UNIVERSITY OF BIRMINGHAM

Vision, Accessing Information and Accessing Benefits

Technical report of findings to December 2013

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Glossary

CCTV	Closed circuit television
DfE	Department for Education
DLA	Disabled Living Allowance
DSA	Disabled Students' Allowance
DSO	Disability Support Office
DWP	Department for Work and Pensions
ESA	Employment and support allowance
FE	Further Education
HE	Higher Education
ICT	Information and communications technology
ILS	Independent Living Skills
LVA	Low vision aid
NEET	Not in Education, Employment or Training
PIP	Personal Independence Payment
QTVI	Qualified teacher of visually impaired children
RNIB	Royal National Institute of Blind People
SEN	Special Educational Needs
SENCo	Special Educational Needs Coordinator
Statement	Statement of Special Educational Needs
UCAS	Universities and Colleges Admissions Service
VI	Visual Impairment

VICTAR   Visual Impairment Centre for Teaching and Research

VTS   Visiting Teacher Service

Year 11 cohort   Participants were in school Year 11, aged 15-16 when recruitment commenced in summer 2010

Year 10 cohort   Participants were in school Year 10, aged 14-15 when recruitment commenced in summer 2010

Year 9 cohort   Participants were in school Year 9, aged 13-14 when recruitment commenced in summer 2010

Executive Summary

This research project was designed in 2009 by a team from RNIB and VICTAR (Visual Impairment Centre for Teaching and Research at the University of Birmingham) in response to the Research Brief prepared by RNIB: "Longitudinal study from age 14 of blind and partially sighted young people in the UK".

The key objectives of the project are:
1. To track the process of transition for blind and partially sighted young people from age 14 for five years
2. To identify the roles of professionals involved
3. To identify the factors that improve or reduce a young person's chance of gaining employment

The project includes the following key phases:
1. Recruit and survey visual impairment services
2. Through these services, recruit and survey a sample of Year 9 and 11 students with visual impairment
3. Follow-up surveys of the sample of students with visual impairment

The first stage of the study took place between Autumn 2009 – March 2012, and was funded by RNIB, resulting in a number of outputs (e.g. Hewett and Douglas, 2011a; Hewett and Douglas, 2011b, Hewett, Douglas, Ramli, and Keil, 2012).

The second stage of the study is funded by the Nuffield Foundation, and had centred on follow-up surveys of the sample of students with visual impairment, as described above.

This report focuses on data collected in Easter 2013 (short catch-up interviews to establish participants' plans for the next academic year) and more extensive recorded telephone interviews conducted in autumn 2013. The primary focus of this wave of interviews was to get a better understanding of the young person's visual impairment and how they manage this with the equipment that they use and adaptations that they make. Questions were also asked about the young person's experience of disability living allowance/personal independence payments, due to the interviews coinciding with a government restructure of this benefit provision.

This report is part of a series of technical reports which presents all findings in the project so far. These technical reports will be followed by a number of focused reports which will aim to explore key themes, particularly making use of the longitudinal nature of the data.

In Phase One, participants were recruited in school years Year 9 and Year 11 across the English Midlands regions and Wales, to take part in the longitudinal study. By June 2011, 81 young people had been recruited into the project. Due to loss of contact with some participants, and others saying that they wished to withdraw from the project, this number had reduced to 75 by Easter 2012.

During Easter 2012 interviews, it was found that a number of the Year 11 cohort were intending to repeat their current school year, giving us three distinct groups:
- Year 9 cohort (moving up to Year 12)
- Year 11 cohort (repeating Year 13)
- Year 11 cohort (finishing higher education).

The decision was made at this stage to go back to the services from which the original cohorts were recruited and 'top-up' the sample from those who would have been in Year 10 at the time of initial recruitment (hence referred to as the Year 10 cohort), and now moving into Year 13, thus joining those participants in the Year 11 cohort who were repeating Year 13. Over summer 2012 an additional 7 participants were recruited, meaning a total of 80 participants within the project. By autumn 2013 there were 76 participants still involved in the research. 68 of these were interviewed during summer 2013 and 64 during autumn 2013.

SECTION A: LONGITUDINAL STUDY

Setting and plans: Summer 2013
In summer 2013, the 68 participants interviewed were following a variety of pathways. These included university (16), sixth form/FE college (38), employment (6), apprenticeships (2) and those who were NEET/Other (6). One participant who had been at university had dropped out, whilst another had been unsuccessful in completing the first year having had difficulties in accessing the course, but intended to repeat the following year. Ten of the participants who were in sixth form/FE college were looking to make the transition away from further education. Two participants who had previously been in apprenticeships had been offered permanent jobs within their respective companies, and four

participants who had previously been NEET had successfully obtained jobs/apprenticeships.

Churning
We have observed, over a number of waves of data collection, some evidence of participants 'churning' within the education system. By this we mean evidence of young people who are repeatedly taking educational courses at the same qualification level (or even lower levels) but not appearing to progress forwards, thus being 'held up' in the system. This was evident during the 2013 interviews for 12 of the young people.

Destination of students: Autumn 2013
At the time of the autumn 2013 interviews, of the 62 participants who took part in the interviews, 28 were continuing in further education, 20 were at university, 6 in employment, 2 taking apprenticeships, 2 NEET, and 4 pursuing 'other' options, including voluntary work.

First year experiences at university
More detailed accounts of the participants experiences of the transition to university will be given in a forthcoming report. Of the 17 participants who started at university in autumn 2012, two did not complete the first year. In one case the young person dropped out because they did not enjoy the course as much as they had anticipated, whilst the other participant had experienced serious difficulties on the course associated with his visual impairment. He hoped to return the following year and repeat the first year. The fifteen remaining participants described themselves as 'very happy' or 'happy' with their plans to continue at university for the next academic year, whilst the young man who had difficulties in accessing his course reported being 'unhappy'.

University applications
Nine participants in the 2012-2013 year went through the UCAS application system, and applied for a wide range of courses. All but one of the students declared their visual impairment. Of these nine participants, only 7 of them ultimately went to university in autumn 2013. One participant did not achieve the necessary grades for his choice of university, whilst another deferred her place in order to take a gap year abroad.

Participants seeking employment/apprenticeships
Six participants were seeking either employment or apprenticeships at the time of the summer 2013 interviews. These participants who had not

been successful in finding employment until now, tended to be members of the cohort who had lower qualifications, with five of the six having a highest qualification level of GCSE or equivalent. There appeared to be a general trend of those who were seeking apprenticeships struggling to find suitable opportunities advertised.

Participants in employment/apprenticeships

By the time of the autumn 2013 interviews, eleven of the participants had successfully obtained a job (9) or apprenticeship (2). The young people were in a wide range of roles, including customer services, childcare, computing, manual work, retail, cleaning, administration and accountancy. Prior to starting their job, 10 of the young people had disclosed their visual impairment to their employer. Six of the employers had made provisions for the young person's visual impairment in their workplace whilst five young people said that such provisions were not needed. None of the participants have made contact with the Access to Work scheme to investigate how they could be supported in the workplace.

SECTION B: VISION, ACCESSING INFORMATION AND EQUIPMENT

Registration of sight problems

Twenty one of the participants reported that they are registered as blind, 23 as partially sighted, whilst 11 said they were not registered. The remaining 9 were unsure of their registration status. The majority of participants could not remember the registration process as they were very young when this occurred. A number of reasons for registration were identified by the participants including it being a form of evidence of their visual impairment, as a way to access support, giving the young person a perceived much needed advantage, when considering other disadvantages that they might face in relation to their visual impairment. Eleven participants were not aware of any advantages of registration, and in three cases they/their families had simply been following instructions from their ophthalmologists.

Eye conditions

The majority of the participants were able to give some detail of the eye condition that causes their eyesight problem. Fifty two people described knowing the medical name of their visual conditions, naming a wide range of visual conditions, symptoms and signs. Twenty two said that they knew their visual acuity measure and visual field or how to get it.

Explaining eye conditions

When asked to explain how their vision affected them, the young people gave a variety of responses. These included describing what they can see, giving medical explanations, explaining how their visual impairment affects their daily functioning, describing adjustments that they need to make, and describing side effects they experience, whilst others said that they did not feel they could explain it. Five of the participants do not have any light perception at all, whilst 26 can see well enough to recognise a friend across a road.

Described implications of their visual impairment

Thirty three of the participants report that they worry about their eyesight at least 'some of the time', with three saying that they would worry 'all of the time'. There does not appear to be any relationship the frequency of worrying, and the severity of their visual impairment. Twenty eight of the participants said that their eye condition means that their level of vision can vary from day to day, and gave various explanations for this including level of tiredness, lighting, and the weather. Forty one said that they suffer with eye strain or fatigue when reading or using a computer, and twenty one have difficulties with glare when using screens.

Operations

Twenty four of the participants have had operations on their eyes in the past that have changed their vision. In some cases they have had multiple operations. Two participants said that they have definite operations that are scheduled, whilst nine thought it was a possibility for the future.

SECTION B: EQUIPMENT AND ACCESSING INFORMATION

Ways of reading

The most common medium for reading used by the participants was electronic, although in 47 cases this did not involve using additional speech software. Over half read using print, whilst other common ways were having someone read to them, using audio material, using E-readers and braille.

Use of low vision aids

Twenty seven of the participants use magnifiers for reading. The participants reported using a variety of low vision aids, including different types of hand-held magnifiers, binoculars, and closed circuit television. Of those who reported not currently using low vision aids, twelve had used them in the past. The majority of the participants were first

introduced to low vision aids by their visiting teacher service, but other sources include their school, or hospital/low vision clinic. All of those who had received their low vision aids through a hospital/low vision clinic/optician had received training in using them. Fifteen of the participants rated low vision aids positively, whilst seven talked negatively of them. Various difficulties were described in using low vision aids, such as being given low vision aids which were impractical to use, not being able to use them quickly enough in a lesson, experiencing difficulties with lighting, finding them generally hard to use, and experiencing eye strain when using them. Common uses of low vision aids included: reading large blocks of text; reading text when cooking; using a mobile phone; reading labels; using public transport; watching a show/sporting event and reading maps. It was noted that some participants who use large font sizes are not making use of low vision aids.

Accessing printed documents
Of the fifty one participants who regularly use written text, 33 used standard to large print (up to point 17), 13 large print (point 18-27), and 5 very large print (point 28 and above). Despite using low vision aids, two participants still needed to request 'very large print', with one participant needing size 36 font (compared to size 72 font that they would require if not using a low vision aid). The most common ways of communicating in writing with fully sighted people were electronic communication such as email, text message, electronic documents and social media.

Accessing IT
The most common ways in which the participants would be able to use a computer include using it with no adjustments at all (35), with some basic adjustments (29), with specialist magnification software (22) or with specialist speech software (20) (or a combination of these). Six participants spoke of how they would use the inbuilt accessibility software available on their Apple Mac. In order to make computers more accessible to them, twenty two of the participants spoke of some basic adjustments that they make, including changing the font size, using the zoom function, changing the mouse point, enlarging icons, changing screen resolution and changing the contrast. The most commonly used and highly regarded specialist software used by the participants is Jaws. For some of the participants there appear to be gaps in training for using such specialist software. In two cases, despite being at a specialist resource base for pupils with vision impairment, the blind participants were not taught how to use a computer at all. Many learned how to use the accessibility software they use through collaboration with friends.

Using mainstream technology

The young people use a variety of electronic devices, including mobile phones (62), tablet computers (27), e-readers (7) and MP3 players/iPods (4). They use their mobile phones for a variety of reasons, including texting, phone calls, social networking and accessing the internet, whilst uses of tablets include accessing the internet, social networking, games and email. A number of the young people spoke about how the different devices that they are using have proved particularly accessible to them as young people with visual impairments. Several valuable features that are available in these devices were identified including: zoom options; inbuilt screen readers; the ability to enlarge text; the ability to change the contrast/brightness; and voice activation options. The participants also gave specific examples of how they would use their mainstream devices as tools to help them with their visual impairment. Examples given included: the participants using their devices to make it easier to access information; using them for navigation/travel; using the inbuilt camera as a magnifier; making use of specialist apps; accessing online shopping and using phones as flashlights.

Importance of ICT to the young people

Over 80% of the participants saw ICT as being either 'essential' or 'important' in their lives, with only 8% of participants saying it was either 'not very important' or 'not important at all'. Those who were registered as blind were more likely to see ICT as being 'essential'. Several explanations were given for why the young people considered ICT to be important to them in their everyday lives. In many cases it was simply due to the fact that ICT is central to modern society. However, there were some points made by several of the participants which could be seen as being specific to those who use ICT as a way to make adjustments for their visual impairment. This was particularly the case for those young people who are reliant on speech software.

SECTION B: USE OF BRAILLE

Experiences of learning braille

The experiences of the twenty young people who had learned braille differed according to whether they had had their visual impairment since birth (or a very young age), if the onset of their visual impairment was after they started school, or if they were considered 'borderline' as to whether they needed to learn braille or not. Four of the participants who had had their visual impairment since a very young age first started to learn braille before they had even started primary school, whilst five first

learned once they entered primary school. Three did not learn braille until later on in primary school after initially learning to read print, and in one case the participant (who since then has used braille in preference to print) felt this was too late. Three of the participants who have learned braille did not have a visual impairment at the point at which they started school. In each case the response to teaching the young people braille appears to have been fairly rapid, although for one participant it was necessary for their parents to apply some pressure on the local authority. Five of the young people appear to have been on the borderline as to whether specialist teachers considered that it would be appropriate to teach them braille or not, meaning they did not receive any tuition until later in their school careers, and in three cases, insufficiently to be able to make practical use of it. In most cases it was the decision of the QTVI for the young person to start learning braille, but in some cases the participants reported that their parents did intervene, particularly in terms of getting braille tuition started as early as possible. All but two of the participants had braille tuition exclusively with a QTVI. They all received one to one tuition, but in a variety of settings including mainstream school with a visiting teacher, special school, resource base and at home. The age at which the young people learned braille seems to be a factor in how responsive they were to it. There were frustrations reported by those who had already learned to read print, and then had to 'start again' with the basics of learning braille.

Using braille
The most common uses of braille by the participants included: revising; studying; short note-taking and labelling items. The most common ways in which they would access braille are through hard copy and using an electronic braille display. 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 who use electronic forms of braille, such as a braille display or a braille note. When choosing between using braille or electronic formats, six participants said they would sooner use speech, whilst two would prefer an electronic form of braille. Eight participants said it would depend on the situation they were in. Examples of when they would prefer using braille include when delivering presentations, revising and taking exams, learning new languages, in lectures, learning details, reading small bits of text, and reading books. Examples of when they would prefer using electronic material include when writing essays, reading large portions of text such as an essay, and when they have to read something quickly.

How important is braille to the participants?
The young people were asked to explain the importance of braille to them in their everyday lives. The responses that were given could be grouped into four broad categories. The first type of responses were describing the importance of braille on a functional level, such as it being a good learning tool, being important for accessing braille signs, and also being important for general literacy. The second type of response involved comparing braille to a sighted person reading print, and seeing it as an important back up if technology were to fail. A third type of response came from those who spoke of braille with a sense of emotional attachment and fondness, illustrating that they had a deep appreciation for braille. Finally, there were those who responded by saying that braille was no longer part of their everyday life, although this was not necessarily their choice - they simply had limited opportunities in which to use braille.

SECTION C: ACCESSING BENEFITS

Due to the recent government announcement that Disability Living Allowance (DLA) will gradually be phased out in favour of a new system called Personal Independence Payments (PIP), several questions were posed to the participants on their experiences of DLA and PIP.

Uptake of DLA and PIP
Of the 61 participants, 40 received DLA, five were unsure whether they received DLA or PIP and 16 did not receive either. Receipt of DLA was associated with registration status – all 20 people who were registered as blind were in reception of DLA and 17 (77%) of those registered as partially sighted. Of the nine people who were not registered, only two were in receipt of DLA. A variety of explanations were given by the eleven participants who had not applied for DLA or PIP including not knowing whether they would be eligible, not needing or wanting it and not having heard of it.

DLA awards and components
Being in receipt of an indefinite (as opposed to a time limited) award appears to be more common amongst participants who are registered as blind. Of the 18 people in receipt of an indefinite award, 11 of those were registered as blind. Fifteen of the participants did not know the term of their award. Throughout this section there was evidence that the young people do not know very much about the benefits that they receive. Participants received a range of award rates reflecting their personal circumstances as individuals with a visual impairment.

How the young people would use DLA

Thirty-nine of the participants listed 74 different things that they would use their DLA money for. These could be grouped into 18 different categories, the most common being transport, adding to savings, everyday items, food, low vision aids, leisure activities and technology. Although not explicitly expressed it appeared that for some young people it was the first or one of the first times that they had explicitly thought about what they use their DLA money for.

Perceived importance of receiving DLA

Thirty three of 36 participants considered DLA to be 'important' or 'very important', with only one person saying that it was 'unimportant'. Two people were unsure of the importance of their contribution received through DLA. Comments made by the young people highlighted differences in opinion held by individuals regarding the reasons for DLA's existence. Some saw it as compensation for the extra costs of disability and others as compensation for disability in general.

Applying for DLA

Twenty-six of the participants spoke of their experiences of applying for DLA. Seventeen said that their parents completed their DLA application, five completed the form themselves, and four could not remember. Many of the parents of the participants had applied for DLA for the young people as the application often happened at the time of diagnosis when the young people were babies/young children. Although many of the participants were unable to talk specifically about their application process as they did not remember it, or it was dealt with by their parents, four spoke of the ease of the process. However, ten spoke of their difficulties and frustrations with it. Some of the problems related to process difficulties in accessing the application form. For a number of participants one of the major frustrations was that people had to restate their case or go for medical assessments when it was "obvious" to them, by virtue of their registration status or their eye condition that they were eligible for DLA. Whilst professional, specialist advice in applying for DLA could have been helpful, some of the participants reported having had no advice or even having received unhelpful advice. Only one of the participants had applied for DLA and been unsuccessful. He had not thought about appealing the decision. He had not received any specialist advice with regards to his application. There were instances of the participants not agreeing with the rate/component of their DLA. In a small number of cases the young people or their parents appealed their original outcome. Two of the participants also spoke about wider changes that had happened and its impact on their circumstances,

appearing to refer to a chance in the law in 2011 which guaranteed a higher mobility rate of DLA for people registered severely sight impaired.

Awareness and thoughts on DLA and PIP policy changes
Twenty five participants were aware that people on DLA are going to be gradually switched over to PIPs, whilst twenty-four were unaware of this fact. Generally participants at the time of interview were unconcerned about the changeover from DLA to PIP as they saw the changes as being far away in the future. A difference in awareness was observed, according to the award that the participants received, with those who already receive DLA being more likely to be aware of the changes. However, for those already in receipt of DLA, only 23 (58%) people were aware of the forthcoming changes. Although the numbers of those in receipt of a fixed award are small, we observed that they were less likely than those in receipt of an indefinite award to be aware of the upcoming changes. Many of those who were aware of the changes did not know much about it beyond that it was happening. A few of the participants viewed the changes with cynicism and saw it merely as a money saving exercise. However, some of the young people were concerned about the changes, with many reporting a lack of firm knowledge and information on the process and the likely outcomes. There were concerns that the assessments were going to be carried out by those who do not understand the real life experience of a person with a disability.

1 Background of the RNIB Transitions Project

1.1 Project Overview

This is a technical report in relation to post-16 transitions from school to further and higher education, training, and employment of blind and partially sighted students. This report focuses on data collection conducted in summer 2013 (June-September) and autumn 2013 (October-December).

The research project was designed in 2009 by a team from RNIB and VICTAR (Visual Impairment Centre for Teaching and Research at the University of Birmingham) in response to the Research Brief prepared by RNIB: "Longitudinal study from age 14 of blind and partially sighted young people in the UK". The research started in May 2009 and is being carried out in three stages of work:

- Phase 1 – Recruitment and survey of educational services (autumn 2009);
- Phase 2 – Survey of young people with visual impairment (summer 2010);
- Phase 3 – Longitudinal case studies (autumn 2010 and beyond).

This report presents data in relation to the third phase of work. The survey was particularly concerned with the young people's visual impairment, and the tools, equipment and strategies that they use. This is a technical report which presents findings from the summer and autumn 2013 interviews. It will be followed by a series of focused reports that aim to explore key themes, and will particularly make use of the longitudinal nature of the data.

1.1.1 Recruitment

Young people were recruited into the project through the 18 local authorities, 2 resource bases and 1 special school that had been recruited during Phase 1 of the project. At the time they were asked to identify all the Year 9 and Year 11 students with a visual impairment that they were supporting. Each service provider was asked to complete a short questionnaire identifying the students:
- initials
- gender
- ethnic group

- preferred reading format
- whether they had additional disabilities
- whether the student could independently complete a questionnaire
- details of anything else which could affect the student's potential involvement

Being able to 'independently complete a questionnaire' was used as the project inclusion criteria for the study. All those students who met the criteria were invited to take part through pre-prepared information packs. Those who consented to take part were consenting to be involved in the longitudinal project (with the freedom to request to withdrawal at any time). By March 2013, consent forms had been received from 88 young people, although not all have taken part in every stage of the data collection process.

Table 1: Participant Levels of each cohort during each data collection period

	Year 11	Year 10	Year 9	Total
Summer 2010	47	N/A	31	78
Autumn 2010	46	N/A	N/A	46
Spring 2011	47	N/A	28	75
Summer 2011	41	N/A	27	68
Easter 2012	40	N/A	28	68
Autumn 2012	39	6	25	70
Summer 2013	36	6	26	68
Autumn 2013	34	6	24	64

There have been eight stages of data collection so far:
- Summer 2010 - questionnaires either on paper, online or via telephone interviews. This data collection related to Phase 2 of the project - surveying young people with a visual impairment;
- Autumn 2010 - phase 3 commenced with follow up telephone interviews of the Year 11 group, ascertaining how they had done in their GCSE examinations and what they had gone on to do next;
- Spring 2011- telephone interviews with both the Year 9 and Year 11 cohorts to review their transition experiences (Year 9 cohort moving onto GCSEs and Year 11 cohort moving into further education, and apprenticeships);
- Summer 2011 – telephone interviews with both the Year 9 and Year 11 cohorts, focusing on their use of social networking sites and mobile phones;

- Easter 2012 – short follow up interviews with Year 9 and Year 11 cohorts to see if participants were still happy to take part in the project, and to see what their plans were for the next academic year;
- Autumn 2012 – longer interviews with Year 9, 11 cohorts and the new Year 10 cohort, which focused on independence and the additional curriculum.
- Summer 2013 – short follow up interview with Year 9, 10 and 11 cohorts, with the interviews being focused towards the participant's current pathway.
- Autumn 2013 – longer interviews with Year 9, 10 and 11 cohorts, which focused on the young persons' visual impairment, as well as investigating more the equipment they would use and adjustments they would make. Questions were also asked on the young people's experience of disabled living allowance or personal independence payments.

This report relates to data collected in the two most recent surveys during summer 2013 and autumn 2013.

1.2 Summer 2013 Catch-up interviews

The summer 2013 interviews were conducted with the young people over the summer holidays. There were four different versions of the interview, according to the pathway that the participant had been following at the time of previous interview. The interviews covered the following topics:

Pathway 1: University (N=17)
- Current circumstances and reasons for any deviations and future plans
- Experience of disabled student allowance
- Experience with the university disability support office
- Accessing lectures and learning material
- Arrangements for examinations and other assessed work
- General life at university

As this interview schedule was more extensive than the schedules for the other three Pathways, the interviews were recorded using an Olympus Dictaphone which connected to the researcher's telephone and later transcribed. The majority of the information collected in these interviews will be presented in a future report, which will look at the

experiences of the participants who entered university for the first time in September 2012 and September 2013.

Pathway 2: Continuing in Sixth form/College (N=41)
- Current circumstances and reasons for any deviations and future plans
- Exams experience
- Plans for next academic year and any preparations made

Pathway 3: In employment/apprenticeship (N=5)
- Current circumstances and reasons for any deviations and future plans
- Access to work; disclosure of visual impairment
- Experience in applying for work
- Details about role, and any adjustments that have been made for their visual impairment

Pathway 4: Looking for employment/apprenticeship/voluntary work/NEET (N=5)
- Current circumstances and reasons for any deviations and future plans
- Those who are now in work: details of role; application process; disclosure of visual impairment; access to work; adjustments
- Those who are still looking for work: current strategies and experience

The summer 2013 survey was completed by 36 participants from the Year 11 cohort, 6 participants from the Year 10 cohort and 24 participants from the Year 9 cohort.

1.3 Autumn 2013 Vision interviews

The autumn 2013 survey was completed through a telephone interview with all cohorts. This was a longer, semi structured interview. Due to the length of the interview, and the more open nature of the questions, all interviews were audio recorded using an Olympus Dictaphone which connected to the researcher's telephone and then later transcribed. The interviews covered the following topics:

Section A: Current setting and plans for the future
1. Educational outcomes
2. Current setting, including details of any changes in setting
3. Future plans

Section B: Vision, accessing information and equipment, DLA/PIPs
1. Participants visual impairment and registration
2. Accessing information and equipment used
3. IT Skills and use of mainstream technology
4. Braille
5. Disabled Living Allowance and Personal Independence Payments

The autumn 2013 survey was completed by 64 participants (24 of Year 9 cohort, 6 of Year 10 cohort and 34 of Year 11 cohort).

2 Sample demographics and representativeness

A detailed analysis of the sample demographics and representativeness was provided in Hewett, Douglas and Williams (2011). At the time, the following key points were noted:

1. There is an underrepresentation of Asian or Asian British young people
2. There is an overrepresentation of those with additional special needs, Statements of Special Educational Needs, Braille users and young people from Wales

The small sample size must be taken into account when assessing the representativeness of our sample to the population. However, overall the sample does appear to be a good representation of the population.

For a more thorough breakdown of the representativeness, please refer to the 2011 report.

3 Analysis and Reporting

3.1 Data management

Data collected in the summer 2013 pathway 2-4 interviews was recorded by the researcher on pre-prepared interview schedules during the course of the interview, before being entered into the project database, a IBM Statistics SPSS 20 programme. The data collected in the summer 2013 pathway 1 interview and the autumn 2013 interviews were audio recorded using an Olympus Dictaphone, transcribed by the researcher into Microsoft Word, before being entered into IBM Statistics SPSS 20. Open responses to questions were analysed using the qualitative analysis tool NVivo 10.

3.2 Analysis of questions and reporting style

The responses to closed questions were analysed through simple summary statistics using IBM Statistics SPSS 20. These are presented in table format with both counts and percentages (where appropriate). Shorter open questions were themed and coded into IBM Statistics SPSS 20. The results from this analysis are either presented in tables, or described, in accordance to what was most appropriate. Any themes are illustrated using quotes.

