half of the participants felt their visual impairment would have an impact upon their ability to live independently. Unsurprisingly, those who have more severe visual impairments were more likely to conclude that their visual impairment would have an impact upon their independence. Despite several of the participants initially describing themselves as being prepared for independent living, when they were posed with specific challenges they might face, it became apparent that there were areas they could struggle with.

### **Some young people have limited understanding of their visual impairment**

The participants had varying experiences in learning about their visual impairment (which in no small part reflects the considerable range of ages at which their eye conditions were first identified and diagnosed). Just under half remembered a specific point in time when someone explained to them that they had a visual impairment, and what had caused it. Others recalled learning about their sight condition over time, sometimes through asking questions. There were also those who reported never having had their condition explained to them, or in some cases sharing that no one was able to explain it to them because the medical professionals themselves did not understand it. Several other themes emerged from the accounts the young people offered, including: feeling their sight condition was difficult for them to understand; feeling they had a lack of opportunity to find out more about their sight condition (for example, some participants were discharged from the hospital eye clinic at a young age); finding the period around diagnosis/learning the details of their sight condition was an emotional time; not wanting to invest the time understanding it, but rather to 'get on with life' (although for some this view changed as they got older); different approaches and emotional responses from parents; and insufficient understanding of their visual impairment by both the young people and others (e.g. teachers), and how this had an impact on their education. Of particular concern were nine participants who rated their understanding of their visual impairment poorly.

I kind of grew up with it, so no one really explained it to me.

### **A quarter of young people with a visual impairment have additional health problems or disabilities**

About a quarter of the participants reported having a health problem or disability in addition to their visual impairment. A small number of the participants reported having to attend very regular appointments for their eye (and associated) conditions, which impacts upon their everyday life including potential full-time employment.

I still go for regular check-ups. I am down to go for blood tests, to make sure my liver, kidneys and immune system are not failing. And then I am down to [hospital] normally every month to maybe six weeks having check-ups, where they will check...whatever!

We have also noted throughout the longitudinal study that many of the young people have eye conditions that mean their level of sight loss has changed, and is likely to continue to change.

## **Many young people with visual impairment have limited understanding of registration of sight impairment and the associated benefits**

The majority of participants could not remember registering as having a sight impairment as they were very young when this occurred, and in some cases were unsure if they were registered, or what category of registration. There were some concerns over the lack of engagement the young people have made with the principle of registration and the purpose and advantages of it. This was also true when talking with the participants about Disabled Living Allowance (DLA) and Personal Independence Payments (PIPs) (non-means tested benefits designed to help with the extra costs caused by disability) – again, the level of understanding and engagement was very low.

## **Transition Services**

### **Mixed levels of support when preparing to make transitions**

In Phase One we identified that most young people received advice and preparatory support for transitions up until the age of 16 as part of an official Transition Review. However, there appears to be less specialist support available for transitions after this age.

I remember having one in Year 10 or 11 which was specifically focused on transition, and that was quite helpful because we kind of put together an action plan and stuff, with my parents and the school and stuff... But actually the time at which a meeting probably would have been most helpful would have been in sixth form, the transition to university, which I don't think I had, or if I did I don't think it was focused on transition.

Connexions are one example of a service that has been drawn upon by some of the participants. For example, one participant after completing a college course was very unsure of what to do next and spent a period of time Not in Education, Employment or Training (NEET). He received regular support from a Connexions advisor who supported him into an apprenticeship. Another participant found the continuity of support provided by a transitions officer at RNIB Cymru helpful.

I can't really emphasise how helpful she has been, to be honest. Because she has been consistent since when I was 14 all the way to now, she has always been a support through uni and everything, when I was at [college], finding me these work placements that I did, thinking about when I graduate, she was on

the ball... She would help me with my job search and finding somewhere to live if I needed something. So she was a really valuable resource that I have been able to tap into.

### **A 'postcode lottery' of services**

A Freedom of Information Request by RNIB identified a 'postcode lottery' of services available for children and young people with visual impairment from local authorities (LAs) in England. In 2014, legislative changes in England extended entitlement of specialist support to young people with SEND up to the age of 25 if they are in education or training. In spite of this, visual impairment services in over a fifth of LAs were not supporting young people in post-school settings. While some services were actively seeking to improve provision to these older learners, it was apparent that others were not. This is reflected in the experiences our participants described in the most recent interviews – none of them had an Education Health and Care plan (EHC plans), and very few even knew what an EHC plan was. EHC plans are a key mechanism for recording what a child and young person with SEND wants to achieve and what support is needed to do this.

### **Making a difference**

When reflecting upon the young people's experiences, it is helpful to consider the resources that are available to them as they navigate their transition to adulthood: individually-based resources include academic attainment and important independence skills, while socially-based resources include support mechanisms, services, inclusive practice by services and employers, and also policies and legislation. How the balance between these different resources is experienced will inevitably vary from person to person. Importantly, the balance will change with time and place — so the resources available to a 16-year-old at school will be different to the resources available to an 18-year-old at university. It is this change, and the tensions and challenges associated with this change during periods of transition which is exposed by the research.

The research is being used in practical ways to help improve the transition experience of young people with visual impairment. The work is ongoing, but examples that draw directly and indirectly from our work include:

- Resources to help young people with visual impairment transitioning into higher education ('Starting University' available at [www.rnib.org.uk/young-people/startinguniversity](http://www.rnib.org.uk/young-people/startinguniversity))



- A toolkit to assist special visiting teacher services to design their services around educational outcomes, which include independence (available at [www.natsip.org.uk](http://www.natsip.org.uk) )

The Longitudinal Transition Study has continued into a third phase, and is currently being funded by Thomas Pocklington Trust. In this phase of research we continue to work with our participants, learn from what they tell us about their experiences of transitioning into the labour market and independent living, and develop practical resources based upon their advice.

For further information on the Longitudinal Transitions and fully referenced reports, visit the project website at:  
[www.birmingham.ac.uk/VICTAR](http://www.birmingham.ac.uk/VICTAR)