SECTION A: LONGITUDINAL STUDY

1 Current setting and plans for the future

1.1 Setting and plans: Summer 2013

Interviews were conducted with the participants, with schedules pre-prepared according to the pathway that they were following, as reported at the last round of interviews in autumn 2012. In summary, the following types of interviews were completed:
- Pathway 1: University (N=17)
- Pathway 2: In college/FE (N=41)
- Pathway 3: In employment/apprenticeships (N=5)
- Pathway 4: Looking for employment/apprenticeships/other (N=5)

These interviews took place between June-August 2013. The young people were asked if they could tell the researcher about their current setting, and also about any changes that had occurred in their plans they originally reported in the autumn 2012 interviews. One participants who had been at university in the academic year 2012-2013 had completely dropped out of university and was now NEET. A further university student had completed the first year, but was going to have to repeat it after having a great number of problems in accessing both the course and the end of year examinations. The table below shows the reported destination of the participants:

Table 2 Setting of participant: Summer 2013 (N=68)

	Total (N)	Total (%)
University	16	23.5%
Sixth form/FE college	38	55.9%
Employment	6	8.8%
Apprenticeship	2	2.9%
NEET/Other	6	8.8%
Total	68	100.0%

At the time of the summer 2013 interviews, there were 38 participants still in sixth form or FE college. Ten of these participants were in their final year of taking A-levels/BTEC Level 3 courses or equivalent, and so were looking to make the transition from school/college that summer, whilst 22 were taking A-levels/BTEC Level 3 courses of equivalent, but still had another academic year to go. Finally, five were taking qualifications below the Level 3 level, and likely to progress onto a

higher level after completing their courses (although one participant was planning on making the transition into employment that summer).

A participant who had been in college in the 2012-2013 academic year reported that he had dropped out of his course as he was no longer enjoying it, and had decided to look for employment instead (however at the time of interview he had not been successful in finding anything). Two participants had dropped out of their college courses before completion as they had been struggling in accessing their courses due to difficulties associated with their visual impairment. They were both NEET at time of interview. Finally, one participant had dropped out of her course due to bullying by course mates, and had started on a government training scheme.

Of the five participants who had been in employment/apprenticeships at the time of the autumn 2012 interviews, two were still in employment, one remained in an apprenticeship, and two who had previously been in apprenticeships had been offered permanent roles with their companies.

Of the five participants who had previously been looking for employment/ apprenticeships, or doing something different, one was now in an apprenticeship (after moving on from an employment preparation scheme), two were now in employment and two were NEET.

Table 3: Primary planned destination of participants (2013-2014 academic year)

	Y11 cohort Total (N)	Y10 cohort Total (N)	Y9 cohort Total (N)	All cohorts Total (N)	All cohorts Total (%)
Further or continuing with FE courses	4	0	24	28	41.2%
University	19	6	0	25	36.8%
Employment	7	0	0	7	10.3%
Apprenticeship	1	0	2	3	4.4%
Likely NEET	3	0	0	3	4.4%
Other	2	0	0	2	2.9%
Total	36	6	26	68	100.0%

During the summer 2013 interviews the participants were also asked what their planned destination was for the next academic year. Their responses are summarised in the table above. Over three quarters (78%

or 53) were anticipating still being in education (either at FE college/sixth form, or at university). Ten participants who had already secured employment/apprenticeships anticipated continuing in their roles. Three of the 5 participants who were NEET/Other at the time of interviews had no plans other than to continue looking for work, whilst two participants who were NEET at the time of interview had arranged voluntary placements.

Churning

We have observed, over a number of waves of data collection, some evidence of participants 'churning' within the education system. By this we mean evidence of young people who are repeatedly taking educational courses at the same level (or even lower levels) and not appearing to progress forwards, thus being 'held up' in the system. This was evident during the 2013 interviews for twelve of the young people. Their experiences can be summarised as follows:

1. Two young people felt that their college (one with a specialist resource base for students with vision impairment) was not able to support them sufficiently, and they were being restricted in their studies. After failing in their initial funding applications and appealing a number of times to the local authority, they were able to move to a residential special college for students with VI

2. One young person decided to repeat the same course/level again the following academic year after failing the previous year

3. One young person decided to start again on a different course, but at the same level.

4. One young person had spent a year at a special school for pupils with vision impairment, but was moving to a different specialist school which provides more vocational type courses, although they did not have a particular course in mind

5. One young person was taking another year in sixth form to study an additional A-level intensively in one year after changing their mind on which course they wanted to study at university. This followed perceived access problems for the subject that they were particularly interesting in studying at university. Whilst they enjoyed this subject, they had concluded that it was not one which came naturally to them. Rather the additional work that they would have to put in to compensate for this, along with the challenges they might face as a result of their visual impairment, would be too significant.

6. One young person had moved into their final A2 year after taking three years to complete AS levels. The first two years were spent in a school where they didn't feel adequately supported in relation

to their vision impairment, and they moved to a college for the third year.

7. Two young people had successfully completed their A-levels over two years, and then decided to restart college to study additional subjects after changing their mind about what they wanted to study at university.. One of the two had been unable to follow their first choice of subject at sixth form because the school had said they would be unable to keep up with the course. They did not 'engage' well with their alternative subjects, and as a result felt they did not get the grades they were capable of. They were therefore going back to study again at a different institution.

8. One young person who was studying a vocational qualification at college, was asked to leave the course part way through as they were struggling with fitting in the placement work (they were finding it too tiring and had to cut down their hours). At the time of the summer 2013 interviews they were looking for alternative college courses, but could not find anything else they were interested in. They had been provided with options by their college, but did not think them appropriate as they were of a lower qualification level.

9. One young person had taken one year of a level 1 college course, and hoped to progress to level 2, but had dropped out due to problems with fellow students, and had instead enrolled on a skills based training course at a different college

10. One young person had been taking short courses at college (e.g. flower arranging, cake decorating), although they were not interested in taking the skills further and using them in a career.

1.2 Destination of students: Autumn 2013

As part of the autumn 2013 interviews, the young people were asked again about their chosen pathway, and any deviations from summer 2013 were investigated further.

Table 4: Destination of participants (September 2013) (N=62)

Setting	Planned pathway summer 2013: Total (N)	Planned pathway summer 2013 Total (%)	Actual pathway autumn 2013: Total (N)	Actual pathway autumn 2013 Total (%)
Continuing in further education	27	43.5%	28	45.2%
University	22	35.5%	20	32.3%
Employment	5	8.1%	6	9.7%
Apprenticeship	3	4.8%	2	3.2%
(Likely) NEET	3	4.8%	2	3.2%
Other	2	3.2%	4	6.5%
Total	62	100.0%	62	100.0%

The table above shows the intended destinations of participants, as reported during the summer 2013 interviews, and compares this with their actual pathways as reported in the autumn 2013 interviews, for the 62 participants who completed both interviews. There were a number of changes in either destination, or in the finer details of the young people's plans:

- One participant who had left college to pursue employment had been unable to find a job, and had decided to start another level 3 qualification
- One participant had not achieved the required grades for university, and had decided to take a gap year before reapplying
- One participant who was half way through A-levels decided to restart on a different course
- One participant who had been unemployed found a job
- One participant who had made the decision to switch courses after their first year of A-levels decided that they preferred their original course, so switched back again
- One participant was made redundant from his job, but had found a new job

2 Individual transition pathways

Specific questions were asked to the young people about their chosen pathways. The experiences of those at university, and of those who were applying for university will be reported in more depth in a forthcoming report, which will focus specifically on the experiences of the participants in making the transition to university. This section focuses briefly on the experiences of those at university, as well as a more detailed focus on those in employment and apprenticeships, and those who are NEET.

2.1 First year experiences at university

Interviews were conducted with 17 participants who had started at university in autumn 2012 to establish how they had found the transition into their first year at university.
Of the 17 participants, two did not complete the first year. In one case the young people dropped out because they didn't enjoy the course as much as expected. In the other case the young person was unable to access the course, or the assessments at the end of the year, due to problems associated with their visual impairment. He reports that material was not made available to him in either his preferred print format, or electronically. He also reports that when he attended his examinations, he was unable to read the papers.

Table 5: How happy the participants at university were with their plans for the next academic year.

How happy are you with your plans for next academic year?	Total (N)
Very happy	11
Happy	4
Quite happy	0
Quite unhappy	0
Unhappy	1
Very unhappy	0
Total	16

The 16 participants who were continuing at university were asked to rate on a scale ranging from 'very happy' to 'happy' how happy they were for their plans to continue at university the next academic year. All participants but one described themselves as either very happy or happy. The one participant who described himself as 'unhappy' was the student referred to above who had been unable to access his course all year. At this stage he was still waiting to hear whether he would be allowed to repeat the year, or if he would be able to transfer to a different course.

The participant who dropped out of university felt that the course he was studying was not right for him, and made the decision to leave after the first semester. He planned to use the time to reconsider his options, and indicated that he may apply to go back to university and study a different course. However, at the time of the autumn 2013 interviews he had not reapplied for university, and had not begun exploring any other possible options.

2.2 University applications

Nine participants went through the application process for university during the academic year 2012-2013. Some characteristics of these participants are presented in the table below:

Table 6: Characteristics of participants who applied for university during academic year 2012-2013 (N=9)

Characteristic	Total (N)
Gender	
Male	5
Female	4
Registration type	
Registered blind	8
Registered partially sighted	0
Not registered/unsure	1
Reading format	
Braille user	8
Large print user (point 16+)	1
Standard print user	0

The majority of these participants are from our Year 10 cohort, of which all but one are registered blind. The participants were applying for a wide range of courses, ranging traditional courses like English to more practical science based courses. They applied to universities from all over England and Wales, and in all cases their choices would mean that it would be necessary for them to live away from home. Three of the participants had applied for four year courses.

All but one of the participants declared their visual impairment when applying to university through UCAS. The participant who chose not to declare his visual impairment on the UCAS form reported that it was not compulsory to do so, and that he had instead sent a letter to the university explaining his visual impairment.

Of these nine participants, only 7 of them ultimately went to university in autumn 2013. One successfully obtained a place on their chosen course, but deferred for a year to go and do voluntary work abroad, whilst another participant did not achieve the grades needed for his first choice and reserve choice university, and decided instead to take a gap year, and reapply for the next academic year.

2.3 Participants seeking employment/apprenticeships, NEETs and 'Other'

During the summer 2013 interviews, those participants who were considering looking for employment or apprenticeships were asked questions about the type of work they were looking for, the support they had received and their strategy for looking for opportunities. Participants who were NEET at the time of interview were also asked about their experiences in looking for work. It should be noted that some participants were undecided about what they wanted to do after college, and were considering employment/apprenticeships as just one of multiple options. Their responses are still included here, even if they did not pursue this pathway in the end. Their experiences were also followed up during the autumn 2013 interviews.

At the time of the summer 2013 interviews, there were six participants who were seeking employment or apprenticeships. Three were just looking for employment, two for apprenticeships only, and one was seeking both options. Five of the participants interviewed were sharing their experiences in looking for work for the first time, whilst one participant had been unemployed since the end of the previous academic year, and had been seeking work for all that time.

Finally, one participant who was NEET had arranged for voluntary work for the next academic year. She had been due to do this the previous year, but there had been delays in getting it set up. She was very optimistic about the experience that she would be getting, and had no plans to look for employment or apprenticeships in the meantime.

2.3.1 Type of job/apprenticeship

Six participants described themselves as seeking either employment or apprenticeships at the time of the summer 2013 interviews. Some characteristics of these young people are presented in the table below:

Table 7: Characteristics of participants who were seeking employment/apprenticeships at the time of the summer 2013 interviews (N=6)

Characteristic	Total (N)
Gender	
Male	3
Female	3
Registration type	
Registered blind	2
Registered partially sighted	1
Not registered/unknown	3
Preferred reading format	
Standard print	1
Large print (point 16+)	4
Braille	0
Electronic	1
Highest level of qualification	
A-level and equivalent	1
GCSE and equivalent	5

The gender of these six participants is evenly split. Two of the participants are registered blind, one partially sighted, whilst three were either unsure or their registration status or not registered. The majority of participants are large print users, whilst one individual prefers using an electronic format along with magnification software. It is particularly interesting to note that five of these six participants who are NEET have a highest qualification level of GCSE and equivalent.

The participants were asked if they had considered the type of job or apprenticeship that they would like to obtain. Four of the six appeared to have quite clear ideas of what they would like to do. These included:
- Retail work (2)
- Working within the disability sector
- Engineering

One of the participants who appeared to have less developed ideas responded that he was looking for "anything", whilst the other had not really explored available options, but had heard from a friend that there

were government apprenticeships available, so had decided that he was going to pursue those.

2.3.2 Experiences in looking for jobs/apprenticeships

Four of the participants referred to in this section had started actively looking for jobs/apprenticeships. The individual experiences of the participants are explored below:

Participant 1:

Participant 1 is registered as partially sighted. He was taking a course at college, but dropped out part way through, after deciding that he was not enjoying it as he had hoped. Instead he decided to look for a job. He was mainly looking for jobs in retail and had applied for a few positions, but had had no response to his applications. He had not found the job centre "great for finding opportunities". He also felt restricted by having to rely on using public transport, which is only available during the daytime in the area where he was living. His main strategy for finding work was to go into shops and hand in application forms for specific jobs as well as speculative copies of his CV. He had not found any difficulties in completing the paper applications. At the time of his autumn 2013 interview he had decided to go back to college after not having any success in finding work, reporting that "I applied everywhere but nothing came up".

Participant 2:

Participant 2 is registered as blind, and relies on very large print and magnification software to use a computer. He was taking a level 3 college course, but felt forced to drop out part way through as he was struggling to access the course, and did not feel adequately supported. He was mainly looking for employment in the disability sector and applied and obtained a suitable job after it was spotted by a friend. This was for a casual, zero-hour contract, which he was very enthusiastic about. However, by the time of the autumn 2013 interview it became apparent that the job was not what he had hoped, and he had become very discouraged. After several months, of firstly waiting to have CRB clearance, he had only been offered work on one occasion, and despite reminding the employer that he was available for work, had not been given a further opportunity.

Participant 3:

Participant 3 is not registered visually impaired. She had been taking a college course, but decided to drop out after having difficulties with

some fellow students. When asked what type of work she was looking for, her response was "anything". At the time of the summer 2013 interviews she had not started looking for employment, responding that she had been "so stressed over everything else up until now". At the time of the autumn 2013 interviews she had gone back into education and was taking a course in customer service and still considering her future options.

Participant 4:

Participant 4 had been taking A-levels, but had failed the first year. He was doing some casual work for his Father, but was seeking an engineering apprenticeship. At the time of the summer interview he had applied for 10-15 apprenticeships and had received responses to a few of them, but had not had any interviews. He was mid-application for some other possible roles. He had found the opportunities on the internet via a dedicated apprenticeship website, and reported having had no difficulties in accessing the website. We were unable to speak with this participant during the autumn 2013 to find out whether any of his later applications were successful.

Participant 5:

Participant 5 is registered as blind. At the time of the summer 2013 interview, he had just completed a course at a special college for students with vision impairment, and was planning on looking for an apprenticeship. He had heard of some apprenticeships that were available through the Welsh government and intended to apply for one of them. He had been having problems with his computer, so said that he had been unable to make further investigations. At the time of the autumn 2013 interviews the participant reported that he had not been able to find anything suitable for him to apply for, as the apprenticeships scheme had already closed at the time he went to apply. Ideally he would have applied for something prior to completing college to have fitted in with these timings. He also indicated having difficulties in finding something that he felt would cater for him with his visual impairment: "I can't seem to find any that suits me. My needs and stuff like that." He had done some volunteering, but the organisation he was helping at had changed the focus of the work they were offering him to something that he was not as interested in, so he had decided to leave.

Participant 6:

Participant 6 is not registered visually impaired. She had successfully completed a Level 3 BTEC and achieved high grades. After leaving

college she decided to look for apprenticeships or jobs in both retail and animal care, but had been unable to find anything. To help boost her CV and with the support of her local job centre she did some voluntary work in a local charity shop for part of the week, and applied for jobs and apprenticeships the rest of the week. She had had some interviews, and at the time of summer 2013 interview felt that she was getting closer in securing some kind of position. Positively, at the time of her autumn 2013 interview she had successfully secured a temporary job in retail.

It has been well documented in recent months the challenges that young people in the UK are facing in finding employment once they have completed school and college (e.g. see Department for Education, 2013). As such, the experiences that our young people are facing in their struggles to find suitable placements are not unique. However, it would be appropriate to emphasise how in our longitudinal research it has been a common theme over several interviews that the young people have been struggling to find apprenticeship opportunities, although it is not entirely clear whether this is because there are limited opportunities available, or if it's because the young people are unsure where to look. Of the small number of participants in this project that have successfully obtained apprenticeships, two of those did so through sending speculative applications.

There has also been concern recently within the government and media about the increase in the number of employees on zero-hour contracts, and the negative effects that these are having on UK society (e.g. Guardian, 2014). This is illustrated in the experiences of participant 2 who was offered a zero-hour contract by a local society for visually impaired people with assurances that regular work would be available. As part of the role he had to wait to receive CRB clearance and consequently was inactive for a number of weeks. However, since receiving clearance, he has only been offered work on one occasion. Whilst it could be seen that this would be discouraging for any young person, it could be argued that it is even more so for a young person with a severe visual impairment, particularly as in the case of this young person who already had strong doubts that he would be able to find someone prepared to employ him.

2.3.3   Support in seeking jobs/apprenticeships

The five participants who had just left sixth form/college were asked about any support that they had received when considering applying for jobs and apprenticeships.

The responses given by the participants indicated that they had had limited support in looking and applying for positions, although in the majority of cases they had only just completed their courses. One participant said that they had received some support from tutor whilst another participant had had support from family members. A further participant described how they had received careers guidance as part of their school syllabus, but had not found it particularly helpful, describing it as "pointless really" and "monotonous".

They were also asked if they were aware of any support that may be available to them once they were in work, specifically in relation to their visual impairment. One participant who was applying for jobs said that they had heard of Access to Work, whilst one participant who was looking for apprenticeships had also heard of the scheme, but was unsure if it would provide support to someone taking an apprenticeship or not.

2.4   Participants in employment/apprenticeships

During the course of the summer and autumn 2013 interviews, 11 participants were interviewed who had successfully obtained a job or apprenticeship. The table below provides a summary of the interviews that were conducted:

Table 8: Interviews conducted with participants in employment/apprenticeships

Interviews conducted	Total (N)
Participants interviewed in both summer and autumn 2013	7
Participants interviewed in summer 2013 only	1
Participants interviewed in autumn 2013 only	3
Total number of interviews conducted	18
Total number of participants interviewed	11

Seven participants in employment/apprenticeships were interviewed during both the summer and autumn 2013 interviews. One participant was interviewed in summer 2013 only, and three interviewed in autumn 2013 only (in one case, this was because the participant had been

NEET during the summer 2013 interviews, but had successfully obtained a job by the autumn 2013 interviews).

Table 9: Total number of participants in employment/apprenticeships during an interview conducted in 2013

	Total (N)
Participants in employment	9
Participants in apprenticeships	2
Total	11

Nine of the participants we spoke with during the 2013 interviews were in employment and two were in apprenticeships. When comparing this figure with previous tables in this report, please remember that this figure is combining the participants who declared that they were in employment or apprenticeships, across the two waves of interviews. Therefore, in total 11 young people so far have obtained employment or an apprenticeship.

2.4.1   Summary of data collected

Summer 2013
The eight participants who completed the summer 2013 interviews were asked questions on the following:
- Details on their current role, how they initially found the role, the application process, accessibility of the application process, whether they declared their visual impairment, (if an apprenticeship or temporary job) how long their position will last for
- Details of any provisions that were made for their visual impairment during the application process
- Details of provisions that have been made for them in their role in relation to their visual impairment
- Details of their general experience in applying for jobs/apprenticeships
- Details of any information and advice they received before making applications, including disability specific advice

Autumn 2013
The autumn 2013 interview was less structured. Participants were asked to update the researcher on what they were currently doing. Any who had recently entered employment or an apprenticeship were then asked

about their current role, and their experiences in applying for the role, particularly in relation to their visual impairment.

As the summer 2013 interviews were more focused on employment/apprenticeships than the autumn 2013 interviews, the presentation below focuses on the summer 2013 data, but where relevant some of the data collected during autumn 2013 is also incorporated, and this is clearly stated in the report.

2.4.2 Overview of the participants in employment/apprenticeships

Table 10: Characteristics of participants who were in employment/apprenticeships at the time of the summer/autumn 2013 interviews (N=11)

Characteristic	Total (N)
Gender	
Male	3
Female	8
Registration type	
Registered blind	0
Registered partially sighted	4
Not registered/unknown	7
Preferred reading format	
Standard print	9
Large print (point 16+)	2
Braille	0
Electronic	0
Highest level of qualification	
A-level and equivalent	9
GCSE and equivalent	2

The table above shows some of the characteristics of the eleven participants who were in employment/apprenticeships at the time of the summer/autumn 2013 interviews. The majority (8 of the 11) of these participants were female. Seven of the participants were either not registered, or were unsure whether they were registered or not. Nine of the participants used normal print, whilst two needed large print (one used point 16, and the other point 24-32). Nine of the eleven participants

had qualifications of A-level or equivalent. One of the participants who had GCSE and equivalent qualifications was taking a qualification equivalent to A-level as part of her apprenticeship. It is particularly notable that none of the young people who are registered as blind had transitioned into employment at this stage.

2.4.3   Type of work roles

The young people were asked about the type of position that they have. Their responses are listed below (for those who were taking apprenticeships, this is indicated in brackets):

- Customer service (apprenticeship)
- Child care x 2
- Computing
- Manual work
- Retail x 3 (1 apprenticeship)
- Cleaner
- Administrator
- Accountant

Short case studies of a selection of the participants and the background of how they initially obtained their role are presented below:

Participant 1:

Participant 1 is unsure of his registration status, but is confident that he should at least be eligible to be registered as partially sighted. If receiving paper copies of material, he would request a size 24-32 point font, although he would sooner receive material electronically and make his own adjustments. At the time of the autumn 2013 interviews, he had been with his employer for approximately two years. He started working in his role in computing after a speculative application and series of interviews, after which he was offered an apprenticeship. After successfully completing the apprenticeship he was offered a permanent position within the company. He did not require any provisions to be made during the application process.

Participant 2:

Participant 2 is registered as partially sighted. At the time of the autumn 2013 interviews, she had been working at a supermarket for approximately two years. Within her role she has varies responsibilities including working on the checkouts, putting out stock and cleaning. She had had previous part-time experience working in retail, so prioritised that sector when applying for jobs after leaving college. She

applied for her job using the company website, and made the access of that website easier for her by using specialist magnification software. Recently she has started the training to move up to a supervisory position.

Participant 3:

Participant 3 is not registered visually impaired. After completing college in summer 2012, she enrolled on an employment skills course, which was designed to help equip her with necessary skills for the work place, as well as providing work experience. By summer 2013 she had successfully obtained an apprenticeship in customer service. She described her responsibilities as including being first point of contact for customers, managing a switchboard and using the organisation's computer systems. She originally found the details of the job on the organisation's website. She did not need to make any adjustments to the application form in order to complete it, as it was already in a manageable font size for her. She chose not to disclose her visual impairment until after being offered the position as she did not feel it was necessary to do so before that stage.

The participants have managed to secure and maintain a wide range of jobs. It is particularly encouraging from the case studies to see that the young people have been progressing in their roles, with participant 1 being offered a permanent job after successfully completing his apprenticeship, participant 2 starting the process to move up to a supervisory role, and participant 3 securing an apprenticeship after completing an employment skills course.

2.4.4   Provisions made for the young people in relation to their visual impairment

Table 11: Has the young person disclosed their visual impairment?

Characteristic	Total (N)
Yes	10
No	0
Not stated	1
Total	11

Ten of the participants stated during the interviews that they had disclosed their visual impairment to their employer, whilst in one case it was not clear if they had or not. One participant said that they made the disclosure after being offered the job, whilst two participants said that

they disclosed at the time of interview, but also emphasised that they reassured the person interviewing them that their visual impairment would not affect their ability to do the work.

Table 12: Are provisions made in the workplace for the young person's visual impairment?

Characteristic	Total (N)
Yes	6
No	0
Not needed	4
Not stated	1
Total	11

The participants were asked about any adjustments that had been made for them in the workplace, and if relevant, for more details about what the provisions were, and who would provide them. Six participants reported that provisions had been made for them, whilst five reported that they did not need any adjustments to be made by the employer (in some cases this was because they could make their own adjustments), whilst in a final case it was not clear whether adjustments had been made or not.

Some of the adjustments that the participants said their employers/colleagues had made:
- Providing a larger monitor
- Providing specialist accessibility software
- Colleagues helping read smaller writing if young person requested
- Providing enlarged materials

Some of the participants also spoke of adjustments that they themselves had made, these included:
- Magnifying images on the screen/change text size
- Using low vision aids
- Making adjustments to the computer to make it easier to use

2.4.5 Participants experiences in seeking jobs/apprenticeships

The participants were asked about their experiences in seeking jobs/apprenticeships, both in terms of their general experience, and also specifically in relation to their experiences as a young person with a visual impairment, as well as details of any specific help or advice that they may have received. The experiences of three of the participants are presented below as short case studies:

Participant 1:

Participant 1 had had a mixed experience in his initial job search, after finding that there were limited opportunities on the official apprenticeship websites, but managing to find his own position through a speculative application to a company he was interested in. He did not receive any advice specific to his visual impairment whilst seeking his role, but felt that he could have benefited from it. He found limited, but good advice on apprenticeships for disabled students on his local council website, but again, could have benefited from more information.

Participant 2:

At the time of the autumn 2013 interviews participant 2 had been working at a supermarket for approximately two years. She approached her initial job search by handing out CVs, completing online application forms and using the job centre website. She accessed websites with the use of specialist accessibility software, and did not recall having any difficulties. At the time at which she had already started her job, she had not heard of Access to Work. She did not feel as though she needed any further advice relating to careers guidance and her visual impairment.

Participant 3:

After completing college in summer 2012, participant 3 enrolled on an employment skills course, which helped equip her with skills needed for the work place, as well as providing work experience. She applied for a number of roles prior to being successful for an apprenticeship. She did not have any difficulties in accessing the application forms that she completed during her job search. She did not receive any disability specific advice when making her applications, but did not feel that such advice was necessary for her.

A previous report 'Young people's progress and views of independence aged 16-19' (Hewett et al, 2013) provides further details of the young people's knowledge of Access to Work.

It is interesting to note that none of the eleven participants who had entered work/apprenticeships at this time had made contact with Access to Work, even though in a number of cases they were already aware of the scheme, and one participant had specialist accessibility software provided by his employer rather than through Access to Work. None of the participants appear to have struggled in their roles, although there is a possibility that Access to Work would have been able to help them in

ways that they and their employers had not considered. However, it is worth noting that in general the participants who had successfully transitioned into work/apprenticeships at this stage were generally ones who had reported being less affected by their visual impairment, whilst those with more severe visual impairments were either still in sixth form/college or had progressed to university, and so were not yet at the stage of needing to draw on Access to Work.

2.5   Future projections for the longitudinal research

Table 13: Projected entry date into the labour market

Date expected to enter labour market	Total (N)	Cumulative percentage (%)
Already in employment	9	12.3%
2014	7	35.6%
2015	17	45.2%
2016	11	60.3%
2017	16	82.2%
2018	3	86.3%
Unknown at present	10	-
Total	73	-

The table above shows our projections, based on the young people's long terms plans, for when they are likely to enter the labour market. The majority (82.2%) are expected to have entered the labour market by 2017, whilst ten of the participants (14%) were unsure of their plans to make such projections, but it is possible that they also will have entered the labour market by this stage. It should be noted that the majority of young people who have more severe visual impairments have chosen to go to university, and therefore we are likely to have limited evidence of participant experience of entering the labour market (and use of Access to Work) until these participants graduate in 2016 and onwards.

SECTION B: VISION, ACCESSING INFORMATION AND EQUIPMENT

3 Vision

3.1 Registration of sight problems

Several questions were asked in relation to registration as severely sight impaired/blind or sight impaired/partially sighted with the Social Services. These included asking the participants whether they were registered (and if applicable reasons for not registering), their experiences of registration and their main reasons for choosing to become registered.

Table 14: As far as you know, are you registered as blind or partially sighted? (and if so, as what?)

Registration type	Total (N)	Total (%)
Severely sight impaired (blind)	21	32.8%
Sight impaired (partially sighted)	23	35.9%
Registered, but don't know which category	1	1.6%
Not registered	11	17.2%
Don't know	8	12.5%
Total	64	100.0%

Over two thirds (44) of the participants reported they were either registered as severely sighted impaired or sight impaired, whilst two knew that they were registered, but did not know the category of registration.

Table 15: Do you know if you are eligible to be registered as blind or partially sighted?

	Total (N)	Total (%)
Yes, I am eligible	2	16.7%
Unsure if eligible or not	10	83.3%
Total	12	100.0%

The participants who were registered as SSI/blind were asked if they had been registered as partially sighted prior to being registered as blind. This was the case for three of the 21 participants, whilst two could not remember, which is understandable as many of them were

registered at a very young age. A further participant reported that they had previously been registered as blind, but when they moved to a different region, the ophthalmologist that they spoke with said that their level of visual impairment was not sufficient for them to be registered as blind, and instead their registration was changed to sight impaired (partially sighted)

Those participants who stated that they were not registered or unsure if they were registered, were asked whether they knew if they were eligible to be registered as blind or partially sighted. Two participants reported that they were, whilst ten were unsure. This was followed up by an open question on why they had chosen not to register. This question was directed to five participants who either knew that they were eligible for registration but had made the decision not to apply or in discussion demonstrated that they were aware of what registration was, but had not investigated it further.

For one of the participants, despite his mother being registered as having a visual impairment, it was something that he had not considered or engaged with himself.

> "I definitely know that I am not registered blind, but partially sighted, I'm not sure. Possibly, possibly. But possibly not if I am honest with you, but go for no I think. I don't know very much. I know my mum is, so unless she has headed that up. I might ask her when she gets home from work and see if she knows anything else. If not I can get myself registered…If I am honest with you it really hasn't crossed my mind at the moment. I definitely would look into it. I don't know how beneficial it would be to myself, but I would certainly look into it. Later today I think."

Two participants were unsure if they would be eligible or not to be registered, and had not investigated this further.

> "I'm not sure to be honest. I think I would be a bit borderline"

> "Hmm, I am not sure, because I am so borderline on like all of the different things, I feel like if I was to try and register and they said no, then I would have a case to fight if I wanted to get registered, but at the same time, I don't know, because I can't see well enough to drive, which would sort of indicate that I've not got good enough eyesight to… I don't know. Because for someone with a visual impairment, I can see quite well."

Perhaps their reluctance to investigate this further was because they did not really anticipate any benefits from doing so, as illustrated by the response from this participant:

> Researcher: "Is it something that you have ever thought about looking into?"
> Participant: "Not really, because I don't think I would benefit very much from it."

Two of the participants had actively made the decision not to pursue registration, as they were concerned that in doing so, they would be "labelled".

> "I just feel that it's a label that it will restrict me from doing things that I really want to do."

> "I never really wanted to be labelled as I've got a visual impairment, I'm just a girl who wants to get on with it. I don't want a label or people saying ooh is that font big enough for you. I just want to crack on with things."

Table 16: How long ago were you certified by an ophthalmologist?

	Total (N)	Total (%)
As a baby	14	21.9%
As a young child – no recollection	14	21.9%
As a young child – some recollection	9	14.1%
As a teenager	2	3.1%
Doesn't know if registered	8	12.5%
No knowledge of registration history	6	9.4%
Not registered	11	17.2%
Total	64	100.0%

The young people who were registered were asked if they knew how long ago they were certified by an ophthalmologist. In most cases this was when they were very young. Over 20% (14) of the young people said that they were diagnosed and registered as a baby, so obviously have no recollection of the process.

> "It was very early on when I was a baby. I don't know exact dates – it was when I was really young."

> "I've been registered as blind since when I was born."

Fourteen participants were a bit older at time of registration, but still have no real recollection of the process that their parents/carers went through.

> Participant: "I was certified when I was 7, so just over ten years ago."
> Researcher: "And do you remember much about that?"
> Participant : "No, not really."

A further nine were registered when they were children, but did remember a bit more about going through the process and how they found it.

> Participant: "I'm not exactly sure, but I think it was about 15 years ago now, or 14, I'm not sure. Around that time."
> Researcher: "So I imagine you can't remember much about it?"
> Participant: "No, I was about 4 or 5 I think. I don't remember much. I just knew I wasn't the same as everyone else."
>
> Researcher: "Thinking back then, can you remember how you found it?"
> Participant: "Reasonably ok. I just knew I wasn't the same, and I needed help with stuff, that's about it really I think."

Finally, two participants had been registered more recently:

> Participant: "I don't know that one, I'm sorry. It must have been two years ago now. Because I did it to get the DLA in my name."

The responses given by the participants demonstrated that in many cases they did not really know what registration is, and the purpose behind it, so had not really engaged with it.

> Researcher: "Do you remember much about the process?"
> Participant: "No. Not at all."
> Researcher: "So was it just family that took it on?"
> Participant: "Yep."
> Researcher: "Do you know why they decided to that?"
> Participant: "No, I don't even know what it means. Well I know what it means but I don't know what it does exactly"

It is understandable that when their children are younger, parents would not want to overwhelm them in talking about registration. However at this

stage of the project the participants are now young adults who will be starting to access services targeted for adults. Therefore their apparent lack of knowledge of the registration process and its purpose is of some concern.

The nine who were registered as children and had some recollection of the process, and the two who were registered more recently shared some of their experiences. One person described how they had had difficulties in getting people to accept their visual impairment:

> "It wasn't exactly hard to get my certification, that wasn't the problem.. The doctors agreed that there was a problem with my eyes sight but the problem was understanding what the problem is, when there is no visible problem. That was the hard part. There was times when people were calling you a liar. That was the hard part. Being called a liar when you're not."

For another person it was a trigger for getting important specialist support and equipment:

> "So I would have been 12. I remember it all - I was at one of the hospitals and there was a gentleman…and we were talking to him, and I was having a lot of problems with school, with adjustments and things and said you know what's your eye condition, you should be registered partially sighted, and he put me through to this yellow card and I got my disability badge and we went to the blind centre and we got… cos I struggled with the remote for my telly, so I had this massive remote off them which I never used because it was far too big and I had a black book and it's got lines on it so you can put it on plain paper and follow the lines. To get me to write with straight lines better. I had keyboards and magnifiers. I had a talking watch put I got rid of that cos they used to have a go at me cos it kept going off in lessons so I never used that again. All kinds of different things."

Another participant described how although she received her diagnosis when she was a young child, as a family they were not linked with the specialist support that they should have received. Whilst this support should not be linked to whether the young person and their family had chosen to follow the route of registration, she still associated the two:

> "Well, we didn't know anything about it for quite a few years, the doctors were saying I was partially sighted, and the optician, her

saying it, and we never actually found out that we could get help as such, until I was in comprehensive, and I was roughly 14 years old, when I started getting help…It was when the, Mr [name removed] a very lovely man, who works amongst the RNIB, he helps children in schools with equipment, getting around school, helping the family out with any queries of what they are entitled to, and things. So it was really when I was 14 that my parents understood that they were entitled to that, and I was entitled to help in school and stuff."

Two participants, were more aware of the registration process because their eyesight had changed over time. For one individual whose vision was gradually getting worse, this had been a difficult experience for them:

Participant: "I found it difficult to be honest, I still find it difficult, because I could see, and everyone assumed that I could see it. But it's hard to explain it."
Researcher: "Yeah, I can understand that. Did you get any support for going to the registration, or did you get any specialist advice beforehand, or anything like that?"
Participant: "Not really, no, I didn't get anything to be honest. Sort of went on my own to be honest"

"I think it was years ago, but at the time I was registered as blind as well. It changes. Because my eyesight fluctuates…I think it was… I don't remember that much about it, it would just have been whenever I got check-ups, and the doctors would just provide evidence, things like that."

3.1.1   Reasons for choosing to become registered

The young people were asked to share their main reasons for choosing to become registered (or in most cases if they were aware of the reasons why their parents had chosen to complete the registration process on their behalf).

a) Evidence/Communication tool
For many (11), they saw it as a way of giving evidence of their disability, or a way of communicating their visual impairment to others.

"It's just people know you are straight away if you registered, like on the paperwork kind of thing. So you don't have to go into detail

about what the problem is, because they would already know, because I am registered, so I think it is a good thing."

"Ermm not really apart from just proof of visual impairment really. Cos you get your certificate of visual impairment which you need for… kind of things like getting a rail card and stuff like that."

Researcher: "Would you advise other young people with a visual impairment to get registered?"
Participant: "Yes I would despite the fact that it singles you it makes your life easier. If someone says so and so, you can say look I am registered, and people don't discount the proof, because doctors are seen as infallible. So it does take that weight off."

b) Support

Similarly, many (14) saw registration as a means to be able get access/easier access to practical and/or financial support.

"The advantages are that you get like support, allowances are higher, if you're registered blind, it's more convenient really when you need that support."

"Get extra support, if you wanted to claim DLA, it probably helps you in that respect. And also if you are trying to claim help at school, or going to university like I did, it can help there too."

"After I was registered I got a lot of help from the school and the connexions advisors helping me chose what to do after I leave school."

Ten of the participants gave specific examples of types of support that they had accessed as a result of being registered:

"Like I get a bus pass because I can't drive obviously. I think I can get DLA."

"Help in education, bus pass, disability services and benefits."

c) Advantages

One participant felt that registration gave a much needed advantage, whilst another felt that they would be disadvantaging themselves if they were not to register:

"Just that it is difficult without help sometimes, so basically give yourself any advantage that you can."

"I think it's a disadvantage if I am not, and people don't understand why sometimes I can't see and I struggle."

However, eleven of the participants said that they were not aware of any advantages of registration.

Researcher: "Do you know the benefits of being registered?"
Participant: "No, not really."

"I don't know, mum sorted all that out for me"

"Again, I don't know the benefits. Can you tell me the benefits of registering, because I have no idea."

d) Following advice
In three cases, the young people said that they had registered following advice received from their ophthalmologist. Their responses indicated that they were not really aware that they, or their families, were able to make a decision in whether they wished to register or not.

"Yeah, yeah, I think it's because of the specialist recommendation, it was his suggestions, I think my parents just went along with whatever he said."

"It wasn't really my choice, as I say, my eyesight deteriorated and I was a bit scared and said that I need to get this checked out, and you know, the next minute I am registered blind."

3.1.2   Reflections on registration

The participants who were registered and aware of what registration entailed were asked whether they would recommend registration to other young people with visual impairments. Of those asked, only one participant said that he would as he didn't 'know any different', and presumably didn't feel like he could give a balanced perspective.

Eleven participants said that they would recommend registration. Whilst not all of them could identify benefits of doing so, they could not see any disadvantages to it.

"Yeah, I would do, because it gets recognised then, so you don't have to hide the fact, sort of thing, I don't know. It's just people know you are straight away if you registered, like on the paperwork kind of thing. So you don't have to go into detail about what the problem is, because they would already know, because I am registered, so I think it is a good thing."

"Err Yeah. I guess so. There's no point not doing it I guess."

"Yes definitely. It's a privilege to have disability. I know a lot of people take the mick with it and they will claim for something that they haven't even got. But when you're at my age and you're in college, and your parents have had children like mine, they can't really afford to give you money here and there, it does help you out."

Those who were not aware of the registration process or of its benefits were offered a copy of an RNIB guide on the subject. All participants who were invited to receive a copy accepted.

3.2 Eye conditions

The young people where asked some questions which focused more specifically on their eyesight, the eye condition that causes their eyesight problem and also how their eye condition affects them.

3.2.1 Medical details of your eye condition

Table 17: Do you know the medical name of the eye condition that causes your eyesight problem?

	Total (N)	Total (%)
Yes	54	84.4%
Yes – after prompt	1	1.6%
No	9	14.1%
Prefer not to say	0	0.0%
Total	64	100.0%

The majority (55 of 64) of the participants were able to give some detail of the eye condition that affects their eyesight problem. The 52 people who described knowing the medical name of their visual conditions named a wide range of visual conditions (e.g. Glaucoma), symptoms (e.g. photophobia) and signs (e.g. Nystagmus), and many described having more than one of these.

Table 18: Do you know your visual acuity and visual field, or how to get it?

	Total (N)	Total (%)
Yes	7	14.3%
No, but I know how to get it	15	30.6%
No	27	55.1%
Total	49	100.0%

We also asked the young people if they knew their visual acuity and visual field, or at least how to get this measure. Only seven of the young people really understood what we meant by visual acuity and visual field and were confident that they had access to this information, whilst a further fifteen believed that they would be able to get it (typically by speaking with their ophthalmologist at their next appointment). Over half (27), however, said that they would not know how to get this information.

3.2.2   Explaining eye conditions

The young people were asked "can you tell me in your own words what is wrong with your eyesight?"

The responses given to this question have been analysed for themes. We looked at the ways in which the participants approached answering these questions, and presented in the table below.

Table 19: Can you tell me in your own words what is wrong with your eyesight - type of response

	Total (N)	Total (%)
Described what they can see	37	57.8%
Medical explanation	32	50.0%
Effects on their daily functioning	15	23.4%
Described adjustments that they need to make	14	21.9%
No reference /can't explain	4	6.3%
Don't understand condition	3	4.7%
Side effects they experience	2	3.1%

NB: Participants could answer in more than one way

a) Describe what they can see
Thirty seven (over half) of the young people answered this question by describing to the researcher what they see, or how their eye condition can cause a variation in what they see. Within this broad theme ten more specific themes were identified.

General struggle to see properly

Nine of the participants' responses spoke of a general struggle in being able to see.

> "Basically I have difficulty seeing without glasses and I don't see out of my right eye as I do my left."

> "I can't see everything. I have to wear my glasses to make sure that I can see clearly. That's all."

No vision/only light perception

Nine participants reported that they had no vision in either one or both of their eyes.

> "I can only see out of my one eye!"

> "I am totally blind. Does that help? I think that sums it up really."

One participant shared that one of their eyes only has light perception

> "I've got light and dark in my right eye, which means that if my left eye is closed, I can still tell light and dark."

Focusing

Six participants shared that their eye condition resulted in them having difficulties in focusing:

> "I struggle focusing when changing vision from looking down at some paper, to up on a board. I struggle to focus the further distance, and then readjust to looking at a bit of paper. That's the best I can say at the moment."

> "There is damage to my optic nerve, which means that signals from my eyes to my brain are impaired, so this means that without a lot of focus, well I can't really focus on a lot of things. It takes me a lot of time to do."

Eyes shaking

Linked to focusing, five participants spoke of how they have conditions which can mean that they experience rapid eye movement which they cannot control, and when this happens it will impact on what they can see:

"My eyes move, and I can't control that. That causes me to have issues focusing on things in the distance, so, for example, writing in the distance I can't read that because I can't focus on it."

"The problem is on occasions, when I am tired, my eyes sort of wobble from side to side. It depends on how tired I am, or whatever, but when they do wobble, it is hard for me to see things when it happens."

Visual field
Six participants reported that their eye condition has impacted on their visual field:

"Just a slightly restricted visual field"

"It's central vision loss, it affects your peripheral as well, slightly."

Specific difficulties
- Five reported that they would have difficulties seeing things at a distance ("For me, it's basically I can't see medium to long distances")
- Five reporting having difficulties with the clarity of what they see ("don't think what I am seeing is necessarily darker than what normal people can see, I think it's just that everything else is less detailed, that's the only thing")
- Three reported having difficulties with depth perception ("the only problem with the vision, is that my depth perception is awful, I can't judge slopes or steps very well for example")
- One participant explained that their condition is very variable and can range from them having limited difficulties to their eye completely closing up and not being able to open their eyes to see anything

b) Medical explanation
Thirty two participants gave responses which spoke of the medical explanation behind their visual impairment. Within this broad theme six more specific themes were identified.

Named conditions
Twelve participants reported the name of the medical conditions that they had, and in some cases this was more than one:

"It's ocular albinism…"

"…Lebers Congenital Amaurosis…"

Damage to eye

Eleven participants in describing their eye condition reported that their eye(s) had been damaged in some way:

> "I just think it's the nerve endings that are damaged I think. Something like that."

> "There is damage to my optic nerve, which means that signals from my eyes to my brain are impaired, so this means that without a lot of focus, well I can't really focus on a lot of things. It takes me a lot of time to do."

Development problems/Birth defects

Six participants reported that their eye condition came as a result of development problems/birth defects:

> "Then the optic nerve in my right eye, for some reason, they haven't figured it out yet, but they think it's because I didn't develop properly when I was a baby, when I was like in my mums womb, so that doesn't work particularly well, so I don't have any sight on my right eye."

> "It's a birth defect that goes through one eye and just the back of the other."

Genetic conditions

Four participants spoke of having genetic conditions which cause their eyesight problem:

> "It's a protein deficiency in the retina of the eye, caused by a genetic defect."

> "A defective gene died off when I was 9, and it took a certain amount of vision with it."

Eye function

Four participants' responses described how their eyes were not functioning as they should:

"The photoreceptors in my retina don't function correctly which means that I have limited vision."

"My left eye pulls inwards, and also I have tunnel vision. I have forgot the name for it also, but when I focus on things, my eyes like twist in. I am not sure what that's called."

Brain processes

Finally, two participants stated that their eyesight problems related to processing problems:

"My brain does not interpret properly the messages that come from my eyes, and do not send back the correct information."

c) Effects on their daily functioning

Fifteen of the participants helped explain what was wrong with their eyesight by describing how their condition impacts on their daily functioning:

"My eyes are very changeable like. I knock my feet about a lot. If something's uneven when I'm walking along. I knock my feet a lot. I stumble. I notice when I run or jog it gets worse obviously. Also my peripheral vision is rubbish. On a bad day everything is too far away. If I put a glass on the counter my fingertips are too far away. I knock it over like."

"It stops me seeing objects from a distance, or reading small print, and stuff like that. I can't judge distance as well."

d) Describing adjustments that they need to make

Fourteen of the participants spoke of the adjustments that they needed to make as a result of their eyesight problem:

"Basically I have difficulty seeing without glasses and I don't see out of my right eye as I do my left. And sometimes I need reading glasses because my eyes can't see small print."

"I have to have plain backgrounds on things. If something is plain I can see it very easily. Even far in the distance, it's fine as long as it's all one colour."

e) No reference/can't explain/don't understand condition

Four participants felt that they couldn't explain what was wrong with their eyesight, and in some cases this was due to the fact that they had no other experience that they could reference to:

> "I've not really got anything to compare to because I've never had full sight so I couldn't really tell you what's necessarily wrong with it."

> "It's to do with focusing on things, I should imagine. It's difficult, because I have never known any different."

Similarly, three participants weren't confident in explaining the problems with their eyesight as they did not really understand it:

> "Well, I can, but I am not sure it's very accurate, because I have been told several different things."

f) Side effects

Two participants spoke of side effects that they experience as part of their eyesight problem:

> "Because I do get very, very drained. And it gives me headaches. And I have had migraines. Just now and again."

> "It's just that my vision's always blurred, and it's really painful, and it can affect my studies, because of the pain, and also the fact that my vision for long periods of time can be affected, such as doing excessive reading and stuff like that."

Table 20: Assuming comfortable lighting conditions, can you see well enough to (N=64):

	Yes (N)	Yes (%)
1. Can I check, in a room during daytime, can you tell by the light where the windows are?	59 (No=5)	92.2%
2. Can you see the shapes of the furniture in a room?	57 (No=7)	89.1%
3. Can you see well enough to recognise a friend if you get close to his or her face?	51 (No=13)	79.7%
4. Can you see well enough to recognise a friend who is at arm's length away?	49 (No=15)	76.6%
5. Can you see well enough to recognise a friend across the room (average size)	40 (No=24)	62.5%
6. Can you see well enough to recognise a friend across a road (average 2-lane road)	26 (No=38)	40.6%

The table above shows responses to a series of questions that were designed to establish the extent of the young persons' visual impairment. The first question starts off by establishing whether the young person has any light perception, and then the questions continue in the form of a scale. Once a participant has answered 'no' to a question, none of the questions that followed that particular question were asked. In some cases where it had already been established that a participant could see sufficiently to see the shapes of furniture in a room, the question sequence asked commenced at question 3.

We observed that 59 of the participants (92.2%) have some form of light perception. This means that of the 64 participants there are 5 who are totally blind (no light perception). At the opposite end of the scale, 26 of the participants (40.6%) reported that they would be able to recognise a friend across a road.

A further set of questions were asked to establish how well the young people were able to see print (this question was missed out if it had already been established that the young person was not able to read any print at all)

Table 21: Can you see well enough to, (and if relevant to you, wearing glasses or contact lenses)?

	Yes (N)	Yes (%)
Can you see well enough to read ordinary newspaper print, without a LVA?	30	46.9%
Can you see well enough to read a large print book (N14), without a LVA	44	68.8%
Can you see well enough to read a newspaper headline, without a LVA?	51	79.7%

Thirty of the participants (46.9%) would be able to see well enough to read newspaper print, without using a LVA, whilst 44 (68.8%) could read a large print book, and 51 (79.7%) could read a newspaper headline.

3.3 Further implications of a visual impairment

3.3.1 Worrying about eyesight

Table 22: How much of the time do you worry about your eyesight?

	Total (N)	Total (%)
None of the time	13	20.3%
A little of the time	18	28.1%
Some of the time	26	40.6%
Most of the time	4	6.3%
All of the time	3	4.7%
Don't know	0	0.0%
Total	64	100.0%

The table above shows that 33 (51.6%) of the participants worry about their eyesight at least 'some of the time'. The table below shows these responses according to the participants' registration type.

Table 23: 'How much of the time do you worry about your eyesight' against 'registration type'

	Severely sight impaired (blind)	Sighted impaired (partially sighted)	Not registered	Other	Total (N)
None of the time	6	4	1	2	13
A little of the time/Some of the time	13	17	8	6	44
Most of the time/All of the time	2	2	2	1	7
Total	21	23	11	9	64

It is interesting to observe that there is no real difference in how much time the young people spend worrying about their eyesight, and the severity of their visual impairment. Of particular note is the fact that only one of the eleven participants who say that they are not registered reported that they never worry about their visual impairment, whilst two report that they worry most or all of the time.

One of the participants who reported that they worry 'all of the time' was struggling with the fact that their visual impairment was getting gradually worse, and they had recently gone from being registered partially sighted to blind. Another had started at university that year, and described how for the first time they were really facing living life as a blind person. The final person had been experiencing difficulties at home and was no longer living with their parents, which could explain to some extent why they struggling in this way.

3.3.2 Pain or discomfort experienced

Table 24: Do you ever have any pain or discomfort in and around your eyes (for example, burning, itching or aching)?

	Total (N)	Total (%)
None	37	57.8%
Mild	12	18.8%
Moderate	7	10.9%
Severe	5	7.8%
Very severe	3	4.7%
Don't know	0	0.0%
Total	64	100.0%

The majority of the participants (37 or 57.8%) do not have any pain or discomfort in their eyes as a result of their visual impairment. Eight however reported that they experience 'severe' or 'very severe' pain or discomfort. When considering their transition into employment, this is factor which would be worth investigating further; as such discomfort is likely to impact on how well they would be able to perform in a full day's work, as well as obviously impacting on their general quality of life.

3.3.3 Difficulties experienced with eyesight

Table 25: Is the difficulty you have with your sight greater or less than it was a year ago, or is it about the same?

	Total (N)	Total (%)
Greater than a year ago	6	10.0%
Less than a year ago	8	13.3%
About the same	45	75.0%
Not sure	1	1.7%
Total	60	100.0%

The participants were also asked if the difficulty that they have with their sight is greater or less than it was a year ago. The majority (45 or 75.0%) reported that it was about the same. A further eight (13.3%) reported that the difficulty was less than a year ago, but in most cases explained that this was because they had managed to adapt more to their visual impairment, and therefore it was not necessarily the case that the level of their actual visual impairment had changed. A further six reported that they had greater difficulty than a year ago.

Table 26: Does your eye condition mean that your level of vision can vary from day to day?

	Total (N)	Total (%)
Yes	28	43.8%
No	31	48.4%
Not applicable – no light perception	5	7.8%
Total	64	100.0%

The young people were also asked if their eye condition means that their level of vision can vary from day to day. A large proportion (28 or 43.8%) reported that their level of vision can vary from day to day. We asked these 28 to provide further explanation of this. Their responses have been categorised into the table below:

Table 27: Does your eye condition mean that your level of vision can vary from day to day? Explanations given

Explanation	Total (N)	Total (%)
Tiredness	12	42.9%
Lighting	12	42.9%
Weather	8	28.6%
Overuse of eyes	3	10.7%
Part of condition	2	7.1%
Hormones	1	3.6%
No pattern	1	3.6%

a) Tiredness

Approaching half (42.9% or 12) of the young people said that their level of vision is affected by how tired they are.

> "Yep! Definitely. If it's at the end of the day… They have tried to do eye tests, I think they tried to do an eye test on me at the end of the day once, and then my professor got them to check it three times, because I was seeing like three lines on a line chart less than… He thought something had happened to my eyes, but I just said 'nah, it's because I am a bit tired'."

> "If I am tired for example, my eyes will move more, which then causes my eyesight to deteriorate, the harder it is to focus on things. So, if I am tired for example, my eyes will be worse."

> "This is possibly because of how I can get from it, the amount of focus, I get tired and I get migraines and things like that, that might somewhat effect how well my eyesight seems to be."

b) Lighting/Weather

Very closely linked to one another were the explanations of differing lighting and weather conditions. Some of the young people described how the weather could impact on their vision, for example, if it was a sunny day and there was a lot of glare, or an overcast day with limited light. Others extended this to also include lighting in general, for example, if it was night time or lighting inside a building.

> "It can do, with the weather, especially outdoors. If it's a really, really sunny the one day, or if it's been raining one day and then it's sunny, the glare is just, it's really bad, or if it's a day like today, if it's cloudy, then it's better for me. And then obviously it's really

dark and raining, then it's too dark then. It's just depending on the weather."

"Yeah. The night time is difficult in the dark. It's a lot difficult compared to the day. My night time vision is not the best vision at all. Or if I've come in from sunlight , and it's really sunny, really bright outside, then I've come in, I'll just bump into things like tables and chairs. I've done that on numerous occasions."

"It tends to, but I think that's mainly due to the light conditions more than anything else, because they always vary from day to day. And you fall into patterns. My friends can tell when an area is suitable for me to go on my own, or where any area is not suitable…"

c) Overuse of eyes
Whilst this could also be linked to tiredness, three participants described how they would struggle more if they had been overusing their eyes:

Researcher: "Were you saying that sometimes you struggle when you have been concentrating too hard?"
Participant: "Yeah when I've been at the computer screen for a long time. Staring at computer screens or watching TV."

"It just depends on what I've been doing. Like if I've been reading for a long time my eyes'll start getting messed up."

d) Part of their condition
Two participants reported that the variation in their vision was simply a part of their eye condition:

"Let's say, if I have a lot of pain in my eyes, then it will put pressure on the optic nerve, therefore my vision would decrease. And if there's high pressure in my eye, it could impact my vision as well that way."

e) Hormones
One participant said that they had noticed a correlation between their level of vision and when they had their period, and had been advised that hormones can affect vision:

"I have also found that when I am on my period, my sight gets worse. I spoke to someone at […] about it, and they said that it was quite common. It's all to do with balance and stuff really, with

your hormones throwing you off, that's a definite thing, it's really noticeable with that."

f) No pattern
Finally one participant reported that whilst they do notice quite a difference in their level of vision from day to day, they were unable to distinguish a pattern.

> Participant: "It depends on the day, like some days I will get up and it will be absolutely perfect, and other days I will get up and I can see the calcium floating around. Other weeks I will get up and it will just be blurry, completely and utterly blurry, I mean, I am talking to someone and I am like 'who are you?!'"
> Researcher: "Thanks. And have you noticed any pattern with that, or is it completely random?"
> Participant: "It's just completely and utterly random."

Table 28: Do you ever suffer with eye strain/fatigue when reading, or perhaps when using a computer?

	Total (N)	Total (%)
Yes	41	64.1%
No	10	15.6%
Not applicable – would never use print	13	20.3%
Total	64	100.0%

The young people were asked whether they ever suffer with eye strain/fatigue when reading or using a computer. Over 80% of those who use print said that they would. We asked them to tell us more about this. Their explanations for the eye strain/fatigue which they experience are presented in the table below.

Table 29: Do you ever suffer with eye strain/fatigue when reading, or perhaps when using a computer? Explanation from those who do experience eye strain/fatigue

	Total (N)	Total (%)
Length of time	17	41.5%
Size of font	10	24.4%
Particularly when reading on paper	8	19.5%
Particularly when reading on computer	4	9.8%
Lighting	5	12.2%
Refocusing	1	2.4%

a) Length of time

Unsurprisingly, the most common explanation given by 17 of the participants is the length of time that they spend reading or using a computer:

> "Yeah. If I've been reading for probably an hour and I try to squint, it quite hurts."

> "If basically I overwork them, then they don't like it. So it's if I overwork them in any regard. Which is why low vision aids and CCTVs don't really work, because it's still… I am still looking at a computer screen."

> "Sometimes if I do read too long my eyes will start hurting."

b) Size of font

The next most common explanation related to the size of font, with ten participants reporting that reading smaller fonts would eventually affect their eyes:

> "Yeah I suppose I do a bit. If I'm trying to read something small Even though I know I can't read it I still try and read it and then my eyes start to strain and stuff like that."

> "That depends on the size of the font…I would say about a size 36 font, I would generally read. Maybe half an hour."

> "Yeah, my preferred format would be size 18, and I would always find that the font has a big impact, like for example, I like you know, Comic Sans. I read that better because all the letters are so separate, so it helps me see better."

c) Particularly when reading on paper/on the computer

Twelve of the participants stated that their eyes were particularly affected by either reading on paper or reading on the computer.

> "When I use a computer, I use it a lot, because obviously I use it every day for work, I think that will eventually take its toll on my eyes. There's nothing I can do about that really."

> "If I use a computer for long periods of time, and also the brightness of the screen, because my right eye is more blurred than my left eye, there's not a balance between the eyes, so it

makes one eye more tired than the other, so it can affect my vision that way as well."

"I'd say reading is more strenuous on myself, I think."

"I think it's worse with reading."

d) Lighting

Five participants reported that lighting conditions would impact on eye strain/fatigue.

"It's worse in poorly lit conditions."

Participant: "My kindle usually hurts my eyes more."
Researcher: "Can you think why that is?"
Participant: "I usually sit outside while I'm reading and light reflects off the screen"

e) Refocusing

One participant reported that they particularly experienced eye strain/fatigue when in a situation where they were having to repeatedly refocus:

"Yeah, if I have to focus on something, like when reading a long book, it can strain my eyes as well, yeah. Like I say, if I have to keep looking up to read something, and then looking down to write it down, if I am having to do that for an entire lecture, at the end of the lecture, my eyes do feel very strained at the end."

Table 30: Do you have difficulties with glare when using screens, e.g. computer or tablet computer?

	Total (N)	Total (%)
Yes	21	32.8%
No	30	46.9%
Not applicable	13	20.3%
Total	64	100.0%

Twenty one of the young people reported that they do have difficulties with glare when using screens. Those who said that they did have difficulties were asked to explain further how it affected them, and also give details of any ways in which they could make adjustments so it was less of a problem to them. The young people identified a variety of ways in which glare on screens may affect them:

a) Length of time
For three people, their difficulties from glare would affect the amount of
time they felt able to use a computer for:

> "Just sometimes it's hard to look at the screen for long periods of
> time. I just can't see properly, I don't know how to explain it really.
> It's just… it's very hard to read what's on the screen with any sort
> of glare. It hurts my eyes if I look at it… it's hard enough to try and
> read it."

b) Not able to see the screen clearly
Two people described that they would not be able to see what was on
the screen clearly:

> "Can't see it really. If there's glare on something I just won't be
> able to see it."

c) Worse when already have a headache
One person reported that they are only really affected by glare if they
already had a headache:

> "It can be, it depends what I am like on the day. If I have a
> headache, then it will be, if I haven't, then it probably won't."

d) Type of screen
Another person, seemed to have particular problems linked to the type
of screen that they were using:

> "Yes. With the PC, it may sound pretty weird to you, but when I
> look at it, I can see the colours rather than what is actually on the
> screen, if you get what I mean. I can break down the colours, I can
> see like green, orange, I am looking in the screen, rather than
> looking at a page. .. it's just the LCD screen, and that kind of stuff
> on it, it's just, I don't know, something to do with the pixels or
> something, and it just, it gives me like really bad pressure
> headaches."

e) Using computer at night
One participant described having minor issues with glare when using a
computer at night:

> "I do sometimes at night, but not much really"

f) Contrast

Another participant felt that their problems with glare came from not being able to adjust the contrast on websites:

> "Yes that's one complaint that I do have with websites, because you cannot change the background colour, Wikipedia and all these other academic sites you use, the background is white and it is absolutely horrible but there is nothing I can do. I can't do anything about that, so it's a nightmare."

Some of the young people also described some adjustments that they might make to minimise the effect of glare:

g) Make adjustments to the computer

The most frequently mentioned adjustment that the young people reported that they would make, was making adjustments to the actual computer. Ten of the young people spoke of different adjustments that they would make:

> Researcher: "Would you make any adjustments?"
> Participant: "Yeah, I've made the computer screen maybe slightly darker. If you are sitting in a dark room, maybe at 11 o'clock at night or something, if you have it really bright, it's going to strain your eyes anyway. So I turn it down a bit."

> "Yes I usually have to turn the brightness down or I have overlays that I can put over them."

> Participant: "Yeah, I have to lower the glare, yeah."
> Researcher: "Is it ok then?"
> Participant: "Well, I don't know, I have to get the balance right. I can't have it too dark either. It can be a bit of a balancing act."

h) Change adjustments to the lighting in the room

Three people said that they would change the lighting in the room:

> "If the blind was open in the room, I would close it, and turn the light on."

> "Yeah, so like at uni my window, like where my window is, it means the sun always shines onto where my computer is, so I have to keep my curtains closed when I am working."

i) Make adjustments by changing position
Two people reported that they would change their position in the room and get to a place where the glare was minimised:

> "If it's at college I just well can I move somewhere else. Or whatever."

j) Make adjustments by taking breaks
One person said that they would deal with the effects of glare by taking regular rest breaks:

> "At college when I am doing work, I have computers, I think it's the glare that makes my eyes bad, so I take breaks every ten minutes to like ease it."

3.3.4   Operations

Table 31: Have you had any operations on your eyes in the past that have changed your vision?

	Total (N)	Total (%)
Yes	24	37.5%
No	40	62.5%
Total	64	100.0%

Participants were asked whether they had had any operations on their eyes in the past that had changed their vision. Over a third of the participants (24 or 37.5%) reported that they have had an operation on their eyes in the past which had affected their vision in some way. Those who said that they had had an operation were asked to give the researcher more information about this. The table below presents the type of responses that were given by the young people:

Table 32: Have you had any operations on your eyes in the past that have changed your vision? Types of response from those who have had operations

	Total (N)	Total (%)
Multiple operations	10	41.7%
Cataract operation	7	29.2%
Direction of eye	5	20.8%
Regulate eye pressure	4	16.7%
Secure retina	4	16.7%
Risk	3	12.5%
Does not know details	3	12.5%
Implant	2	8.3%
Tumour	1	4.2%
Save some sight	1	4.2%

a) Multiple operations

Ten of the participants reported that they had had more than one operation, and in some circumstances, several over a number of years:

> "The first ones that I had were to take the lens off my right eye. The cataract ones. Then a Molteno tube in my right eye, then one in my left eye. Then I had an R-ed tube put in my left eye, and they were for draining in my eye because the pressure was too high. But the one in my left eye, the Molteno tube, didn't work the first time so they had to put a different one in. But the other one is still in, so I've got two in there."

> "Oh loads. When I was little I had laser to reduce pressure. About 3 or 4 years ago I had two retinal detachments. They were pretty big ops. But I've always had little things to like, I've got tubes, since when I was like a baby to help regulate eye pressure. Because with glaucoma it's all about the pressure really. And making sure that your eyes are regulating the liquid that is coming in and out. Make sure that your eye doesn't get under too much strain. So it's just stuff like that, but the last two years have been pretty good. I've had no ops."

b) Cataract operation

Seven of the participants reported that their operation was linked to cataracts:

"At two weeks old I think. I had so much cataract in my eyes that my mum knew straight away, when I was born, she was like 'she has cataract in her eyes, she has the same eye condition as me, she needs an operation. So they went and called the ophthalmologist like the day after I was born, so they knew it was kind of happening, so they did it very early"

"I had the cataracts removed and then I had laser eye treatment as well."

c) Direction of the eye

Five of the participants described procedures relating to correcting the direction of their eye:

"I think they made my eyes look straight. Something like that. They pulled the muscles. I think. I can't remember now."

"Yeah I've had one. It was basically cos if I was looking at the board I would be looking at it at a 30 degree angle. Not straight on. So they improved that"

d) Regulate eye pressure

Four participants reported that they had operations which were designed to help regulate their eye pressure:

"Then I had an R-ed tube put in my left eye, and they were for draining in my eye because the pressure was too high."

"When I was about 11/12 I had an operation to drain fluid behind my eyes, that was to do with the glaucoma. That was to reduce the pressure a bit more."

e) Secure retina

Four participants described having procedures which aimed to secure their retina:

"The main one that I can remember… That was basically to secure my retina."

"When I was really young, when they reattached my retina, that obviously changed my vision, but I don't remember any of it."

f) Risk

Three participants spoke of an element of risk which was attached to the operations which they had:

> "Then aged 15-16 they said 'oh we'll have to operate'. If they didn't operate I wouldn't be able to drive and my eyesight would have gone blind. So I had to risk it. There was a chance that I would go blind, but I had to risk it anyway."

> "Well I had lots of operations at the beginning and some of the people in that think it might be the reason why I lost my sight."

g) Does not know details

For three of the participants, whilst they believed they had had operations in the past, they did not know any details about the procedures that they had had:

> Participant: "Yeah I had like a couple. I think when I was in Year 7 or Year 8."
> Researcher: "And do you know what they did in those operations?"
> Participant: "I think my uncle knows."

h) Implant

Two participants reported that as part of the operation they had, they had had implants put into their eyes:

> "Intraocular lens implant. They had to take my eye's lens out and put a prosthetic one in. It's what they do for people that have cataracts."

i) Tumour

One participant shared that an operation to remove a tumour had affected their vision:

> "Well I had an operation when I was 6 to remove my brain tumour, but that was on my brain so I don't know… but they couldn't remove all of it so then 3 or 4 years later it started growing again so I had to have radiotherapy, but then that's it at the moment."

j) Save some sight

Finally, one participant reported that they had had an operation designed to help save some of their sight:

Participant: "When I was really little, they did to try and save some sight."

Researcher: "Do you know if that was successful at all in any way?"

Participant: "It was as successful as it could be because I can see some things."

Table 33: Do you have any operations planned for your eyes that are likely to change your vision?

	Total (N)	Total (%)
Yes – planned	2	3.1%
No	46	71.9%
No - nothing planned, but believe it could be a possibility in the future	9	14.1%
No – nothing planned but hoping there may be future plans	4	6.3%
Unsure	3	4.7%
Total	64	100.0%

Participants were also asked whether they knew of any operations that were planned for the future that were likely to change their vision.

- Two of the participants reported that they knew they were due to have operations in the near future, whilst 46 reported that they were not expecting to have an operation at any point.
- Nine of the participants believed that having an operation could be a possibility at some point, but at that point in time there was nothing planned.
- Four participants said that there were no operations planned, but specifically said they hoped there would be plans for this in the future
- Three participants were unsure whether future operations were a possibility or not

The relevant participants were asked to give further information about any potential operations. Their responses are given in the table below:

Table 34: Do you have any operations planned for your eyes that are likely to change your vision? Open response

	Total (N)
Potential for medical advancement	10
Would not want an operation	8
Nothing that can be done	5
Operation only an option if eye condition worsens	5
Would be open to having an operation	3
Waiting for operation to be arranged	2
Conducting own investigations	1

a) Potential for medical advancement
Ten participants saw their possibility of having operations in the future as being linked to potential medical advancements:

> "No, I don't think there's any operation that can change my vision, unless there's some really clever thing like replacing my eyes, or a stem cell thing."

> "Not currently, no, they haven't said anything about any operations. But it might be that they find a way of curing the condition in the future, who knows."

b) Would not want an operation
Eight of the participants shared that they would not like to have an operation in the future for a variety of reasons, including:
- being concerned that it would make their eye condition worse
- concerns about undergoing the actual medical procedure
- not trusting doctors
- seeing their visual impairment as part of their identity as a person

> Researcher: "Do you know if that's a possibility in the future?"
> Participant: "Well, I know I can't have laser eye surgery or anything like that, because they said it wouldn't work. I think I'm… I don't think I would go down that route anyway, I think it might make it worse. I think I am ok as I am, some people haven't got a lot to lose, but I think I have, so that I can see ok. If I did have an operation or something, it could make it worse. So I will just stay as I am."

"Because I've dealt with it for 17 years. I feel that if I had an operation I wouldn't be me. I wouldn't be myself."

c) Nothing that can be done

Five participants reported that an operation was not a possibility for them as there was nothing that could be done. In most cases this was because they had multiple eye conditions, making their situation more complex:

"No. I mean I have heard of an operation for people who have got Nystagmus, but I doubt that, with the other eye conditions. Cos you have to have certain eye conditions to have it. I doubt it."

d) Operation only an option if eye condition worsens

Five participants shared that their likelihood of having future operations was linked to the possibility of their eye condition worsening (and the understanding of potential treatment was quite speculative):

"I know that scientists are working on gene therapy, and also there's a little camera lens that they put in when you go completely blind, and it takes like thousands of pictures a second, and transfers it to your brain and makes you able to see. But I have to be fully blind for both of them I think."

e) Would be open to having an operation

Three of the participants said that they would be open to the possibility of an operation in the future, if the option were given to them:

"If they offered that operation to me again I'd say yes. But it's not been suggested or anything."

f) Waiting for operation to be arranged

Two of the participants knew that they needed to have operations in the immediate future, but were waiting for these appointments to be arranged. In one case they had delayed the operation as they were concerned that it would impact on their university studies:

"I need surgery on my left eye, but I have delayed it, because I want to continue with my studies. And because I have delayed it, it's impacting me even more in my left eye."

g) Conducting own investigations

Finally, one participant reported that they had been conducting their own investigations into medical procedures for their eye condition:

> "I am starting to look at laser eye surgery, but I am not sure what that would actually do."

4 Equipment and access information

The third section of the interview schedule focused on the tools, tactics and equipment that the young people might use in relation to their vision in everyday life. Many of these questions were ones that had been used previously in the Network 1000 survey (see for example Douglas et al, 2006).

4.1 Glasses and contact lenses

Table 35: Do you wear glasses or contact lenses (this could include tints/dark glasses):

	Total (N)	Total (%)
All of the time	25	39.1%
Most of the time	4	6.3%
Some of the time	13	20.3%
Not at all	22	34.4%
Total	64	100.0%

In total, 29 (45.4%) of the participants said that they wear glasses or contact lenses 'most' or 'all of the time', whilst 22 said that they never wear glasses.

Table 36: What do you wear your glasses or contact lenses for?

	Total (N)	Total (%)
Reading at near distance	32	76.2%
Other close-up uses, e.g. sewing (not TV)	31	73.8%
Distance vision, e.g. TV, walking around	29	69.0%
To shield against bright lights/protect your eyes	23	54.8%

The most common reasons for wearing glasses were for reading at near distance (32), other close-up uses (31) or looking at things at a distance (29), whilst just over a third (23) would wear glasses to shield against bright lights or to protect their eyes.

4.2 Ways of reading

Table 37: I'd now like you to think about all the different ways in which people can read. Do you read using (tick all that are relevant):

	Total (N)	Total (%)
Ordinary print (with or without a magnifier)	42	65.6%
Large print (with or without a magnifier)	42	65.6%
Electronically (without speech output)	47	73.4%
Electronically (with speech output)	28	43.8%
Someone who reads to you	34	53.1%
Audio material	31	48.4%
E-reader	30	46.9%
Braille	18	28.1%
Other	2	3.1%

The participants were asked about the various different ways in which they access written material. The most common way reported was reading electronically, but without using additional speech software (47 or 73.4%). Over half read using print (with or without a magnifier). Other commonly reported ways included:

- having someone to read to them (34 or 53.1%);
- using audio material (31 or 48.4%);
- using an E-reader (30 or 46.9%);
- braille (18 or 28.1%).

All of the participants would be able to access written material in either print or braille. Other ways of reading suggested included using a coloured overlay and using an electronic braille display.

4.3 Use of low vision aids

Table 38: Do you use magnifiers for reading, for example, reading newspaper or magazine articles, headlines, labels or packets, your post, or instructions?

	Total (N)	Total (%)
Yes	27	42.2%
No	25	39.1%
N/A as do not read print at all	12	18.8%
Total	64	100.0%

The participants who accessed print were asked whether they ever used magnifiers for reading, with various examples of scenarios where this might be appropriate being given. Over half (27 or 52%) of those who use print said that they do use a magnifier.

Table 39: What low vision aids do you have? (For those who can read print N=52)

	Total (N)	Total (%)
Magnifier – hand held without a built in light	15	28.8%
Hand held magnifier with a built in light	11	21.2%
Binoculars – monocular or hand-held telescope	10	19.2%
Other	10	19.2%
Pocket magnifier (often used for 'outdoor' tasks such as shopping	8	15.4%
CCTV	5	9.6%
Magnifier - on a stand with light	1	1.9%
Magnifier – on a stand without light	1	1.9%
Magnifier – attached to glasses	0	0.0%
Magnifier mounted in/on glasses	0	0.0%

All 52 participants who are able to use print were asked about any low vision aids that they might have, even if they did not necessarily use them anymore. The most common type of low vision aids that the young people had were hand held ones, either with or without a light (N=11 and N=15 respectively). Other common types of low vision aids included pocket magnifiers (8) and CCTV (5). Additional examples of low vision aids that were given include:
- Electronic handheld magnifiers
- Scanner
- Line magnifier
- Magnifier on their phone
- Video magnifier

Table 40: [If do not use low vision aids] Have you ever tried using low vision aids, for example magnifying glasses, lights, telescopes or CCTVs?

	Total (N)	Total (%)
Yes	12	54.5%
No	10	45.5%
Don't know/Can't remember	0	0.0%
Total	22	100.0%

Those participants who are print users, but reported that they do not use low vision aids were asked whether they had ever used low vision aids in the past. Over 50% (12) said that they at least tried using low vision aids in the past.

The young people were asked to give more details about the low vision aids that they used or had used. Prompts asked included:
- When did you first start using them?
- Who taught you how to use them?
- How do you find using them?
- What type of things would you use your low vision aids for?
- Do you have any difficulties in using them?
- Would you use magnifiers at home?
- How about outside of the house?
- How did you find using them in school/college.

These questions were asked to all participants who reported that they had used low vision aids, even if this was not something that they would do now. The responses given to these questions are presented below.

a) First introduction to low vision aids
Thirty four of the young people who have used low vision aids were able to give some indication of how old they were when they first used low vision aids. There was quite a range of response, with one participant reporting that they first used them during pre-school, whilst another said that they did not have an opportunity to use them until they were in college.

> "Ever since I was, well, I don't know, when I first started to read I guess. I had my glasses before that. Probably about 2 I think, or 3 maybe."

Researcher: "Can you remember when you first started using your magnifier?"
Participant: "Yeah it was mid-way through my first year at college. So I'd say about January, February time."
Researcher: "Who told you about these?"
Participant: "I saw my mates with one, at college, and I just had a look and thought that this could be really helpful. So I got one."

Table 41: Approximate school setting when participant first used low vision aids

	Total (N)	Total (%)
Pre-school	1	2.9%
Primary school	15	44.1%
Secondary school	17	50.0%
College	1	2.9%
Total	34	100.0%

The table above shows the approximate school setting that the young people were in when they were first introduced to low vision aids. Half of the participants who could recall when they first used a low vision aid reported that it was when they were in secondary school, whilst just under half said it was when they were at primary school.

Table 42: Who first introduced you to low vision aids?

	Total (N)	Total (%)
Visiting Teacher Service	15	48.4%
School/SENCo	5	16.1%
Hospital/Low vision clinic	6	19.4%
Parents/carers	2	6.5%
Charity	2	6.5%
Friend	1	3.2%
Total	31	100.0%

The 31 young people who could remember who first had introduced them to low vision aids reported a wide range of sources. The most common source was through the visiting teacher service (15 or 51.7%). Other sources included:
- their school (in some cases they specifically mentioned their SENCo or being part of a specialist resource base)
- the hospital
- their parents/carers
- specialist charities

- a friend.

b) Training in use of low vision aids

Table 43: Who provided training in using low vision aids?

	Total (N)	Total (%)
Visiting Teaching Service	11	47.8%
Hospital/Low Vision Clinic	6	26.1%
SENCo/School	3	13.0%
Charity	2	8.7%
Optician	1	4.3%
Total	23	100.0%

Some of the young people spoke of training that they received when they were first given their visual aids. The following recollected receiving training:
- 11 of 15 who received their visual aids from the Visiting Teaching Service
- All 7 of those who attended a hospital/low vision clinic or who had received their visual aids through an optician
- 3 of the 5 who received their visual aids through school
- The two who received their visual aids through a charity

The only two people who were confident that they had not received any training were those who were given their low vision aids by their parents/carers.

The only participants who spoke about having an opportunity to explore low vision aids and explore which would suit their individual needs best were those who had attended low vision clinics.

Participant: "Yeah, I went to LVA training."
Researcher: "And what did that involve?"
Participant: "I think we went to the hospital, and they showed me which one was, how you worked each one, and tried to find out which one was best for me."

One participant had been given an electronic magnifier previously by her visiting teacher service, but then made the decision to visit a low vision clinic at a later date.

Participant: "The first electric one I got was, that was definitely given to me, the first one was given to me in school, that was given to me at first year GCSE. And then about a year ago, I got an updated one. That one we found ourselves."
Researcher: "Were you ever taught how to use the magnifiers?"
Participant: "First I was shown briefly by the person who gave it to me. The second one we went to an open day sort of thing and they had tutorials to see what would be best, and it was going through that that I picked one. A person helped me seeing how it worked, to see which one would be best. That was my optelec."

c) Participants' experiences of using low vision aids

Table 44: Summary of how the participants report finding using low vision aids (N=52)

	Total (N)	Total (%)
Opinions – Overall positive	15	28.8%
Opinions – Overall negative	7	13.5%
Opinions – Do not need LVAs	10	19.2%
Difficulties – Impractical	12	23.1%
Difficulties – Too slow/hard to maintain pace needed	4	7.7%
Difficulties – Lighting	3	5.8%
Difficulties – Hard to use	3	5.8%
Difficulties – Eye strain	2	3.8%

The young people were also given an opportunity to share their thoughts on low vision aids. These responses have been investigated for themes. These general themes are presented in the table above, and then discussed in more length below.

Overall position opinions
Fifteen of the participants in their responses indicated that overall they viewed low vision aids positively.

Two shared that although sometimes they may experience challenges in using them, for example feeling self-conscious, they saw them as beneficial.

"At primary school I found it a bit embarrassing because I wasn't the same as everyone else, and I had to use the big magnifiers to see everything, it was a bit embarrassing then, but as I got older, I just got used to it, I know I need them. At school I would try not to

use them, I was struggling then, and I'd make myself struggle just so I didn't have to use the magnifying glass or whatever I needed to use, but now I just don't bother struggling, I know that I need it, I am just hurting myself if I don't use them. It's better for me if I do use them, use the magnifying glasses and things, whatever I need, I use it."

In one case some of the low vision aids that they had been given were not particularly helpful for the young person, but they did have at least one low vision aid which was.

"Fine. Some were more helpful than others. The domes were less helpful. You can't find a line or whatever. The CCTV things were helpful."

Others gave responses which demonstrated that they valued visual aids and would regularly use them:

"They are ok now, but when I first got one, when I was in Year 9, they were big and ugly, but now they are a bit more discrete, I don't mind using them at all."

"I think they helped me quite a lot. I think I would have struggled a lot more without them, because that was the time that we were introduced to the fact that we would be doing a lot of reading. And there wasn't, because it was books and things like that, it was difficult to enlarge them or anything like that."

Overall negative opinions

Seven of the participants expressed negative feelings towards low vision aids, and in one case quite passionately so:

"Magnifiers are the worst things that have ever been invented. They're just… Cos you're focusing on one part and by the time you've got to the next part you miss half a line and you miss these bits and these bits. It's just absolute hell!"

Three participants described how they felt that low vision aids had been imposed on them by professionals:

Researcher: "Have you ever had any kind of low vision aids at all?" Participant: "Yes I have. I was the age where I really had no grounds to oppose it."

"Like, do you know at school you have a SENCo, a special needs person? And the last one we had she was very, she looked at visual impairment in a very old fashioned way, she had the idea that every single visually impaired person can use the same things, and when I tried to explain to her that I can't, she got a bit, you know, she tried to give me like hand hold CCTVs and magnifiers, and I said to her it's not working… so yes, I have had people, I think it's a way of cutting corners, because it means you don't have to enlarge every single thing, then it's my job to kind of remember the magnifiers and stuff, but it just doesn't work."

"Yeah, it was my choice, despite a lot of different people telling me what I should be using, and why I should be using it, so actually ultimately, they didn't really know. Sometimes they think they were being really helpful, but they were being more of a hindrance, because they weren't letting me cope in my own way."

In three cases the main cause of negativity was the young person feeling self-conscious in using them:

"Like a magnifying glass? I don't feel comfortable with that at all. Because with a magnifying glass, it just feels awkward to be honest. If I have a magnifying glass, everyone could be watching, so it feels really bad. "

Do not feel that they need Low Vision Aids
Ten of the participants who had previously used low vision aids had made the decision that they did not benefit from using them:

"I never used them at all. I didn't need them at all. I used them like once, that was a dictionary, a very small dictionary."

In one case this was because the young person's eyesight had changed and therefore they did not have the same needs as before:

"At the time it was when my eyesight went quite bad. It could change from day to day from really good vision to really not very good vision at all. So having that there was really good. I didn't really use it after year 10 because they started stabilising it up."

Two participants were given reading glasses which made the use of low vision aids redundant:

Researcher: "Could you see magnifiers or low vision aids having any use for you now?"
Participant: "Yeah if I didn't have my reading glasses."

A further two participants would no longer use low vision aids now that their circumstances have changed:

Researcher: "These days would you use your low vision aids?"
Participant: "No. There's not much text, so there's no real need for them really."

Participant: "Yeah, but I don't really need them anymore."
Researcher: "What makes you say that?"
Participant: "Everything these days practically is electronically."

Difficulties – Impractical
When discussing difficulties that they may have faced when using low vision aids, twelve participants identified ways in which the low vision aids have been impractical.

Nine participants considered the low vision aids that they had been given or used in the past not to be fit for purpose:

"I've got a small electronic magnifier, I've just remembered that I've got the camera one. It's ok if I've actually got the time and it will change my background for me. But it's not very good cos it can't go into the very corners of the spines."

"I used to have one with a built in light, about 6 months ago, but that wasn't really good enough, because it was quite a small one, so it was really hard to read."

"With handheld magnifiers it's a bit uncomfortable to read standard print books because it's a lot of strain on the arms, because I basically have to have them pressed against my face for an hour. So it's quite tedious and strenuous."

Six participants reported that the low vision aids that they had used were too large for them to be able to use. This included large low vision aids being difficult to use in a school context where they would be constantly moving between classrooms, and equipment that was difficult to use because of the way it had been designed.

"Yeah. I had a CCTV, but it's really big and bulky, so I had to leave the lesson to go and use it, and it just means me missing out on too much."

"It did get annoying sometimes cos it was big and you had to move it across."

"Yeah cos I do find that small magnifiers are unhelpful. Cos they have great big grips. "

"Well it was quite big. It got in the way if I had to write things down."

Difficulties – Too slow or hard to maintain the pace needed

Five participants reported that they found reading with low vision aids too slow and in some cases they would struggle to maintain the pace that was needed:

"It wasn't efficient. I was reading one line and they were reading three lines."

"I'd struggle at times because we used to be reading in a class, when I was in primary school I would be following along with a magnifying glass, and it'd just slow me down, and I'd always lose where I am. Where everyone else was."

Difficulties – Lighting

Three of the participants found using magnifiers difficulty because it affected the lighting on what they were trying to read:

"No. It's just… because I need a lot of light to read stuff, so if I magnify the paper, then the light is going down on the magnifier and then it's like reflecting back at you, so you've got all the light all spotted on the magnifier, so I can't actually see using it."

Difficulties – Hard to use

Three participants described other ways in which they find low vision aids difficult to use in particular circumstances:

"Tried to use monocular when train travelling but when you're trying to look at the departure boards at train stations like Paddington it's extremely difficult. I don't find it very helpful unless I get very close to it. I have tried using it but I haven't had that many

opportunities to try, to properly test it. I haven't been travelling that much but I do occasionally."

"They can be, at times, quite annoying really, to get the right magnification on them, and hold it at that distance, to then carry on reading, you can lose your place quite easily"

"It's still not perfect, because it's still a bit fiddly with trying to write and read with the magnifier at the same time, it needs a lot of juggling around, but it's really better than nothing, so it's fine."

Difficulties – Eye strain

The final difficulty identified by two of the participants was that of eye strain:

"When I use a magnifier, my eyes start running."

Researcher: "And do you have any difficulties in using them?"
Participant: "A little bit, because I find I strain my eyes quite a lot."

When reviewing the difficulties that they young people have had when using low vision aids, particularly in the context of how few participants recalled having opportunities to experiment with the different types of aids available, it does raise the question of whether the young people who have had difficulties with using low vision aids have been prescribed with the most appropriate aid for them. For example, one participant reported having difficulties with using a hedgehog magnifier due to lighting, but since attending a low vision aid clinic, they now regularly use an electronic magnifier.

"I used to just have this thing called a hedgehog, which was a block of magnifying glass. But that one got difficult to use, because you need the right light for it. So now I use an electric handheld magnifier, and that I take with me most places."

Alternative adjustments to using low vision aids

Eleven of the young people in discussing their use of low vision aids identified other adjustments that they or others could make that they felt would make low vision aids redundant.

Seven spoke of accessing material electronically:

Researcher: "So how did you come that you stopped using them? Was it a gradual thing?"

Participant: "I think it was my transition into going into IT, I think, it just became less and less needed."

Participant: "No, the only thing that I find useful is like on my iPad, I can make the text really big when I am reading, so that kind of reduces the risk of eye strain. Pretty much just using normal everyday technology to my advantage, rather than take this special stuff."

Five spoke of getting material enlarged instead:

"I only used it a couple of times. It is good, but everything is enlarged anyway, so I didn't need to use it."

"No, not often, because I have gone for more the large print copies instead of magnifiers."

d) Uses of low vision aids
The young people were also encouraged to share some of the ways in which they would use low vision aids, both now and in the past. These are presented in the table below:

Table 45: Ways in which young people would use low vision aids

	Total (N)
Reading a large block of text (e.g. newspaper or book)	15
Cooking	4
Using mobile phone	4
Reading labels	4
Using buses (reading timetables, and looking at bus numbers at a distance)	3
Watching a show/sport	2
Reading maps	2

The most common way in which the young people would use their low vision aids would be for reading large portions of text. This would include books, newspapers and magazines. Other uses included:
- Cooking (reading food packets or recipe books)
- Reading text on their mobile phone
- Reading labels (e.g. medicine packaging or the back of DVDs)

- Using buses (reading timetables and looking at bus numbers at a distance)
- Watching a show or sport match
- Reading maps

4.4 Low vision aids and preferred reading format

Table 46: 'Do you use magnifiers for reading, for example, reading newspaper or magazine articles, headlines, labels or packets, your post, or instructions' against preferred font size

	Yes - Total (N)	Yes - Total (%)
Normal to large print (12-17 point)	13 (of 33)	39.4%
Large print (18-27 point)	10 (of 13)	76.9%
Very large print (≥ 28 point)	3 (of 5)	60.0%

As one would expect, use of low vision aids tended to increase as participant preferred font size increased. However, it is interesting to note that five of the young people who fell in either the 'large print' or 'very large print' categories do not use magnifiers, when it could be anticipated that they would benefit from using them. The experiences of these five in using magnifiers, and low vision aids in general, are presented below in the form of five short case studies.

Participant 1:

Participant 1 has vision loss as the result of brain tumour, and did not know if she has been registered as having a sight loss. She has a preferred format of 20 point and was educated in a mainstream setting. This participant reported that they would sometimes get eye strain as a result of reading, which meant she had to stop. She did use low vision aids in the past, but no longer does so as teachers now enlarge any written material for her instead. Her prior experience was with an electronic magnifier which she described as "like a camera that plugs into your laptop and you look through it on to your laptop". She described having difficulties with the magnifier being too large to use practically in the classroom: "well it was quite big. It got in the way if I had to write things down." This magnifier was only available to her when at school, and she did not have any magnifiers at home. When asked how she would read something in small print at home, she replied: "Erm if it's on a computer I usually copy and paste it on to word and make it bigger, or I hold it quite close to my eyes, and hold it under lights as well so I can see".

Participant 2:

Participant 2 has a severe visual impairment as the result of a genetic condition, and is registered as blind. Until recently he has attended a special school for students with visual impairments. He would primarily use a combination of braille and electronic material, but has sufficient vision to be able to read documents in 36 point. Whilst he would class himself as someone who does not use low vision aids, he does have an electronic magnifier that he uses in particular situations, and he does find this useful. His responses demonstrate a degree of consideration to the pros and cons of using low vision aids, and when it is appropriate to use them or not: "I'm a fan, but they have got a time and place. You can't use them when you are out and about… If you are on a train and you are reading a document with a low vision aid, that's fine. If you are on a train and you are reading something that they have got on the tea trolley with a low vision aid, then I think you are going to get a few looks. I have always said this, blind people wonder why sighted people are so dismissive of them, but then they don't ask questions of sighted people. It's stupid!"

Participant 3:

Participant 3 is registered as partially sighted and has a visual impairment as a result of genetic eye condition. She has a preferred reading format of 18. She would quite often struggle with eye strain, and would attribute this to overworking her eyes: "If basically I overwork them, then they don't like it. So it's if I overwork them in any regard. Which is why low vision aids and CCTVs don't really work, because it's still… I am still looking at a computer screen." She would never use low vision aids, having tried using them previously after being encouraged to do so by her school SENCo, but then concluding that they were not suitable for her. She saw the school asking her to use low vision aids, rather than enlarged material as a way of them 'cutting corners': "I think it's a way of cutting corners, because it means you don't have to enlarge every single thing, then it's my job to kind of remember the magnifiers and stuff, but it just doesn't work".

Participant 4:

Participant 4 is unsure whether he is registered as partially sighted or not, but is confident that he would be eligible to be registered. His visual impairment is caused as a result of retinitis pigmentosa, and he request written material ranging from 24-32 point. He no longer uses low vision aids, but did use a dome magnifier and monocular in the past. These low vision aids were given to him by his visiting teacher

service who also took the time to show him how to use them. The participant recalls them as being very useful and could think of several examples of how he would have used them in school: "I remember the dome magnifier came very useful during geography for map reading. History class with some of captions below things. Things like that really. Books from the library. Things like that really. I used it quite a lot actually." He reports stopping using low vision aids as the result of his transition into IT, and therefore (he concluded) not needing them anymore. Important written documentation these days he would choose to access electronically "I tend to get things mostly electronically anyway. My internet bills, my phone bill, all come electronically, for my own benefit really." In recent situations where he has needed a magnification tool, he has made use of a magnification app installed on his iPhone: "I do have a magnifier app actually, I used it the other day. I broke the key in my desk drawer at work so I had to read the encryption on the lock to the guy on the phone, and I thought 'how am I going to read that?!' I had an app handy, so I used that."

Participant 5:

Participant 5 is registered as partially sighted. Her vision problems are as a result of albinism, and she has a preferred reading format of 18-20 point Arial. She has tried using magnifiers in the past, and has not had a very good experience, as reflected in her evaluation of them: "Magnifiers are the worst things that have ever been invented!" Her dislike towards magnifiers comes from a negative experience at school: "I used to have a monocular but by the time I'd focused it and adjusted it so I can see we're on to the next powerpoint – so I'm just lacking behind." Instead of using a monocular in college, she now has a laptop in lessons and follows the powerpoint on that.

4.5   Accessing written documents

The young people were asked the question "if you were to receive written documents to read, what font size would you request". They were also asked to differentiate between the font size they would request if they were using low vision aids, and what they would request if not.

The responses given to this question are presented in the tables below. In some cases the young people gave a range of font sizes (e.g. size 14-16). In these instances the largest font size that they gave was recorded.

Table 47: If you were to receive written documents to read, what font size would you request if you were not using any low vision aids?

Font size	Total (N)	Total (%)
Standard to large print (12-17 point)	33	51.6%
Large print (18-27 point)	13	20.3%
Very large print (≥ 28 point)	5	7.8%
Unsure – rarely accesses print	1	1.6%
Not applicable – would not access print	12	18.8%
Total	64	100.0%

Just over half of the participants (33) would request standard to large print, whilst 13 would request large print and 5 very large print (one of whom would need to use 72 point). Twelve of the participants are braille users and would never access print.

Table 48: If you were to receive written documents to read, what font size would you request if you were using any low vision aids?

Font size	Total (N)	Total (%)
Standard to large print (12-17 point)	14	21.9%
Large print (18-27 point)	1	1.6%
Very large print (≥ 28 point)	2	3.1%
Unsure – rarely accesses print	1	1.6%
Not applicable – would not use a LVA	34	53.1%
Not applicable – would not access print	12	18.8%
Total	64	100.0%

The table above shows the preferred font size for 17 of the young people who would regularly use low vision aids to assist them in accessing written material. Despite using low vision aids, two participants would still need to request 'very large print' with one participant needing size 36 font (compared to 72 font if they were not to use a LVA)) and another needing size 28 (compared to 36 font if they were not to use a LVA)

Table 49: How do you communicate in writing with sighted people? (N=64)

	Total (N)	Total (%)
Pen (writing)	41	64.1%
Electronic document (e.g. word/PDF)	61	95.3%
Email	62	96.9%
Social media	58	90.6%
Text message	62	96.9%
Some other way	5	7.8%

The young people were asked how they would communicate in writing with sighted people, and a variety of options were given, in the order presented above. The most common ways were via some form of electronic communication, such as email (62), text message (62), electronic document (61) and social media (58). Forty one of the participants would communicate through handwritten notes. Included in those who would not were those who would not use print, and also some who said that their handwriting was not good enough for them to be understood by others.

Other ways mentioned were:
- Writing on iPhone with text set to large
- Typing things up and then printing them off
- Using various apps on their mobile phone, such as Whatsapp
- Writing on a whiteboard
- Asking parents to write it

4.6 Accessing IT

4.6.1 Preferred ways of accessing computers

Table 50: In what ways are you able to access a computer? (N=64)

	Total (N)	Total (%)
Computer with no adjustments	35	54.7%
Computer with basic adjustments (e.g. enlarged icons; mouse pointer)	29	45.3%
Computer with specialist magnification software	22	34.4%
Computer with specialist speech software	20	31.3%
Computer with specialist speech and magnification software	6	9.4%

Other	19	29.7%

The participants were asked about the various ways in which they would be able to access a computer, and given a variety of suggestions as shown in the table above. The most common ways would be using a computer with no adjustments made to it at all (35 or 54.7%) or a computer with basic adjustments (29 or 45.3%). Twenty two (34.4%) would know how to use specialist magnification software whilst 20 (31.3%) would be able to use specialist speech software. Using specialist combined speech and magnification software was the least common amongst the participants with just six (9.4%) saying that they would be able to access a computer this way.

Other ways that the young people suggested that would access a computer included:
- Using an Apple Mac which has an inbuilt screen reader and magnification
- Using a braille display
- Using dictation software
- Using Windows which has an inbuilt magnifier
- A specialist mouse with inbuilt magnification software

Table 51: In what way would you prefer to access a computer?

	Total (N)	Total (%)
Computer with no adjustments	18	29.0%
Computer with basic adjustments (e.g. enlarged icons; mouse pointer)	15	24.2%
Computer with specialist speech software	7	11.3%
Computer with specialist magnification software	6	9.7%
Apple Mac inbuilt magnification and/or speech	6	9.7%
Computer with specialist speech and magnification software	4	6.5%
Combination of braille display and keyboard	2	3.2%
Combination of magnification software and basic adjustments	1	1.6%
Using dictation software	1	1.6%
Using a specialist mouse with magnification software	1	1.6%
Using a Windows magnifier	1	1.6%

Total	62	100.0%

The young people were then asked what their preferred way in which to access a computer was. The most common ways were through either a computer with no adjustments (18 or 29.0%), or a computer with some basic adjustments (15 or 24.6%). Six (9.8%) would use specialist magnification software, six (9.8%) would use specialist speech software and four (6.6%) would use combined specialist speech and magnification software. Participants also identified several other preferred methods in addition to those suggested to them. These included Apple Mac using inbuilt magnification and/or speech (6), a combination of magnification software and basic adjustments (1), using dictation software (1), using a specialist mouse with magnification software (1), using Windows magnifier (1) and using a combination of braille display and keyboard (2).

The young people were encouraged to talk more about their experiences in accessing computers, any training that they had received in the past, and any adjustments that they would make. These responses were coded according to themes and these themes are discussed below. Whilst the discussions were quite varied, it was interesting to look at the differing elements that the young people chose to highlight in their responses.

4.6.2 Basic adjustments participants would make to access computers

Those young people who would access the computer by making some basic adjustments were encouraged to talk about the type of adjustments that they would make. Examples were given by 22 of the participants and are summarised in the table below, then explained in more depth.

Table 52: Basic adjustments to make computers more accessible (N=22)

	Total (N)	Total (%)
Changing the font size	10	45.5%
Zooming in on document	6	27.3%
Changing the mouse pointer	5	22.7%
Enlarging icons	5	22.%
Changing screen resolution	4	18.2%
Changing contrast	4	18.2%
Organising PC with their unique settings	3	13.6%

The most common basic adjustment would be to change the font size of the document that they were working on, or to go into the computer settings and change the default text size to large, to ensure that the text on features like the start menu were as large as possible. This is something that would be done by ten of the participants (45.5% of those who would make basic adjustments).

> "I like to make the font bigger. Whenever someone asks me to do something at work, I will make the font bigger on their computer, just for a second."

> "Sometimes making like the font larger so I can, I don't have to focus as hard when I change my vision."

Six of the participants (27.3%) would choose to zoom in on documents or web pages to make it easier for them to see:

> "I go on Ebay a lot but there's like a thing you just click on it, to go and do it bigger. Cos if it's real small print you can hardly read it, you'd have to zoom in and then scroll across to see it, I just click on that and it just brings it up on the whole page. That's for ordinary people so…!"

Five participants (22.7%) would make changes to the appearance of the mouse pointer, to make it easier for them to locate it when needed:

> "Yeah, make the pointer as big as possible, and dark so that when it goes onto a white page it stands out. When I press the control button there's a light that flashes around the pointer so I know where it is."

Five participants (22.7%) would enlarge icons on the desktop to make it easier for them to locate any programs/options they may need:

> "Definitely make the icons larger so that I can see what they are."

Four participants (18.2%) would change the screen resolution to make everything on the computer appear bigger:

> "I turn the screen resolution to 600 x 900 I think it is. Basically it makes things a bit bigger."

Four participants (18.2%) would alter the contrast on the screen to make it easier for them to see:

> "In the past I have changed the contrast settings. Like I say, I think it flicked it to negative I think, which was quite easy to see."

Finally three participants (13.6%) spoke of different ways in which they may organise their computer to make it easier for them to use. In two cases this involved ensuring some kind of order that they could follow on the computer so they could locate things easier, and in the third case this involved getting their computer to remember internet passwords and settings on websites they would regularly use, to make it a smoother process for them.

4.6.3 Specialist software used by participants

The participants who use specialist software were asked to talk about which type of specialist software they use. The responses from 26 participants are presented in the table below.

Table 53: Name of specialist software used (N=26)

	Total (N)	Total (%)
Jaws	11	42.3%
Zoomtext	8	30.8%
Supernova	6	23.1%
NVDA	1	3.8%

Three main types of specialist software were used by the participants. These were Jaws (a screen reader), Zoomtext (magnification software) and Supernova (speech and magnification. One participant said that they would use NVDA on their home PC. This is a free screen reader, which is similar to Jaws.

Something which has been apparent when speaking with the young people about their use of specialist software is that over the past few years they had tried using a variety of different versions of specialist software (the table above shows the software which they currently use). This serves two important reminders. Firstly, specialist software is constantly evolving, with new versions regularly being launched, so it is important that information is readily available to help users of accessibility software be able to make informed decisions. Secondly, it may take some learning time and experimentation before users find a specialist software which they are happy in using. For example, one

participant had been taught to use Supernova, but was struggling with how compatible it was with the programmes that he wanted to use. Instead he decided to teach himself to use Jaws, and found that he got on much better with it.

4.6.4 Other adjustments participants would use to access computers

Table 54: Other ways of accessing computers

	Total (N)
Voiceover/Magnification on Apple Mac	8
Mouse magnifier	4
Windows magnifier	2

The most common alternative way of accessing a computer that the participants identified, was using the inbuilt magnification or voiceover options which are available on Apple Mac computers. Instead of having to install specialist software on the computer, these are built into the computer's operating system. These options are used by eight of the participants. Similarly Windows has its own version of inbuilt magnification, called Windows magnifier. This was used by two of the participants. Finally, four of the participants described how they would use a specialist mouse. This mouse once connected to a computer has magnification software built into it, which automatically start when plugged into a computer's USB port.

4.6.5 Training received for accessing computers

The participants were also asked about any training that they may have received in the past to help them in accessing computers – whether that be in terms of using specialist software, or being shown how to make the basic adjustments that some had identified.

Many of the participants had received some form of training, or at least a basic introduction to thinking about making computers more accessible. This training came from a variety of sources, as shown in the table below:

Table 55: Sources of training

Source	Total (N)
Visual Impairment Support Service	16
School	11
Parents/Carers	5
DSA	4
Friends	3

The most common source of training identified by the young people was through their visual impairment support service, with 16 of the participants recalling having training at some point through their school careers. One participant who is registered blind, and a screen reader user spoke of how she really benefited from having training at an early age:

> "The local education authority when I was 5. I was lucky – they started it all very early. I could already read braille when I started school. I could read grade 1 so that made things a lot quicker I only had to learn grade 2 when I was at primary school. So then I learnt grade 2 but I learnt to use a laptop at the same time, and I did touch typing and stuff like that. So I finished all of that – the braille and the touch typing when I was 7. Then through the rest of primary school I used braille for most things but occasionally a laptop if we were going on the internet. Stuff like that."

Touch typing tuition which was often delivered by representatives from the visual impairment support service, was something which 15 of the participants reported having had in the past:

> Researcher: "What about one of the teachers from the resource base, did they ever sit down and help you with using a computer, or check that you knew what you were doing? "
> Participant: "A few years ago somebody, one of the new ones sat down with me and taught me touch typing. She took me out of a lesson of my choice, and we did touch typing every week until I learnt it."
> Researcher: "How did you find that?"
> Participant: "It was alright, it was hard at first, but I picked it up, and now I can type really quickly."
> Researcher: "So worthwhile then?"
> Participant: "Yeah, very beneficial."

Eleven of the participants reported having received training through their school. In some cases this was because they were attending a specialist school, which was equipped to provide training in specialist accessibility software, whilst in other cases the participants were picking up useful ways of adjusting their computer through their standard IT classes.

> "I don't think anyone really showed me. I think it was just what you learn when you do your ICT lessons at school. They just show you and it just sticks in your head really. As I said before I just try and change it myself."

> Participant: "So when we first got our laptops at school, that was Year 7, so I would have received in ICT lessons, which were standard in the school curriculum, they would have given us IT training there and then. They would teach us some short cut keys and the ins and outs of the software that we were using. So really at that stage I would have learnt to use it."
> Researcher: "Who taught you how to use Supernova?"
> Participant: "So again it would have been in those IT lessons. Once you get used to using it for a few weeks, you do get very used to it, and have little problems using it."

Five participants said that they had had some form of training through their parents/carers or at least something which had been arranged through their parents.

> Researcher: "And did they offer you, or did someone from the visual impairment service, offer you any guidance for using computers?"
> Participant: No, I didn't really need it, because my dad showed me that when I was really young, so I didn't see I needed it.

> Researcher: "The software that you have got who introduced you to it?"
> Participant: "That was my uncle. Cos he's good on computers. He's got mates, so if he can get me a copy of it he will, to try. He introduces quite a lot to me."
> Researcher: "Has [your visual impairment support service] ever provided any software like that?"
> Participant: "No... Basically their attitude is, you want it, you go and get it."
> Researcher: "So you've never had any formal training on it?"

Participant: No. It's always been a case of, either I learned to do it myself, or I don't learn it at all.

It is interesting that the two participants quoted above, who have received training through family members but not through their visual impairment support services, are both quite dismissive of using specialist accessibility software. Whilst speculative, it is possible that they may well benefit from using such software, but have been introduced to software by people who are not qualified to do so, which has put them off using accessibility software in general.

Four participants spoke of training which they had received as a result of their Disability Support Allowance.

Researcher: "This Zoomtext that you have got, was that part of your DSA?"
Participant: "Yes."
Researcher: "And you got training for using that?"
Participant: "Yes."
Researcher: "And how did you find that training?"
Participant: "Useful, yep, very useful."

A final source of more informal training that three of the young people (who were in special school/college) received, was through their friends:

Participant: "That was with, because by then obviously I had met a lot more people who were visually impaired, so then I could talk to them about what they used, and I got a bit more of an overview about what things were and what they could do, and a bit of a comparison."
Researcher: "So was that more talking to peers then?"
Participant: "Yeah, to be fair, I don't think I have had any official training in anything."

Self-taught or no training
Eleven of the participants described how they were self-taught in either making adjustments on the computer, or in the specialist software that they use. In the case of the specialist software, it would often be the case that they had been taught to use a different version of accessibility software in the past, but had made the decision that they wanted to make the transition to using a different type instead. There were also seven participants who said that they had never received any specific training.

Researcher: Can you recall if you had any tuition in using it?
Participant: No, I didn't. I just worked it out for myself.

"No, I downloaded training manuals in audio book form, read by the voice I was actually going to be using, so it was quite beneficial to obviously get used to how he spoke, and then I just learnt how to use the Mac from there. It was a massive in depth tutorial, so I just learnt to use it from there, and when I got the Mac for the first time, I just picked it up and immediately knew how to use it because I had listened to them over and over and over again."

One particularly interesting example of a young person who is self-taught, is a participant, who not only taught themselves to use accessibility software he also taught himself how to see a computer. His experiences are presented in the form of a short case-study below:

Participant 1

Participant 1 is registered blind (severely sight impaired), and has been since birth. He is not sure of the nature of his eye condition, but describes only having light perception. He was educated in a mainstream secondary school with an attached resource base for pupils with vision impairment. He reported that the resource base that he attended did not teach him how to use a computer. Instead in order to use a computer he learned independently:

"I had to teach myself everything about IT. I had no help from school... Because my school say 'oh you don't need computers, there's no way blind people can access computers', so they just kept the braille machine."

The participant was asked to explain how he went about learning how to use a computer, and he responded with the following account:

"I was 14 and I didn't have a laptop until I was 14. And then I got a message from my friend, and she was saying you should get this programme which is designed for blind. You don't even need a screen reader, it has its own built in speech, so I got my brother to download it me. And it's like a social networking for the blind. So I met a lot of people from there, and they told me about NVDA [a free screen reader], so I downloaded it. I didn't know how on earth to use a computer, didn't even know about the start menu, or how to type, and they all taught me. I went from that social networking site, I got Twitter,

> Facebook and everything. Microsoft Word, I had to learn. So basically it's all them and me slowly getting used to it."

Whilst it is encouraging that this young person felt confident enough to teach himself how to use accessibility software, not all young people will feel capable to do so, or make the necessary contacts to guide them. Whilst we made it clear in the introduction to this report that caution should be made in generalising these findings, it is quite possible that this young person's experiences at school are not unique.

Similarly, it is also important to consider the quality of the young person's learning experience, particularly when they have been self-taught. This can be highlighted in the following short case-study.

Participant 2:

> Participant 2 is registered as blind and has a genetic condition which causes her visual impairment. She has some light perception and would only be able to see the shapes of furniture in a room. Therefore in using a computer it is necessary for her to use some form of speech software. Over the years, as her level of vision has changed, she has learned to use a variety of types of accessibility software.
>
> "I started off with Zoomtext, and then I went onto Hal from Dolphin… It was bought for me at school was through my Statement, but it wasn't very easy to use, I couldn't use it very effectively, because it was a magnifier as well, and the speech wasn't good on it, it kept breaking and stuff. So I got NVDA myself, because it was free and you could just download it off the internet."
>
> At 16 she moved to a special school/college, and was given a copy of the screen reader Jaws. Whilst she had received training in other accessibility software in the past, she never received further training in using specialist speech software whilst at school:
>
> Researcher: "So in terms of using the actual speech side of specialist software, have you ever had any tuition in doing so?"
> Participant: "Er. No! Now that I think about it! Not until this year when I got DSA, and I got training through DSA. Until then, no".
>
> For this participant, receiving training through her DSA made her realise that her experience in using Jaws until that point had not been ideal:

"Yeah, I mean, I have only had six hours of training with Jaws. I didn't have any training with it when I went to [name of school/college removed]. The only way I sort of learnt to use it was sort of through fellow students, and picking up things from other people, so… When I had my training session from DSA, I found I kind of realised quite a lot, but at the same time, I don't know very much if you know what I mean! Like I know quite a lot for the fact that I never had any training, but in terms of everything that Jaws has to offer, I know very little, realistically… The trainer was like 'do you know how to do this?' and I was like 'yeah, yeah', and then she would go 'oh, so you know how to do that?', and I was like 'nooo!' So a lot of stuff I worked out how to do, but in a very sort of long-winded way most of the time, going around the world, doing something that I could do with two strokes of the keyboard, you know. So its shortcuts, stuff like that."

For this particular participant, speech software is her main medium for reading when at university, and therefore it is concerning that she had such gaps in her skills and knowledge when moving to university. It is encouraging that these gaps are now being met through her Disabled Student Allowance provisions. However, not all young people will attend university, or if they were to go, apply for Disabled Student Allowance. Universities might also expect these skills to be in place before the student arrives. This example shows it is quite possible that young people could leave compulsory education without these core skills that they will need to be competitive in the labour market.

4.6.6 Confidence in using specialist accessibility software

Those participants who use or had used specialist accessibility software were asked how confident they felt in using it.

Table 56: How confident do you feel in using specialist accessibility software?

	Total (N)	Total (%)
Very confident	14	37.8%
Confident	18	48.6%
Not very confident	4	10.8%
Not at all confident	1	2.7%
Unsure	0	0.0%
Total	37	100.0%

Of the 37 participants who had said that they had used specialist accessibility software in the past, 32 or 86.5% said that they felt either

'very confident' or 'confident' in using it, whilst there were four participants (10.8%) who were 'not very confident' and one who was 'not at all confident'.

Follow up questions were asked to this, dependant on the nature of the participants reply. Those who had indicated that they were confident in using accessibility software were asked "What has helped you in improving your confidence" and those who indicated that they were not confident were asked "What has restricted you in gaining confidence".

Table 57: What has helped you in improving your confidence?

	Total (N)
Practice	20
Training	5
Other people with visual impairments	4
Being confident in general with computers	1
Being confident in the software	1

The most common reason given for improved confidence in using specialist accessibility software was practice, as identified by 20 of the participants. For many it was a case that they have now been using accessibility software over a number of years and it's become like "second nature". For others it was important to them that they were put in situations where they needed to learn to use the specialist software, and over time this has helped to improve their confidence.

> "I think from just starting from such a young age. It's just so normal to me like, I can't remember not knowing how to use a computer. Cos I started that young, it's not something that I really remember having to learn."

> "Having to use it basically for my work, in all my lessons I think, being in a situation where you have got to use it, you haven't got a choice, you know."

> "Using it so many times. It's practically second nature."

Training was mentioned by five of the participants. This tended to be in conjunction with an opportunity to then practice using the software:

> "Probably just being shown what to do at first, and then practicing it."

Four of the participants felt that they benefited from having the support of other people with visual impairments, who they could look to if needed:

> "Other people using it as well, so if I get stuck, I know there's always people to help"

> "Other VI students, because, when I first got Jaws, it was completely new to me, and even though I had used a screen reader NVDA before, the way they sort of work, its only from picking up things from other people and using it all the time, and playing around with it, you know, trying things out, is how I learned to use it. So practice makes perfect I guess."

Finally, one participant attributed his confidence in using accessibility software to a general confidence in using computers, whilst another reported being confident because he had faith in the software that he was using (particularly in comparison to one that he had used previously).

Table 58: What has restricted you in gaining confidence?

	Total (N)
Do not see a need to improve confidence	1
Being resistant to using it	1
General lack in confidence	1
No training	1
No confidence in the software	1
Not understanding the screen layout	1

The reasons given by the participants for why they thought they had been restricted in gaining confidence were a lot more specific to the individual. One participant when asked if there was anything that could help him in gaining confidence to use it replied "Not really, because I don't really need to, you know. I know how to use it for what I need to use it with. So, I don't really need to use it" demonstrating that whilst he felt he was lacking in confidence, he did not see a need to rectify this. Another participant described how she had been resistant to using accessibility software, and recognised herself as being a barrier:

> "It's myself, because I haven't liked the programs."

A third participant saw his lack in confidence in using accessibility software as part of his more general lack in confidence:

"I don't know. I am not a very confident person, normally. It's just difficult."

A further participant felt restricted due to a lack of training:

"It's not easy. I have no training so I don't know what I am doing."

And another struggled with the fact that he could not visualise how things are arranged on, for example a webpage, to be able to navigate through it:

"I am getting slightly better, and I can now use websites more easily, but I still don't really understand the structure of the internet, the structure of how when you go into a google search, how the websites come up. I keep going into things that, I go into some of the first ones, I look at the first set they give you, when probably I could go into other sets, but I have no idea how to get into those sets that they give you. I may as well go into one that is the first one, because that way that one looks ok. But actually it turns out they are just trying to sell me something, rather than look at information about it. So, sometimes it's a bit confusing, and I think that's why I am a bit unconfident about it."

Finally, one participant's lack of confidence was caused by not being confident in how well the software he used was going to function:

"I think in terms of restrictions Supernova which is the software that we use at the moment, it does cause a lot of issues. It does crash a lot and there are a few issues with it. But at school there is a technician service so we can go to them with any problems we have regarding our laptops and Supernova and they can just sort it out for us usually."

4.6.7   Using mainstream technology

The young people were asked a number of questions about any mainstream technology that they might use. By mainstream technology we are referring to devices which are available to the general public, and not ones which are specifically for people with disabilities. Firstly the young people were asked:

We are interested in any other electronic devices that you may use and what you might use them for. Examples could include, but not

exclusively, tablet computers, E-readers, mobility phones/smartphones. Could you tell us more about any devices you use that might be relevant and also what you would use them for?

Table 59: Electronic devices that the young people would use (N=62)

	Total (N)	Total (%)
Mobile phone	62	100.0%
Tablet computer	27	43.5%
E-reader	7	11.3%
MP3 player/iPod	4	6.5%

All of the 62 participants who answered this question would use a mobile phone, whilst approaching half (27) would use a tablet computer. E-readers are also relatively popular, and used by 7 of the participants, whilst 4 participants use a MP3 player/iPod.

Table 60: Type of mobile phone that the young people would use

	Total (N)	Total (%)
iPhone	33	53.2%
Samsung Smartphones	12	19.4%
Other/Unspecified	14	22.6%
HTC Smartphone	3	4.8%
Total	62	100.0%

Over half of the 62 participants use iPhones, whilst 12 would use Samsung smartphones and 3 would use HTC smartphones. Fourteen of the participants either did not disclose the type of mobile phone they use, or would use some other type of mobile phone, including Nokia, Blackberry and Motorola.

Table 61: What participants use mobile phones for (N=62)

	Total (N)
Texting	37
Phone calls	29
Social networking	22
Internet	18
Games	8
Email	7
Music	7
Camera	5
Audio books	4
Navigation and travel	3
Reading books	2
Writing	2
Watching videos	2
Voice recorder	1
Reading lecture notes	1
Diary/organiser	1
Clock	1

The participants were also asked what they use their mobile phones for. The table above summarises the responses given. This was an open question, without prompts, and in most cases examples were presented by participants as part of a list, hence why no more detail is given.

As would be expected the most common uses of mobile phones as described by the participants are texting (37) and making phone calls (29). Other particularly common uses include using mobile phones for social networking (22) and to access the internet (18).

Table 62: Type of tablet computers that the young people would use

	Total (N)	Total (%)
Apple iPad	20	74.1%
Samsung	3	11.1%
Google	1	3.7%
Unspecified	3	11.1%
Total	27	100.0%

Of the 27 participants who reported owning or having regular access to a tablet computer, three quarters (20) have an Apple iPad, whilst three

have a Samsung tablet and one a Google tablet. Three of the participants did not specify what type they own.

Table 63: What participants use tablets for

	Total (N)
Internet	15
Social networking	9
Games	8
Email	8
Work/study	4
Reading	4
Video messaging	3
Music	3
Videos/TV streaming	2
Watching films	1

The table above shows the various examples that they young people gave, when they were asked what they use their tablet computers for. These examples were very similar to the uses given for mobile phones, a fact identified by many of the young people themselves. The most common uses were accessing the internet (9), social networking (8), games (8) and email (8). Four participants described how they found their tablet computers useful in work/study situations – something which is explored in more depth below.

The young people were then asked if they could tell us more about what they would use their electronic devices for, specifically in relation to their visual impairment.

> We are particularly interested in how young people with visual impairments are using mainstream technology, for example iPads and smartphones as assistive tools to help them with their visual impairment. Is this something that you personally would do? Can you think of any examples?

Accessibility of mainstream technology
In response to this question, a number of the young people spoke about how the different devices that they are using have proved particularly accessible to them as a young person with a visual impairment. Common themes were identified relating to the perceived accessibility of mobile phones, tablet computers and e-readers, and these are presented in the table below.

Table 64: Features identified which make mainstream devices more accessible to young people with a visual impairment

	Mobile phone users Total (N)	Tablet users Total (N)	E-reader users Total (N)
Zoom option	7	6	0
Inbuilt screen reader	7	4	2
Ability to enlarge text	5	1	4
Ability to change contrast/brightness	3	1	1
Voice activation	2	3	0
Large screen	1	0	0
More ergonomic	0	1	0

a) Zoom option

Seven users of mobile phones and six users of tablets spoke of benefits of being able to zoom in on the screen. This is a common feature on touchscreen devices, where you can use your fingers on the screen to control the level of magnification on the screen. Within some devices there is also an option to specify a certain level of magnification that you wish to use, and the device will automatically zoom in to that point when directed, e.g. through a double tap on the screen.

> "On the settings you can enlarge the text, but also when you are reading webpages, you can tap the screen a couple of times, and it zooms in, so the text is bigger."

> "If I had to do any reading, research on the internet and things, that I will use my iPad, because I can just zoom it in, and stuff."

> "And you can just zoom in by touching it. It's so much easier. Cos when I was using my laptop and having to magnify things it was so frustrating it really frustrated me, when you're trying to get work done. You've got to keep moving the mouse around to get the magnifier in the right order, it's just an absolute nightmare! Whereas with the iPad you can put it where you want, and you can move it across slightly, it's so much easier."

b) Inbuilt screen reader

Seven users of mobile phones, four users of tablets and two users of e-readers highlighted the fact that some of these devices come with inbuilt screen reader technology as an advantage to them as a young people

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with a visual impairment. This technology comes built into the devices operating system, and therefore there is no need to get additional software installed on the device.

> "But I do use, now and again, on all three devices, the voiceover feature. That's sometimes if my eyes are tired or the text is really, really small rather than my magnifier. So I just turn that on and use that."

> "So at the moment I am using an iPhone. I would use a handheld magnifier to use it usually but it does come with magnification software and it does come with voiceover. With iPads I could use them easy because Apple have included all the specialist software, accessibility software."

> "I can also set to dictation as well. It is voice activated. I double tap at the start of something and it will read it through. I've got it set on voice activation."

c) Ability to enlarge text

Five users of mobile phones, one user of tablets and four users of E-readers liked the fact that they could change the font size on their devices to a font size that suited them better.

> Researcher: "And why do you like using Kindles or your iPhone?"
> Participant: "Kindles because you can like adjust the size of the font. And that's like the main reason why I got it."

> "I use my Kindle regularly. Because I can make the font size whatever size. If my eyes get tired I can get it to read to me, and also, when I go blind, then I have, I love reading so my ways of reading books haven't gone as well."

> "With regards to my phone, stuff like that? I have got a bigger font on my font, and stuff like that. I've just done that in the settings. I mean, apart from that, I don't have any trouble with it all."

d) Ability to change contrast/brightness

Three users of mobile phones, one user of tablets and one user of e-readers felt they benefited from being able to change the contrast or brightness level on their device.

"I mean, I have changed colour schemes, where the contrast is different with my phone, so the writing is more visible, but other than that, no."

"I use an iPad in my placement for my notes. You can adjust the brightness and the darkness."

e) Voice activation

Two users of mobile phones and three users of tablets described how they find using their devices easier due to the inbuilt voice activation features. This includes being able to dictate messages through voice recognition, and also the ability to give verbal instructions to the device to do something, rather than having to input instructions via the screen.

"It's got quite good speech to text, so sometimes I will say 'text mum message' and say the message, and it will basically type it up and say 'is this what you want to send' and I just say 'send' and it sends it."

"Yeah. I have the voice control thing, so if my eyes really hurt I can talk to it and it will do what I want it to do."

f) Large, clear screen

One user of a mobile phone described how they benefited from the large screen on their mobile phone, and if they were to zoom in, the content would still be really clear, rather than pixelated.

"I have got the iPhone 5. It's got a nice big screen, I can follow parts of a presentation when I am in a lecture, upload it onto my iPhone and I can follow through it…It's usually whenever I use a magnifier on the computer, I can see pixels, whereas the iPhone makes it really, really clear."

g) More ergonomic

Finally one benefit identified by a tablet user was that the design of the tablet means that as a user you are naturally able to get closer to the screen.

"It's much easier than using a laptop, because the keyboard gives you a distance between the screen, and you have to use a magnifier on it, and you still have your head to the screen, whereas with the iPad you can have it as close as you want to."

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Mainstream technology as assistive aids

The young people also gave specific examples of how they would use such mainstream technology as tools to help them with their visual impairment. If the young people were unsure what was meant by the question, some examples were given to them, such as using their phones to get travel times and using specialist apps.

Table 65: We are particularly interested in how young people with visual impairments are using mainstream technology as assistive tools to help them with their visual impairment. Is this something that you personally would do? (N=62)

	Total (N)	Total (%)
Yes	38	61.3%
No	16	25.8%
Unclear from response given	8	12.9%
Total	62	100.0%

Over 60% (38) of the young people said that they would use mainstream technology as assistive tools to help them with their visual impairment. Of the sixteen who said that they would not, in some cases they seemed unaware of the options that may be available to them. For example, one young person said that she would not use her iPhone to read for a long period of time, as the writing was too small, and then continued that she did not have any "magnifying stuff on there", despite the fact that within the inbuilt accessibility options on iPhone there is a zoom function, as referred to by a number of the other participants.

Others who may benefit from using such functions did not have devices which had these options inbuilt in them, including one young person who was waiting for an upgrade on her phone:

> Researcher: "If it was more accessible to you, are there things that you would like to do with it?"
> Participant: "Yeah, I would like to go onto the internet to be honest."

Another participant was aware of some options on his iPhone, and very interested particularly in using some of the accessibility apps available (discussed further below), but had not put this into action yet:

> "I bought it because of the fact that if I ever did need to get something like that, I have the technology available, and then it was there, and I would not really… Not using it for the phone

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factor, but for the app factor. I bought it for my future really, just in case it came in handy."

Table 66: We are particularly interested in how young people with visual impairments are using mainstream technology as assistive tools to help them with their visual impairment. Is this something that you personally would do? Examples (N=38)

	Total (N)
Use devices to make it easier to access text	21
Use screen readers to access information/text to speech to input information	9
Navigation/travel	11
Using inbuilt camera as a magnifier	8
Using specialist apps	6
Online shopping	5
Flashlight	2

The young people were asked to give examples of ways in which they use the mainstream technology that they owned as tools to help them overcome challenges they might face as a result of their visual impairment. The responses that they gave have been grouped together into themes, and are presented in the table above.

a) Using devices to make it easier to access text
The most common example given by twenty one participants was using mainstream technology to help them read text that they would struggle to access otherwise. This could include adjusting the font size on their devices to one which they were more comfortable with, using magnification tools to enlarge text, and using their device as a means of accessing electronic books.

> "If I had to do any reading, research on the internet and things, that I will use my iPad, because I can just zoom it in, and stuff. I used it on UCAS because UCAS is really difficult to reformat it, so my iPad can just zoom it in… Oh yeah, and music. I have some piano music on my iPad, so I can zoom in on it, instead of printing off reams and reams of paper!"

> Participant: "I use it a lot in school, particularly in English, obviously to read the books, it is very useful, rather than having to read off hand-outs, or the laptop, or whatever, you know. Having it on my Kindle it's fine, and I am more comfortable than on my laptop, so."

Researcher: "Do you make adjustments to the Kindle to be able to use it?"

Participant: "I put the text on the largest."

"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."

b) Using screen readers to access information/text to speech to input information

Similarly, nine of the young people use either inbuilt screen readers in their devices to be easily able to access information, or use text to speech to input information.

"Like I have used, on the S3 mini, the phone, I have used the text to speech, as well as the speech to text, which helps to read the emails, as well as read text, it will say, and I can tell it what I want, and the message and send it."

"iPhone definitely does! Like number one it has got a voiceover. That's the main thing. Because most phones don't have it, but with Voiceover you can do anything. Like before when I didn't have my iPhone I had a Facebook account but I never used it because the website is too hard. It's quite easy to learn."

c) Navigation/travel

Eleven of the participants would use their devices to help them with navigation and travel. This ranged from planning routes, to using GPS and accessing train times.

"The only thing I can really think of is just the, again just navigating around the town. I don't need it for much else. As far as assistance goes. But it's a lot cheaper to buy an iPhone with some speech software on it, than it is to buy a Trekker Breeze as a separate purchase. As well as your phone. Because you have already got your phone, and discounting obviously the insane amount that you probably need to put down if you put it on pay as you go."

"If I am at a station, I will always use the phone to look at the train times, because I know they are accurate, and I can see them rather than seeing the board. It has live departure board

information for all the stations as well, so I can use that. And I travel so much, that, you know, I can do that on the move."

"Because my family are in London, so I use the underground map on my iPad, or my iPod, because the normal one is ridiculous. And it will plan my route for me, so I know how to get there and stuff. And google maps. Navigation. It's already installed on my iPad. I've got a train time app, so I can look at the trains without looking at the board."

"Well, I got lots of apps for travelling. I have got apps like the national rail app and the Trainline app for when I am using the railway, and maps is an inbuilt app which is already on the phones, and the iPad when you get them, and that's really good for directions when you are walking around, when you want to get somewhere."

d) Using inbuilt camera as a magnifier

Eight of the young people spoke of times where they would use the inbuilt camera in their devices as a form of electronic magnifier.

"What I tend to do is take a picture of the board, and then zoom in on my phone. Which I guess is using it as a tool."

"I do have a magnifier app actually, I used it the other day. I broke the key in my desk drawer at work so I had to read the encryption on the lock to the guy on the phone, and I thought 'how am I going to read that?!' I had an app handy, so I used that"

"Yeah, often in lectures, if things are small, I can't see it, I just take a picture and zoom in with my phone, if something is too small for me, I will literally just take a picture of it, and zoom in on my iPhone."

e) Using specialist apps

Six of the young people who are registered as blind use specialist accessibility apps which have been designed specifically for people with visual impairments, and are available in the form of apps which can be downloaded to their devices for a minimal charge. The apps used by the participants included audio games, colour detectors, text recognition, scene recognition apps, and braille tuition apps.

"Erm there's one particular game that I play loads called Six cents, and that's just for entertainment you shoot zombies. And it gets harder and harder."

"There's an app you can download called vizwizz. You can take a picture of an object with it, and it will describe what that object is, so that's quite useful if you are trying to identify a bottle or a tin, whatever is in it. It's not easy to use. You have to line it up right, and that takes time."

"I use something called tap tap see, which is an app where you can take a picture of something and it will give you a sort of description of what you have taken a picture of."

"They have got different things like colour detector apps on the iPhone as well, I use that occasionally, and, what else, trying to think that. There is an app called seetext, which is where you, there are a couple of different apps that do this actually, you take a picture of a piece of text, a page or whatever, and in theory it should read out what's on the page what you have taken the picture of. I haven't had massive success with it yet, but I haven't had it for very long. I know other people use it really regularly, so I know it works, I just haven't worked out how to do it yet."

f) Online shopping

Five of the young people use their devices for online shopping, and reported that they tended to find that this was easier to do on mobile phones/tablets than on a computer.

"Use Amazon app, Tesco, and eBay. They are easier to navigate on the phone."

"I do Amazon at the minute, I haven't tried it with supermarkets before. I have been told that some supermarket sites are more accessible than others. I think I heard that Tesco was really bad, and that Asda was a lot better, but I haven't tried it out for myself yet. But mainly things like Amazon and… I found that on apple devices, it's a lot easier to use the apps than the sites in some cases. Like for shops like New Look or Top Shop, clothing sites, it's a lot easier to use their apps, rather than the sites themselves, so it's stuff like that really."

Participant: "I have started using the trainline app to book my tickets."
Researcher: "Is that easier than using the main website?"
Participant: "Yeah."
Researcher: "Can you think why that is?"
Participant: "I don't really know, I just think because it's all in one place."

g) Flashlight

Finally two participants would use their mobile phones as flashlights when it was dark. Both these participants had previously shared that they struggle in poor lighting conditions:

"Ah yes, I've done that before. Sometimes I use my phone as a flashlight for example."

"The only thing I ever use mine for is a flashlight in the dark! It helps me. It is great. Because if there were steps or something, then I am going down there, ten out of ten I would be on my bum! Either that or on my face!"

4.6.8　Importance of ICT to the young people

Table 67: How important is ICT to you in your everyday life?

	Total (N)	Total (%)
Essential	32	50.8%
Important	20	31.7%
Fairly important	6	9.5%
Fairly unimportant	0	0.0%
Not very important	4	6.3%
Not at all important	1	1.6%
Total	63	100.0%

To conclude the section on ICT skills, the young people were asked to rate how important ICT is to them in their everyday lives. They were presented with six possible responses ranging from 'essential' to 'not at all important'. Over 80% of participants saw ICT as being either 'essential' or 'important' in their lives, with only 8% of participants saying it was either 'not very important' or 'not at all important'.

Table 68: 'How important is ICT to you in your everyday life' against 'registration type'

	Essential	Important	Fairly important	Not very important	Not at all important
Blind (severely sight impaired)	18	3	0	0	0
Partially sighted (sight impaired)	8	10	1	2	1
Not registered	2	2	4	1	0
Total	28	15	5	3	1

The table above explores the relationship between the perceived importance of ICT in the young people's lives against their registration type. Those who were registered as blind were more likely to see ICT as being 'essential' whilst those who are registered as partially sighted in the scale provided tended not to rate it as highly, and are more likely to rate it as being 'important'.

The participants were asked to explain the answers they gave. A summary of the type of responses that were made are presented in the table below:

Table 69: How important is ICT to you in your everyday life?

	Total (N)
Important – main medium of work	24
Important – main medium for communication	18
Important – use it everyday	14
Important – makes life easier	8
Important – use for leisure	7
Important – lost without it	1
Important – helps with independence	1
Not important – only use for social networking	3
Not important – causes headaches, so prefer to avoid	1
Not important – not needed for visual impairment	1

Several explanations were given as to why the young people considered ICT to be important to them in their everyday life. In many cases this was due to the fact that ICT is central to modern society, with college and university courses requiring its use for producing and submitting work, communication being geared around email (and in the case of

teenagers around social networking). However, there were explanations given by several of the participants that could be seen as being specific to young people with visual impairment, such as the value of using ICT as a way to make adjustments for their visual impairment. This was particularly the case for those young people who are reliant on speech software.

For example, whilst several participants identified ICT as being their main medium of work (e.g. they would word process essays or conduct research on the internet) one participant described how she uses it for all elements of her studies:

> "Use it for every aspect of education. I get all my textbooks electronically and so that's how I read them or I put them on my braille note so I read them using refreshable braille or I write my essays on a laptop or braille note, so I can print it off or email it directly to tutors and it's how I access class notes and everything like that. I just couldn't function"

Two of the young people took this even further by explaining that ICT was essential for almost everything that they would do in life.

> "I would say it's essential, because it's the main port of…, pretty much everything. For me personally, it's my main way of accessing my academic work. It's my main way of social networking and socialising that way. But even, otherwise, it's my main way of communicating on the phone, because, through my iPhone and stuff. It's my main way of travelling, yeah, it's how I do everything."

> Participant: "I don't know, you just can't really function without it can you? I have always got my emails open, and Facebook, and I do it for all my work, use it for planning most things, so yeah. I guess… the more you kind of know, the more options for making things easier you have got, isn't it.
> Researcher: "Do you think it's particularly the case for you with your visual impairment as well?"
> Participant: "Yeah, definitely."
> Researcher: "Are there any things you would particularly struggle without, do you think?"
> Participant: "All of them. I kind of, I use everything at least once in a day, as something I couldn't really do, any other way."

Eight of the participants also spoke about how ICT makes their lives easier as a young person with a visual impairment:

> Participant: "It makes my life a lot easier."
> Researcher: "Can you explain how it makes your life that bit easier?"
> Participant :"I think writing notes down on my laptop, instead or writing them down. Ease of access for myself. I can email it to myself, instead of writing it down and not being able to read it. Even using the phones as a magnifying glass I think was quite a good one. Yeah. That's about it really. It just makes my life easier. Writing an email as opposed to writing a letter to someone, or having to write something down."

> "It's very important, definitely, it definitely makes things easier and more accessible."

One participant who considered ICT to be 'essential' described how he would be 'lost without it:

> Participant: "I think it's [essential] , because I use it every day. I would be lost without it!"
> Researcher: Can you explain to me, I guess it's hard, but in what way would you feel lost?
> Participant: It's my way of communication, and the iPhone has opened up doors for me, especially now with the iPhone update, it tells you what's on your camera or photos, sometimes. It will say bright, one face, two faces, very blurry, or very bright, or something. It's improving."

Six participants gave explanations for why they did not consider ICT to be of particular importance to them. In three cases they reported only really using ICT for social networking, and felt that this was something that they could live without. Another participant made clear that ICT was not something that they needed to help them with their visual impairment, whilst the final participant said they tried to avoid using ICT as it would cause them headaches, and therefore ICT was something that they would prefer not having to use.

Whilst as identified previously, many of the responses given by the participants were typical of what would be given by the average teenager, it emphasises the changing world that we are living in; one which is becoming increasingly ICT dominant. It is a reminder of how

important it is to ensure that young people with visual impairments are able to access ICT, particularly in terms of being able to effectively use specialist technology, or in being knowledgeable of the ways in which they can use functions available in mainstream technology to their advantage. This is particularly the case for those students who are reliant on speech software to access ICT. For example, the participant quoted above who described how they would be lost without ICT, is in fact Participant 1 from the case studies in section 3.6.5, who had not been given an opportunity to learn to use specialist accessibility software at school. He instead sought the help of contacts that he had made to teach himself how to use a computer. It is evident that since then, ICT has become of great significance in his life. Likewise, many of the young people with more severe visual impairments have described through the course of this wave of interviews how well they are able to use ICT to their advantage, using technology that many may not have considered as accessible to them.

5 Use of braille

Section four of the interview focused on the use of braille, for those participants who used braille, or had at least had some exposure to braille in the past. These questions were answered by twenty participants.

5.1 Experiences of learning braille

5.1.1 Age at which the participants first learned braille

The young people were asked if they could recall how old they were when they first learned braille. Taking their responses, it is most appropriate to explore their experiences by dividing them into three groups:

- Those who had a visual impairment since birth, or a very young age (N=12)
- Those who did not have a visual impairment until they had started school (N=3)
- Those who were considered borderline as to whether they needed to learn braille or not (N=5)

Those who had a visual impairment since birth/young age (N=12)
Four of the participants who report having had a visual impairment since a very young age first started to learn braille before they had reached primary school. In two of these cases, the young person went to a nursery with a specialist VI unit (whilst in the other two cases more specific details of their setting were not specified). One of these young people described how that meant that they knew grade 1 braille before even getting to school:

> Participant: "2 and a half."
> Researcher: "Was that with the local authority?"
> Participant: "I lived in the middle of nowhere so basically I couldn't go to the local nursery so I got sent to a specialist nursery school and yeah there were advantages and disadvantages of special school but I was like 3 so I didn't even notice, and I was just there for a year and what it meant was that I got access to learning braille, so I learnt grade one braille whilst I was there so I could already read to a certain extent by the time I started school."

Five of the participants first learned to read braille once they entered primary school:

"Ever since I can remember, really. So, I was in like Year 1 or Year 2 of primary school, so I was say I was about. [Checks with Mum] Reception, so that was, god knows, Year 1, I was really young."

Finally, three of the young people did not learn braille until a bit further on in primary school, at ages 6, 7 and 8. The participant who did not learn until 8, in reflection, considered this to be too late:

Participant: "It was either 7 or 8… Either way it was a lot later than I should have done, because everyone was saying that I didn't need braille."
Researcher: "Why were they saying that?"
Participant: "I don't know… I haven't got a clue!"
Researcher: "So they were just proposing for you to use enlarged print, were they?"
Participant: "Yeah"

Those who did not have a visual impairment until they had started school

Three of the participants who have learned braille did not have a visual impairment at the point at which they started school. In each case the response to arranging teaching them braille appears to have been fairly rapid. One of the young people who lost his sight aged 5 ½ described how time was allowed for him to build up his tactual skills before moving on to teaching him braille:

Participant: "Not entirely sure, I went blind when I was 5 ½ and I then went… I think it was a good year or so before they even started teaching me braille. I remember learning it straight away, but I don't think they did. I think they gave me a year to build up tactility in my fingers. So I think it was 6 ½, possibly even 7 before I started learning braille."
Researcher: "So how did you get by in your lessons in school in the meantime?"
Participant: "It was that sort of time in your education where you don't really need to be too involved in the lessons. At least, you get involved in the lessons, it doesn't matter if you don't write anything down, you can just be playing with bricks and counting them out. You can be talking problems through."

Those who were considered borderline as to whether they needed to learn braille or not

Finally, five of the young people appear to have been on the 'borderline' as to whether specialist teachers considered that it would be appropriate to teach them braille or not. All five of these participants had had a visual impairment since they were born. The experiences of these five can be summarised as follows:

- Participant 1 has retinitis pigmentosa and their eyesight is gradually deteriorating. They were taught braille very briefly when 15, but these lessons were later stopped.
- Participant 2 has had their eye condition since birth and was taught braille 'on and off' between 11 and 15.
- Participant 3 has had their eye condition since birth, and first started learning braille at 13. This followed disputes with the young person's QTVI who did not think it was appropriate to teach the young person braille. Considering their preferred font size is 36, this seems surprising.
- Participant 4 was diagnosed aged 4, but reportedly was not connected with a local authority visual impairment support service until they reached secondary school. They were first taught some braille at age 17.
- Participant 5 has had a condition since birth which affects their optic nerve. Their eyesight is gradually deteriorating to the point they will no longer be able to use print (they are currently reliant on font size 48 or 36 with a low vision aid). This participant had braille lessons for three years in a special school from age 13, but did not progress beyond grade one braille.

5.1.2 Whose decision was it for you to start learning Braille?

The young people were asked if they knew whose decision it was for them to start learning braille. Due to the young age involved in some cases, they were not all completely confident, but gave the person they thought most likely. Their responses are grouped in the three categories presented above.

Table 70: Whose decision was it for you to learn braille? (Those who had a visual impairment since birth/young age) (N=12)

	Total (N)
QTVI	5
Parents	4
Joint decision	2
Unsure	1

In five cases, it was the decision of the QTVI for the young person to learn braille, or at least start learning braille at that point in time.

> "It was someone in the school, because he was the head of braille, head of VI, I don't know what you call it."

> "Nursery [with attached specialist unit] – cos they knew that I wouldn't be able to read print."

Four participants reported that it was their parent's decision for them to learn braille. In one case, the participant's mother had pushed for their daughter to have the opportunity to learn braille prior to primary school to give her a head start:

> "My mum. She wanted me to start learning braille before I went to primary school, so I had a long start, because obviously it takes a long time."

In another case it appears that there was a resource issue which delayed the young person learning braille (he did not start until 8 years old), and there was some intervention from his parents:

> "I mean, the person who was teaching me braille was two pages ahead of me in the teach yourself braille textbook, so…"

One participant described it as a joint decision between their mother and the sensory support service. Whilst another two participants were unsure, but considered it an obvious decision to have made:

> "No, but I kind of had to, because I couldn't see"

Of the three participants who did not have a visual impairment until they had started school, two were unsure whose decision it was, although in one case they emphasised that it was an obvious decision ("No. I think it was a fairly obviously choice I think, that I was going to start learning braille"), whilst the third, who is not able to access print at all, said it was their parents decision and they had some trouble with the council in trying to access braille tuition:

> "My parents pushed for it, the council didn't want me to."

The five participants who were considered borderline as to whether they needed to learn braille or not reported mixed experiences when first being introduced to the idea of learning braille.

- Participant 1 reported that when in school one day a QTVI came up to her and out of the blue said they wanted to start braille lessons with her.
- Participant 2 was taught braille by her mother, who also had a visual impairment, and thought it was important that she became at least familiar with it.
- Participant 3 reported that it was her mother's decision that she started learning braille age 13, and considered there to have been a resource problem: "We had many arguments with my QTVI who didn't want to teach me braille… Money, basically…It wasn't her who didn't want to teach me, it was the powers who be, didn't want to teach me."
- Participant 4 started to learn braille after her tutor in college (non-QTVI) suggested it would benefit her.
- Participant 5 had a similar experience to participant 1, and was one day informed by a QTVI in her specialist school that they would be learning braille:

  Participant: "Yeah, it was my tutors."
  Researcher: "Did they talk with you?"
  Participant: "I got told I was learning braille and that was it, so I didn't really get a choice."
  Researcher: "And what did you think about it?"
  Participant: "I was a bit scared to be honest"

5.1.3 Who taught the young people to read braille

The young people were then asked if they could give more information about who had taught them braille, and their broad experience. Various prompts were given, such as asking them about the learning setting, the size of the group, methods the teacher used and how they found it.

Almost all of the participants had braille tuition exclusively with a QTVI, whilst one participant also had tuition with her mother (a braille user herself) and a further participant had additional private tuition from a local braille tutor. One participant spoke of having braille tuition and touch typing lessons through a support person at college, but it was unclear whether this person was a QTVI or not.

All participants when they first learned braille had one to one tuition, in a variety of settings, including: mainstream school with a visiting teacher (8); resource base (5); special school (4); private tuition (1); and at home (1).

When asked about their experiences of learning braille, three of the participants who had first learned braille when in nursery school understandably said that they had no recollection of learning braille. However, one participant described how she made very good progress during her time at nursery:

> "It was good cos I could already read it and everything. I was never behind academically because of having to learn braille. So that was good. Basically I could go to primary school and I only had to learn grade 2 but in effect I could get any work that we were given and I could still read it."

A variety of teaching styles were described by the participants. These ranged from teaching braille with a visual approach, to the young person being left to learn independently, to learning through reading braille books.

> "I was at home, and my mum got the braille paper, she got me coloured braille paper so I could see the dots better, and stuff, and she did a few exercises each day, and I was home educated"

> "I learn better if someone stands next to me, showing me what to do, but they said this is what you need to do, wrote it down for me to read, and then they just left me to it, which I lost interest in very quickly, because that's not how I learn."

> "I was on my own, they were teaching me through little braille reading books and teaching me the alphabet in braille and so on and so on. It was very good, I am glad I got taught how to do that, because otherwise I wouldn't have been able to read anything!"

The age at which the young people learned braille seems to have an impact upon how positive they are to it. One young person was extremely positive, and felt that his experience in learning braille was equivalent to a sighted person learning to read (which for him it was).

> "I learnt to… how we learnt it was we had very, very simple books, very simple books, and it was just a case of learning to read that,

and I would have to practice writing, each letter that I learnt I would have to do lines of that, and then reading bits, and then reading bits, and then reading. Pretty much similar to how sighted people learn print."

However, another participant reported that his local authority had been reluctant to teach him braille, so he did not have an opportunity to learn until he was eight was frustrated that by the time he came to read books, the books offered to him were 'childish'. This was something which continued to be a problem to him throughout the time he learned braille:

"I am not sure how many people have moaned to you about the Bill and Jane books? That was what they put me on when I first got there. You don't know? Oh, the Bill and Jane books are, like, it's the braille equivalent of, you know the magic key books which were around for children when I was young? It's those, Biff, Chip, Will, Wilma, the basic sort of sentences that you make, were those. But these were the fingerprint textbooks, and it was always Bill and his adventures, and it was just getting ridiculous, and boring, and childish. I was 14 when I first started working on these, and they are 7 year old books. But they got better in the end, and I worked on some great short stories. And they just worked up from there, and it was fantastic."

There were similar frustrations for a young person who lost her sight in secondary school, as she had been a confident print reader, but when she had lost her sight was only given the opportunity to spend 30 minutes a week learning braille, and therefore moving at a much slower pace than she would have liked. Instead her family hired a private tutor.

Participant: "Yeah, they taught me half an hour a week, so my parents paid for me to have private tuition from someone because they weren't good enough, the council."
Researcher: "Yeah, half an hour a week doesn't sound much."
Participant: "Yeah, I think I learnt ABC in the first week, and after getting my new braille teacher, I learnt the whole braille alphabet in a week."

There were other examples of ways in which the young people were unhappy about the way in which braille was taught to them, and they felt bored and unmotivated by the way in which the learning material was delivered to them:

"But it all depends on how you learn it. In my secondary school they made me copy stuff from a book. That was quite boring. When I'm bored that's it I can't be arsed to do it."

"If I can remember, it was, they basically began by learning letter by letter, because we first had to get familiar with the code, so we had to, we learnt it letter by letter, which I guess was, I would say, boring back then, because it was painstaking, it took time because you had to remember the letters and things. And I would say in the long term I think looking back it was worth it because it ultimately means that I learnt braille."

This last person who was quoted later had a very different experience when he changed schools, and instead had more of an opportunity to practice what he had learned. He found it a lot more enjoyable, and also found that he learned quicker too:

"I think it was quite good because we learnt, we did the code, but we didn't just focus on the code, we did the code and then we used the book which was about 8 volumes long, so we put that into practice, which I found, and I still find more interesting, because then it means you get a real experience of what it's like, so that was quite good. It was quite effective because it only took me a few months for me to learn, it didn't take that long, surprisingly."

Three of the young people spoke about having to miss lessons to fit their braille lessons in.

Participant: "It was in the reception and nursery, so they took me out of the arts lessons I think."
Researcher: "How did you feel about that, or how do you feel looking back?"
Participant: "Well I liked art, so I was probably really annoyed!"

Another participant who had missed lessons in mainstream for braille tuition, after she had moved to special school found it beneficial that braille was part of the daily curriculum:

"With the braille lessons in [special school], they were part of the curriculum, so I wasn't taken out of anything for that, that was better. It was to speed up my reading, rather than my writing, which was something that I hadn't done at all, I hadn't built up until

that point. My braille reading is still quite slow, but it's a lot faster than it used to be. So they were useful, yeah."

Of particular concern is that two of the participants who had learned braille for a brief time, but not made any real progress, both felt that they would benefit from learning braille, but now they were leaving college, reported not knowing where to get this tuition from. Their experiences are explored more in the case studies in section 5.3.

5.2 Using braille

5.2.1 What would they use braille for?

Table 71: What would you use braille for? (N=16)

	Total (N)	Total (%)
Reading a novel	6	37.5%
Studying	13	81.3%
Labelling (e.g. CDs, filing)	10	62.5%
Short note taking	11	68.8%
Long texts (essays)	7	43.8%
Revising	14	87.5%
Other	6	37.5%

The young people were asked what they use braille for. This was an open question, although the different examples given in the table above were asked as prompts. Sixteen participants answered this and subsequent questions (four of the participants despite having been taught braille would not use it anymore). The most common reasons given for using braille were revising (14), studying (13), short note taking (11), and labelling (11). Seven participants would also use it for long texts and six for reading a novel. Six of the participants gave additional examples of uses for braille. These were:
- Reading letters
- Sending cards
- Notes for giving presentations
- Bank statements
- Medication

5.2.2 How would they access braille?

Table 72: In what ways are you able to access braille?

	Total (N)	Total (%)
Paper (hard copy) braille	15	93.8%
Electronic braille note-taker	9	56.3%
Braille Display	8	50.0%

All but one of the participants currently access braille by paper. The one participant who would not use hard copy braille no longer receives paper copies of braille, and instead would use an electronic form of braille. Nine participants are able to use electronic braille note-takers and eight would use electronic braille displays.

Table 73: How would you most often access braille?

	Total (N)	Total (%)
Paper (hard cope) Braille	7	46.7%
Electronic braille note-taker	2	13.3%
Braille Display	5	33.3%
Equal between hard copy braille and braille display	1	6.7%
Total	16	100.0%

The most common ways in which the sixteen participants access braille are hard copies of braille (7) and electronic braille displays (5). Two would use electronic braille note-takers, whilst another participant judged they use hard copy braille and braille display approximately an equal amount.

5.2.3 How much opportunity do they get to use braille?

The sixteen participants were also asked how much opportunity they get to use braille. When approaching answering this question, a lot of the participants made the distinction between using braille at school, and using braille at home. There was a noticeable pattern of those who use braille at school/university then having less opportunity to do so when at home.

For example, this participant would use braille all the time in her studies, but once she got back home from residential college, she would choose to use a laptop instead:

Participant: "I can use it whenever I want. I have access to a brailler all the time."

Researcher: "So on a typical day or a typical week, how often would you use it?"

Participant: "I use it twice a week when I am in my braille lesson, at [specialist college], but at home I don't use it because I just use the laptop."

In contrast, one participant would use braille for leisure, but not for her studies, due to her slow braille reading speed. This was echoed by another participant who would favour her screen reader due to her braille reading skills:

"I just found it a lot quicker to use the screen reader, rather than reading it. I think that if I could read faster, I would probably use it more"

One participant who was on a gap year between school and university had not had much opportunity to use braille during that time:

"Not very much of one. The occasional label on something is pretty much all I see of braille now days, unfortunately. Occasionally I get given books in braille, but not very often."

Three participants who are at university spoke of having more opportunity to use braille. Two of these participants reported that they would be able to access braille every day (although qualified that this was for a particular type of reading), whilst another participant, after two years away from school, would very rarely use braille:

"Every day. Proper braille, like text rather than just numbers, actual fluid reading, like you might read a book, I don't read braille very often at all. But yes, I do read some braille every day."

One participant who was studying a degree at a small institution, which did not have facilities to make braille was not able to use braille on their course, and she was not provided with an electronic braille device as part of her DSA.

Participant: "Not very actually, at all."

Researcher: "Is that your choice?"

Participant: "Kind of, kind of not."

One participant reflected that he found it difficult to get hard copies of braille, whilst another said that she would only get hard copies of braille if she were to order books from the library.

> "It's quite hard to get copies of hard copy braille now. I am at university where it is unusual to have hard copy braille just lying around. At school it was nice and easy."

In contrast, seven of the participants shared how they had greater access to braille because they had use of some form of refreshable braille display – either in the form of a braille display which would work in tandem with their computer, or a braillenote, which is a small specialist portable computer with a braille keyboard and braille display. In all but one of these cases, they had received their device through Disabled Student Allowance. This other person had received her braillenote on loan from her special school. These seven participants use their devices in both studying and leisure situations:

> Participant: "I would say, every day now I have my braille display.
> Researcher: You were saying that you are going to use it for reading novels?"
> Participant: "Yeah, part for my course, and also for leisure, because there are two interesting books that I really want to get, so I am going to try and see how I can get them turned into braille, like get hard braille copies of the books."

> "It's at my finger tips, the braille display, I can use it when I like. With my braille note in lectures, I can type down the questions on it. So it's really whenever I want to, really."

It is also worth noting how versatile these devices are; many have Bluetooth functionality meaning that it is possible to connect them to mobile devices such as mobile phones and tablets, as illustrated in this case:

> Researcher: "So when you are saying that you read novels, and using your iPad, would that be using the braille display to read then?"
> Participant: "Sometimes. It depends where I am, and what I am doing. If I am on a train, I would just read it, get voiceover to read it. But if I am just sat in my room or whatever, I would link it to my braille display."
> Researcher: "That must be nice to have that option."

Participant: "Yeah, it's ideal."

5.2.4 Do they have a preference between using braille or electronic material?

Table 74: Do you have a preference between using braille or electronic material

	Total (N)	Total (%)
Braille	0	0.0%
Electronic material	6	37.5%
Electronic form of braille	2	12.5%
Depends on the situation	8	50.0%
Total	16	100.0%

The 16 participants who use braille were asked if they have a preference between using braille or electronic material. None of the participants preferred braille, whilst six preferred to use electronic material. Eight said that it would depend on the task that they were undertaking, (and also in one case on their mood). Finally, two participants said that their preference would be to use an electronic refreshable form of braille.

Some of the participants gave examples of situations where they would choose each of the mediums. These tended to focus on braille, since that was the focus of this section of the interview.

Situations where they would prefer braille
- Presentations: "If I have to remember, like a speech or anything, a presentation, then I prefer it in braille… Because you read through it, and not listen, if you listen to it you will forget it, but reading through it, it will actually sink in."
- Revising and exams: "For me I prefer to use braille when it comes to revising and for my exams"
- When learning new languages: "And also with languages too, and a foreign languages, it's just easier because it can't pronounce foreign words."
- In lectures: "…but in terms of say lectures and stuff, I think braille would be best."
- When learning details: "If it's something that I have to learn, like learn details, key facts from, then I prefer it in braille."
- Reading small bits of text: "…but I would much prefer to have the voice for going over long bits, and braille for reading the small bits"
- Reading books: "I do love reading books in braille, I have a fondness for braille, I like it…I think it's just, it's just more real, and like trustworthy I guess."

Situations where they would prefer using electronic material
- Writing essays: "But for essays and anything I rather prefer to do it on the computer – it's easier and faster."
- In general for speed purposes: "Electronic is probably faster, because I have my speech quite fast"
- Reading through something: "If it's something that I am just reading for the sake of it, like an example essay something like that, then electronic."
- Long portions of text: "I could do my work entirely with voiceover, but I would much prefer to have the voice for going over long bits."

Finally, one of the participants spoke of how she saw braille as being a good back up for electronic material, indicating that she considered it an important skill to have. However, at the same time she did not consider it to be a realistic choice for day to day use:

> "Whereas braille is a good back up yeah, but it's, you know, if I wanted stuff put into braille for me at uni, it would take so much longer than it already does to make it, it would take longer to read it, and then it would take longer in the end to use it, utilise it, so I think purely on speed of effectiveness, I would say electronic."

Again, braille reading speed is identified as a reason for preferring to use electronic material. Something echoed by another participant:

> "It's because I am slower at reading braille, than I am at listening to something."

5.2.5 How important is braille to them in their everyday life?

Finally in this section, the participants were asked "Could you describe the importance of braille to you in your everyday life?" The responses which were given can be grouped into four broad categories:

Functional
Firstly, there were those participants who described the importance of braille to them on a functional level. Examples included:

Braille being a good learning tool:

> "When used effectively, braille can be a very good learning tool, but I can't use it every single day of the year because I have never

been fluent enough, and it's never been my desire to be that
fluent."

Braille being important for a particular aspect of their studies:

> "Braille is very important to me, because I use it for my languages,
> and I used to use it for maths as well, when I did it. Yeah, it is very
> important because I use it for my work"

It being important to be able to access accessibility adaptations within
society:

> "Because, going on a basic thing, when you are out and about, if
> its somewhere that's accessible, you get braille menus, you get
> braille signs on doors, you get braille on lifts don't you, so braille
> can be used very effectively. I think if braille was more universal
> like that, it would be a lot better, and people would use it a lot
> more."

Braille helping improve literacy:

> "Like electronic reading is good, and audio books are good for
> getting through them quickly, but using stuff like that you lose a lot
> of things like spelling, grammar, you know, punctuation, stuff like
> that, it's important in English and communication, so I would say
> braille is important, definitely."

> "Fundamentally it's being literate. A lot of people say oh braille
> doesn't matter now cos you've got all the technology, you've got a
> laptop, but what about when that breaks or I think as well, people
> who have learnt braille, who are blind, have better literacy skills,
> they can spell better, their grammar is better. Because they know
> how a sentence structure looks, they know how words should be
> spelt."

Equivalent to reading print/a reliable back up
Secondly, there were those participants who compared braille to print,
seeing it as their equivalent of a sighted person being able to read text,
and an important back up with could be relied upon when technology
fails:

> "Braille is like my pen and paper."

"I would say it's very important because ultimately it's what we use, because it's still just as helpful as the electronic because if, for instance, I don't know, hypothetically speaking, your jaws software broke down, then you would fully revert back to braille. I would say it's just as important as jaws, or any other screen reading software. Arguably more important."

"I guess, it's just like, it puts you on an even footing doesn't it, because you can't always have electricity there, so a lot of the time, just being able to, you are not walking around, say you have got to do a presentation, you haven't got to walk around with a pair of headphones on."

"It's pretty important. It's good to be able to have the ability to read like sighted people can. And you never know when you need to."

Not part of their everyday life

Three people responded to this question by making it clear that braille was not part of their everyday life, making it a difficult question to answer. However, this was not necessarily a conscious decision that they themselves had made:

"Braille isn't in my everyday life! I am now doing the impossible. I am trying to think of how I could describe something that's important in my everyday life, though it isn't in my everyday life!"

"I think I do prefer braille, but as I say, it's just the way it is. I don't have access to an instant supply of braille access."

"I don't use it every day! It's good to be able to read your bank statements and stuff, and then not everyone has to know, but you can do that online. But yeah, it's kind of good. It has its use, but it's dying out because of electronic, which is kind of bad…I only don't use it very often because DSA said 'oh you are so good with electronic, you don't need braille'."

Emotional attachment

Finally, there were three participants who spoke of the importance of braille from more an emotional perspective, and with a sense of fondness:

"I don't know how to describe it… It's how I read, and write, it is how I used to read and write, well I still read and write with it… Braille is like my pen and paper."

"Yeah, I think braille is important, because it's different from speech, and print. You have, this is going to sound weird, you have a closer connection to what you are reading with braille, and you sort of, with speech you don't take it in in the same way, because you are not reading it for yourself. With magnification it's hard work to read, with Jaws you don't really get into something. With braille it's more relaxing and enjoyable. It's a challenge to read in braille, because I still find it quite difficult."

"It's important. I don't use it every day now, I could live without it, but I really enjoy it, so I don't want to."

5.3 Access to Information: Case Studies

Whilst the majority of this report has focused on the 64 participants as a whole, it is also interesting to explore the differences in experience of individuals. In this section we present the contrasting experience of two of our participants who are registered blind, particularly in the context of how they are able to access information, and the skills which they have been equipped with once they make the transition into employment.

Participant 1:

Participant 1 has a genetic condition which causes her eyesight condition, and only has limited light perception. She is registered blind. It was clear at the start of her school education that she would not be able to access printed text. She has had a range of educational experiences, starting off in a specialist nursery, before moving to a mainstream primary school. She spent part of her secondary education in a specialist school, before moving to a mainstream sixth form. Participant 1 is able to access information in a variety of ways, including using a laptop with speech software, hard copy braille, and refreshable braille using a braille strip. She first started to learn braille at nursery, and was able to read grade one braille by the time that she moved to primary school. Due to starting learning at an early age, she can't really remember her initial experiences of learning braille. She now regularly uses refreshable braille at college, and when reading large portions of text such as books. She sees braille as being "really important" and sees it as "fundamentally it's being literate". She also received touch typing lessons and lessons in using speech software early on at a mainstream school, finishing her training aged 7. Whilst she acknowledges that she had to miss some lessons in order to have this additional training, she considers it to have been worthwhile: "In all honesty because you're either going to have to stay after school which they won't fund obviously, which is fair enough, or you're going to have to miss some lessons and you're not going to learn the technology, and I'd rather miss a couple of lessons and be able to access the tech and have good reading and writing skills." She would describe herself as "very confident" in using specialist accessibility software, and attributes it to learning the skills at such a young age: "I think from just starting from such a young age. It's just so normal to me like, I can't remember not knowing how to use a computer. Cos I started that young, it's not something that I really remember having to learn." This participant soon plans to make the transition to university, where she will benefit from being able to access material in a number of possible mediums.

Participant 2:

Participant 2's visual impairment is as a result of damage to the optic nerve. Her condition has gradually worsened over the past few years, and she has recently been advised to change her registration from partially sighted to blind. Similarly to participant 1, she spent some time in mainstream education, before moving to a specialist school, and then returning to go to a mainstream college. Her primary ways of accessing information is through using printed text or a computer with magnification software. She would read printed text with low vision aids like an electronic magnifier. If using her electronic magnifier she is able to read print at font size 36, otherwise she would need to use font size 48 or 72. She would tend to access a computer using magnification software, and makes use of the adjustments that can be made to colour contrast through Zoomtext. She had previously used Supernova, which also has a speech element, but has switched over to Zoomtext after being advised that it was simpler to use. She is finding increasingly that when trying to access print, it makes her eyes very tired and she can only read for short periods of time: "Well Facebook, I can be on the computer with Facebook for quite a while, if I am only looking at little bits, and then resting my eyes until someone chats to me, but if I was reading a book, I would only be able to read for about 15 minutes, not even that." Participant 2 also describes how her eye condition is getting progressively worse, and can vary from day to day, something which people around her do not understand: "Yes, yeah, then again people don't understand that. They will say 'well you could see that the other day', I am like 'yes, but today I can't, I'm not lying, you know'". It would appear that her eyesight has progressed to such a degree that accessing print is no longer a long term viable option, however, following advice she is no longer using Supernova, the specialist software she used before that includes a screen reader, and does not appear to have received much training for using it in the past:

Researcher: "Did you get much training in Supernova in the past?"
Participant 2: "I got a little bit more than I did with Zoomtext, but…"

She had some braille tuition for three years when at specialist school, but did not progress from grade 1. When she moved back to mainstream college, no further braille tuition was offered by her local authority. Her overall experience of learning braille does not appear to have been a particularly positive one:

> Participant 2: "I got told I was learning braille and that was it, so I didn't really get a choice."
>
> Researcher: "And what did you think about it?"
>
> Participant 2: "I was a bit scared to be honest".
>
> Participant 2 had to leave part way through a level 3 course at college, as she was not able to access the necessary learning material.

Participant 1 and 2 have had very contrasting experiences in learning to access information, despite having both followed similar pathways of mainstream school, moving to specialist school, and then back to mainstream school. One significant difference which could go some way to explaining their different experiences is that from the time participant 1 first entered the educational system, it was known that she would not be able to access print and would need to learn specialist speech software. In contrast, participant 2's condition has gradually changed over the years (although she states that this was something that was known in advance, so could have been anticipated by various stakeholders). Ultimately, participant 1 is now in a position where she is leaving college, and able to access information using a variety of means, including through specialist speech software, hard copy braille and refreshable braille. However, participant 2 is now getting to the stage where using print is becoming more and more impractical and difficult for her. Whilst she has used specialist speech software in the past, she was in recent years advised to move away from this, to magnification software instead. Unsurprisingly she reports that she worries about her eyesight "all of the time", particularly in context to how it keeps changing:

> Participant 2: "I find all of the time to be honest, because everywhere I look, I can't see. Do you know what I mean. It's weird to say, but everywhere I look I see little dots, and it's a reminder to me that my eyesight is crap."
>
> Researcher: "I guess it will take a bit of time for you to adjust to things, isn't it."
>
> Participant 2: "Yeah. It seems when I adjust to things, they will get worse."

Unfortunately participant 2's experiences are not unique. Another participant in this wave of interviews described how her eye condition is gradually getting worse, and that it is known that she will eventually go blind, and therefore no longer be able to read print. Despite this, and the fact she is soon to leave her college and seek employment, she has not received any tuition in using specialist speech software, and very minimal tuition in using braille. In both these cases, the young people

could soon find themselves in situations where they are not able to independently access information at all.

This prompts the discussion of what exactly is the responsibility of schools and local authorities in situations like this, particularly where the participants' eye conditions are not static, and it is known that their eye conditions will worsen. Should they be meeting the young person's immediate needs, simply ensuring that they are equipped at that point in time to access the curriculum and any associated assessments, or should schools and local authorities be anticipating the young person's future needs, ensuring that they are fully equipped with the skills they are going to need for life after school?

SECTION C: ACCESSING BENEFITS

6 Disability Living Allowance and Personal Independence Payments

Due to the recent government announcement that Disability Living Allowance (DLA) will gradually be phased out in favour of a new system called Personal Independence Payments (PIP), several questions were posed to the participants on their experience of DLA, any applications that they may have made for PIP and their knowledge of the new PIP system.

6.1 Uptake of DLA and PIP

Table 75: Do you get Disability Living Allowance or Personal Independence Payment?

	Total (N)	Total (%)
Receive DLA	40	65.6%%
Receive PIP	0	0.0%
Receive either DLA/PIP – unsure which	5	8.2%
Do not receive either	16	26.2%
Total	61	100.0%

Of the 61 participants, 40 (65.6%) described receiving DLA, 5 people (8.2%) did not know whether they got DLA or PIP, and 16 (26.2%) did not get either DLA or PIP (only one of whom reported unsuccessful application for DLA in the past). None of the participants said they received PIP.

Receipt of DLA was associated with registration status - all 20 (100%) people who were registered as blind (severely sight impaired) were in receipt of DLA and 17 (77%) of those registered as partially sighted (sight impaired). Although the numbers are small, of the 9 people who were not registered as either severely sight impaired nor sight impaired only 2 (22%) were in receipt of DLA. Further information on the criteria used to assess young people's eligibility for DLA is available in the RNIB publication "Benefits for children 2014-2015" (RNIB, 2014).

Table 76: Do you know if you would be eligible for DLA or PIP? What are the reasons why you have not applied for these before?

	Total (N)	Total (%)
Don't know	5	45.5%
Ineligible	3	27.3%
Don't need it	1	9.1%
Don't want it	1	9.1%
Not heard about it	1	9.1%
Total	11	100.0%

The rationale given for not receiving DLA varied (some not knowing and feeling they were ineligible). The self-reporting of ineligibility may be problematic as participants might think they are ineligible when actually they may be. For example one young person commented, "I don't think I can get it whilst I am on the student allowance" when in fact Disabled Students' Allowance should not affect a person's eligibility for DLA/PIP.

One young person who was registered partially sighted spoke about his desire not to apply for DLA as he did not feel comfortable applying for disability specific benefits:

> "I am eligible for it, but I have gone to lengths to make sure I don't have it… I kind of have got a thing against being partially sighted. I mean, I am aware that it is a problem, but I don't really like the idea of using it to my advantage in that way. I don't really like to see it as a fact of my life, I don't like to see it as a source of income. That's what I don't really want."

Likewise another participant commented:

> "I don't want to be either registered or known as disabled cos I'm not disabled. My feeling of it –I'm not disabled. I do have problems with my eyesight, but I get around it. So I don't use it as an excuse. Get on with it!"

Another participant who was registered as partially sighted thought her vision was not seriously enough impaired to apply for DLA.

6.2   DLA awards and components

Table 77: Do you know if your DLA is for a fixed term with review date, or indefinite?

	Total (N)	Total (%)
Fixed award	6	15.4%
Indefinite award	18	46.2%
Don't know	15	38.5%
Total	39	100.0%

Being in receipt of an indefinite award appears to be more common amongst participants who were registered as severely sight impaired. Of the 18 people in receipt of an indefinite award 11 (61.1%) people were registered as blind (severely sight impaired). It is also interesting that 15 people did not know the term of their award which reinforces the observations shown throughout this section that young people do not know very much about the benefits that they receive (and is highlighted in the tables which follow regarding award level and components).

Table 78: DLA components received (care and mobility)

Question and responses	Total (N)	Total (%)
Do you get the care component of DLA?		
Yes	19	55.9%
No	3	8.8%
Don't know	12	35.3%
Total	34	100.0%
Do you get the mobility component of DLA?		
Yes	24	70.6%
No	0	0.0%
Don't know	10	29.4%
Total	34	100%
Care and mobility components combined		
Both mobility and care components	18	75%
Just mobility	6	25%
Just care	0	0%
Total	24	100.0%

Table 79: DLA rate received

What rate of care do you receive?	Total (N)	Total (%)
Highest	2	6.3%
Middle	10	31.3%
Lowest	3	9.4%
Don't know	17	53.1%
Total	32	100.0%
What rate of mobility do you receive?	Total (N)	Total (%)
Higher	11	31.4%
Lower	7	20.0%
Don't know	17	48.6%
Total	35	100.0%

Participants received a range of award rates reflecting their personal circumstances as individuals with a visual impairment. However of more interest for this study is that only a third (13 people) of those claiming DLA knew their award levels. Once again this highlights the finding in this report that many of the young people in the study were less likely to be engaged with their DLA in terms of the award levels/rates, i.e. "the mechanics" of DLA, but had more to say on what they used their DLA for, and its importance.

6.3 How the young people use DLA

Thirty-nine people listed 74 things that they use their DLA money for, which could be grouped into 18 different categories.

Table 80: What do you use the DLA money for? (N=39)

	Total (N)	Total (%)
Transport	24	61.5%
Save	6	20.5%
Everyday items	6	20.5%
Food	5	12.8%
Low vision aid	4	10.3%
Leisure activities	4	10.3%
Technology	4	10.3%
Books	3	7.7%
Clothes	3	7.7%
Glasses	3	7.7%
Rent/board	3	7.7%
Paper	3	7.7%
Cane	1	2.6%
Extra costs because of my disability	1	2.6%
Holidays	1	2.6%
Personal grooming	1	2.6%
See things before I go blind	1	2.6%
Specialised trike	1	2.6%

Although not explicitly expressed it appeared that for some young people it was the first or one of the first times that they had explicitly thought about what they use their DLA for, as seen in the following examples:

> Participant: "Sometimes to buy clothes, other times use for… varies."
> Researcher: "How important is the contribution that you receive through DLA?"
> Participant: "Not sure."

> Participant: "Buying my iPad and stuff. "
> Researcher: "So more kind of equipment."
> Participant: "Yeah."
> Researcher: "And how important to you is the contribution that you receive through DLA?"
> Participant: "Yeah, important."

Any monies received through DLA can be spent (or saved) as an individual sees fit, however a number of participants were keen to make

it clear to the researchers that they used their income 'appropriately'. (This may have reflected anxiety in some participants that they were being assessed or tested. However, this seems unlikely given the research team had worked with these young people for some four years.) For example one participant was keen to explain why she used her DLA money to have her eyebrows waxed:

> "I know it sounds silly, but when you have your eyebrows waxed, I can't do that myself, because you need to have your glasses off, so I pay to have that done. You don't have to, but that's what I use it for, and stuff like that as well, if I can't do it myself."

Transport

Transport was by far the most frequent thing that participants spent their DLA on with some participants using it for frequent hospital appointments and others using it for public transport. Once again we see that the young people were keen to justify their expenditure, for example two participants separately commented:

> "This is going to sound bad but sometimes I use it for taxis, like on Sundays when there are no buses. Taxis and stuff like that mostly. Getting around. And whatever I need to. I hate Sundays – I live in the middle of nowhere!"

> "Because I use public transport, I don't know if it's fair to say more than the average person, but a lot anyway, and I tend to use taxis quite a lot, because I am not that confident on buses, and taxis can be very expensive, as can train fares, so it's my main source of getting around basically."

Saving

Saving was the (joint) second most frequent thing that the participants did with their DLA money; sometimes this was a specific item for example one participant saved £600 to purchase a low vision aid and another young person bought a trike. For others, saving in general was important as they did not know what the future would hold in terms of their visual impairment, for example one young person observed:

> "I think it's wise to save up a bit as well, so I save up, because there is going to be a lot of stuff that I need to buy for my sight condition."

Another participant was unsure about education and employment in the future and saw her DLA as helping to provide a safety net for an uncertain future:

> "I know I've got a lot saved up, so when it comes important I have it to use."

Everyday items and food

Everyday items and food were the joint second and third most cited uses for DLA money

> "So I use it for like buying food at college, for train fares, clothes, going out. Just everything really."

Once again participants were keen to justify their expenses, with one participant pointing out that she was a regular teenager:

> "So some of it I spend it on food, and a fair bit on leisure. I am a teenager, I do go out."

Some of the young people were explicit in highlighting that it is often not practical to clearly demarcate what income is spent on what.

> "It just goes into my account, and then everything gets used for everything, so, I don't know, taxis and trains and food."

> Researcher: "What do you use your DLA money for?"
> Participant: "Living, I suppose. I don't know. I don't really divide it up specifically."
> Researcher: "So it just goes into a central pot?"
> Participant: "Yeah, I just try not to waste money generally, buy what I need to. I treat money without the context of the situation. I try not to be wasteful."

For other young people there was the suggestion that they were establishing the uses for their DLA income in their mind whilst they were responding to the question:

> "I use it for food, transport, rent, that's about it. If I need any aids, like if my magnifier broke, the batteries for it, and the light, things like that."

"I use it to you know, live basically, and also for my photography work, things like that."

"I use quite a lot for everyday life to be honest. There's loads of stuff that I'd love to use it for. Sometimes I use for taxis, but I don't really do taxis. Trains because I go home every so often. Mostly everyday life like food, clothes, shoes, doggy stuff. "

Additionally two of the young people spoke about how the money that they receive from DLA goes to support their family's finances rather than them as an individual:

"I don't really like claiming for things that I don't really need. It's nice to have a bit of money but that money stretches for me. I think my mum would REALLY struggle. Really, really struggle, cos of how many of us there is. So I'm glad that I've got it so I can pay her my board to help her out, and I've still money to be able to support myself, so without it I would really struggle."

A couple of the young people were also happy for their parents to continue receiving their DLA money into their bank account even once they had turned 16 years old:

"Basically they asked if they wanted to put it in my bank account, but I said my mum should keep it because they get me everything I want, and I am not abandoned. I prefer it to go that way, so that I won't waste it."

However on the other hand one young man faced difficulties because his mother wanted to continue receiving his DLA money whereas he felt differently:

"No, I am 16, I should be looking after my own finances now – let me get it".

These examples serve to show that it is important to understand DLA and PIP within the context of the families and circumstances in which the young people are located.

6.4 Perceived importance of receiving DLA

Of the 36 young people who responded to the question "How important to you is the contribution that you receive through DLA?" 33 (91.7%) people thought that the contribution was 'important' or 'very important', with only one person say that it was 'unimportant'. Two people were unsure of the importance of their contribution received through DLA. The importance of DLA is captured in the young people's comments, for example:

> "It's brilliant, yeah. Really helps"

> "It is extremely important… Without that, I would not be able to do anything at all"

> "Oh very much. I don't know what I would do without it, to be honest, because I am not in a job yet."

The comments made by the young people highlight the differences in opinion held by individuals regarding the reasons for DLA's existence.

Compensation for extra costs of disability

Some people saw DLA as a compensation for the extra costs that a person with a disability incurs, e.g.

> "It is important, because things like taxis are expensive, and obviously if I could see, I wouldn't need to use them"

> "It's really helpful. It's really important as well. Because there are extra costs, cos if you weren't visually impaired then those costs wouldn't be there so it's only fair that you get the DLA."

> "I think... the whole benefit is important because it gives me some extra money, because a normal teenager doesn't have to spend as much as I do because of my disability I think that it is good that we have that opportunity to have some extra money."

Compensation for disability in general

Alternatively, some of the young people saw that the contribution that they received through DLA as compensation for having a disability either in terms of having a disability per se, or as a counter to the reduced opportunities that a person with a disability might face. One participant

would use her DLA for "holidays and the like" and another who went on school trips offer examples of the former, e.g.:

> "Because without [the DLA contribution] I would struggle to do half the stuff I do, like school trips and things like that, and I use the DLA money for that so I can see things before I got blind, so I've got photo albums, so it's very important."

Another participant argues that her DLA contribution was important because as a visually impaired young person attending a residential school she was unable to take part in part-time employment her DLA provided her with a degree of independence:

> "…obviously being away at school, it's the money that I have. I can't get a job or whatever, because I am away, and I have to rely on my parents a lot more. It would be quite difficult really. So if you want to be financially independent, other people your age can get a Saturday job or whatever, and you can't, it's quite infuriating. I do think it's important to be able to have your own money."

6.5 Applying for DLA

6.5.1 Recollection of the experience of applying for DLA

Twenty-six of the participants spoke about their experiences of applying for DLA. Seventeen of these people (65.4%) said that their parents completed their DLA application form, five (19.2%) completed their application form themselves, and four (15.4%) people could not remember who completed their DLA application form.

Many of the parents of the participants had applied for DLA for the young people as application often happened at the time of diagnosis, often when the young people were babies/young children.

> "Dad did it. Can't really recall anything at all. I think that I was about six."

> "My mother sorted all of that out."

Furthermore up until the age of 16 parents/carers have to apply for a young person's DLA, they cannot do it for themselves. Some of the young people did however speak about the transition from their DLA going into their parent's bank account to their own, and apart from the

person whose experiences have been discussed above, the remaining participants who spoke about the transfer commented how easy it was.

> "Yeah we just rang up and said I'm 16 now can it be changed to this bank account and we literally just changed it from my parent's bank account to mine"

> "Yeah they just said yeah I'm old enough to have my own money. And I thought it was brilliant!"

Although many of the participants were unable to talk specifically about their application process as they did not remember it, or it was dealt with by their parents, four people spoke of the ease of the process:

> "It was brilliant yeah, really easy"

> "It was fine. No problems at all."

In contrast, ten people spoke about their difficulties and frustrations with the process of applying for DLA. Some of problems related to process difficulties in accessing the application form:

> "I haven't applied, my mum applied for me. I find it quite difficult sometimes, filling in application forms and that. Because it's small, then my Mum does it for me."

> "They send [documents] in print, but even if you ring and say 'I can't read this' they won't send you anything different."

Another participant was also critical of the application process and in particular the fact that a system set up to support people with disabilities, ought to know better:

> "It was long winded, and they don't have electronic forms. .. It's daft, DSA [Disabled Student's Allowance] is exactly the same, you can't get any forms, or any letters they send you, anything like that, in braille, or electronic, and then they expect you to fill them out, so. They used to have a department that you could call them, and they would fill them out over the phone, but because of all the government cut backs they have got rid of them now. They all seem to think that we have got little fairies that sit on our shoulders and pop up to do things!"

One of the participants however was supported by the use of a reader scribe to help facilitate his completion of his application form.

For a number of participants one of the major frustrations of the application process was that people had to restate their case, or go for medical assessments when it was "obvious" to them, by virtue of their registration status or their eye condition that they were eligible for DLA.

> Participant: "I found it a bit stupid because they just did like, they wanted to do a field vision test or something, and to be registered blind you had to be able to see none of it, but what was the point in going to a field vision test. You had to do this test."
> Researcher: "So they should have been able to take that information from your certificate?"
> Participant: "Yeah. Because I think out of 50, I got 4, and still wasn't worth it, and it was like 'really.'"

> Participant: "But yeah, I had the review when I was 16, and that was quite annoying."
> Researcher: "What was annoying about it?"
> Participant: "They asked all these questions which haven't changed. How it affects you. The questions that were asked are very ambiguous."

Similarly, as we shall see later in relation to the changes associated with DLA and the movement towards PIP, some participants were frustrated that they would have to reapply for PIP, or thought that changes in the process of applying for PIP would not affect them as they were in 'genuine need' of support.

A few of the participants who were at residential school/college also spoke about the difficulties of getting the right amount of DLA or understanding how and why their DLA changed, due to differences in the care component whilst at school/college:

> "I had a bit of trouble when I went to [school/college], they stopped my DLA payments altogether for several months because I had gone to[school/college], and there was some issue with them taking away the care component and taking a while to process that, and in the meantime, I wasn't getting anything, for about six months, so my social worker and people got involved, and after that I got a big payback payment, but that's the only issue I have had with them recently."

Getting the appropriate support to help her complete her DLA application whilst at residential school/college was difficult for one participant:

> "You have got to find someone to help, because obviously I was [at school/college], so it's finding someone who has the kind of time around to sit and fill them all out, and [the forms] are ridiculously long-winded."

Accurate, professional, specialist advice is extremely important for people with disabilities as they negotiate the process of claiming for disability related benefits (Banks and Lawrence, 2005; SSMR, 2009; Wilson and Amir, 2008). Unfortunately some of the participants reported having no advice, or unhelpful advice:

> "I had to do my best really. It would have been nice to have some specialist advice, someone on my side. But unfortunately, I did not get any of that."

For one participant the support that he received from college was not helpful,

> "Horrific actually. Yeah, I mean, in theory I got help from college, but it wasn't helpful help really. It was all kind of overwhelming"

This suggests that perhaps that his college was not the most appropriate place to go for specialist advice, although it may have been his first port of call.

A couple of people however spoke about the input from their doctor/consultant in producing lengthy documents to support their claim. Four people did however mention that their parents had sought specialist advice from specific organisations, these being – Action for Blind People, RNIB, and Citizen's Advice Bureau. Previous research drawing upon the experiences of visually impaired people more generally in 2007 found that advice had a positive association with successful DLA claims (Douglas et al, 2008).

6.5.2   The appeals process

Only one of the participants had applied for DLA and then been unsuccessful. He had not thought about appealing the decision, perhaps because he was unsure whether he would be successful or not saying "I was hoping, I wasn't expecting it." He described the application process

as "Not very easy, not very easy at all." He had not received any specialist advice with regards to his application.

A few of the participants spoke about not agreeing with the rate/component of their DLA. One participant who received an indefinite award of DLA in relation to the mobility component, commented:

> "I use the money for,…it's Disability Living Allowance, so for getting any equipment that I need. Any support that I need. It's quite broad really, I use it to assist my everyday life really. It's a shame how I don't get that care, because of the support that I need, I do need it."

In some cases the young people or their parents appealed their original outcome, for example in relation to the care component 7 people appealed their original decision, with 16 (47% of those receiving DLA) people successful on their first application, and 11 people not knowing whether they got their rate of care on their first application.

> "Basically… all I know is that my mum appealed it."

A couple of participants also spoke about the wider changes that had happened and its impact on their circumstances (appearing to refer to change in the law in 2011 which guaranteed a higher mobility rate of DLA for people registered severely sight impaired).

> "We didn't get higher rate mobility. We got higher rate mobility after action taken by the RNIB, in general. That is after they passed that all VI people should get higher rate mobility, before that, it was middle."

> "Blind people didn't used to be able to get high mobility – I've had middle care. But blind people only used to be able to get the lower rate of mobility, but a couple of years ago there was some legislation which said if you are registered severely visually impaired, you can get the higher rate. So what I did was contact Action for Blind People, I actually contacted the DWP, but they kept sending me change of circumstances forms, but I was like my circumstances haven't changed – your circumstances have changed! Like their rules – it wasn't me! But what Action for Blind People did was give me the code for this specific form that I needed so I just requested that form and I got that. I filled it in to state that I am severely visually impaired and I sent off my certificate of visual impairment and they just changed it

automatically from that. Cos it was where their rules had changed, rather than my circumstances."

6.6 Awareness and thoughts on DLA and PIP policy changes

Table 81: Awareness that DLA was going to be changed to PIP, by current DLA award. N=49

DLA Award	Aware of PIP (N)	Aware of PIP (%)	Not aware of PIP (N)	Not aware of PIP (%)
No DLA	2	22.2%	7	77.8%
Fixed award	2	33.3%	4	66.7%
Indefinite award	12	66.7%	6	33.3%
Don't know award / refused to say	9	56.3%	7	43.8%
Total	25	51.0%	24	49.0%

Of the 49 people who responded to this question 25 (51%) were aware that people on DLA are going to be gradually switched over to PIPs, and 24 (49%) were not aware. When examining the data more closely in terms of award we see difference in awareness according to the award that the participants received. For example one participant who is not in receipt of DLA said, "I have no clue what it means. I dunno. I've never really been into benefits or anything like that. I don't know how it all works to start with." It is probably to be expected that those who do not receive DLA are less likely to be aware of the changes to disability benefits however for those already in receipt of DLA it is interesting to note that only 23 (58%) people were aware of the forthcoming changes. It raises questions as to why these young people are not aware of the changes - lack of accessible information and disinterest in the benefits procedures are possible answers. Likewise looking at the differences in awareness in terms of gender we see that 17 (61%) of the females compared with 8 (38%) of the males were aware of the forthcoming changes. While numbers are small, this suggests that some awareness-raising amongst this group may be useful.

Although the numbers of those in receipt of a fixed award are small, we see that they were less likely than those in receipt of an indefinite award to be aware of the upcoming changes. One reason for this may be that those receiving an indefinite award are more likely to have a more severe visual impairment and may view their impairment more central to

who they are or their identity, and may be more attuned to look out for more information about disability. Also people with more significant impairments may feel that any changes to the benefits system are disproportionately more likely to impact upon them negatively. Even so, those on fixed term DLA awards are more likely to need to apply for PIP in the shorter term – so it may be this group who have greater need to know about it.

Many of those that were aware of the changes did not know much about it beyond that it was happening.

> "I have heard about that, but I haven't got a bloomin' clue how it's going to work."

Another participant said that she knew that the change was happening and when asked what she knew she responded, "Not a lot really." In response to the same question a further participant said, "Just that we are getting PIPs, switching to a new type of benefit."

A few of participants viewed the changes with cynicism and saw them as merely a money saving exercise by the government rather than the development of a more person-centred benefits system.

> "But I assume it's a cost cutting thing, so, you know, it doesn't take a rocket scientist to work out we are going to lose money."

> "It's a government method for saving money, sacrificing other people that will need that money to help them be better. I think there are other things that they should be cutting first."

Some of the young people were concerned about the changes, with many reporting a lack of firm knowledge and information on the process and likely outcomes.

> "I have heard a lot, what I have heard about it hasn't been very positive. Most people I have spoken to have been worried about it, saying they are going to be a lot more stern and strict about it, and the way that they assess you, is going to be really sort of, strategic. Someone told me that they assess you from the minute you get there, not the minute that you get in the office, so the way that you get to the assessing place will contribute to your assessment. So whether you take the bus, or get a taxi, or whatever, they will take that into account. I haven't really heard

much about it, because not many people I have spoken to know that much about it. But what I have heard, hasn't been very positive, or encouraging."

"It's quite frustrating that we haven't really been told. I don't feel we have been told many of the impacts. You know, what's going to happen. Obviously it's a very grey area, sort of thing. There's been very little on the news, and things like that, so we don't know the impacts yet. Hopefully they won't be too great."

"I think, the thing with PIP is there is so much contradictory information, it's really hard to have an opinion isn't it. You know, you don't know quite who it is going to affect and how it's going to affect them, so it's really hard to assess where you fit into that, and what you think on it."

Another point that was raised was that people with disabilities are perhaps more likely to struggle with application forms and assessments, yet they are the ones who have to deal with the changes – "it's targeting people who can't defend themselves a lot of the time." In contrast, another young person suggested that as a person with a visual impairment she was in less of a need for benefits as she was more able to work than other people with disabilities, and therefore reclaiming for PIP was just a necessary process:

"From my perspective it doesn't bother me, lots of people say it's unfair that we have to reclaim but it's just how it is, it's just the system - like we could not get any of it! From my perspective yeah the rates might be lower but actually as someone who is blind we don't actually have the right to complain because we can go out and get jobs and have normal lives."

This young person's comment "…like we could not get any of it!" reflects the opinions of some of the other participants, in that they were unconcerned about the changes or were confused as to why they were taking place as they saw themselves as having a legitimate disability that 'should' get PIP.

"No it doesn't make any sense to me. I don't see why I would lose my disability [benefit] to be honest. Even though I'm not critically ill, or physically disabled, there's a lot more things I need the benefit. It's not like a little injury… I don't need to claim but I have the right to claim it. Whereas a lot of people claim it when they don't have

the right. Which annoys me. They're claiming this, and claiming that. You don't need it! It affects my independence because I haven't got the living skills, I can't see a cooker, can't see a washing machine. I'm very vulnerable by myself. I can't drive. So it does affect my independence, even though I act as though it doesn't effect. It DOES in certain circumstances."

"I don't support the Conservatives. I don't know what they are changing, I just know they are changing, but I am assuming that I should get what I get now, because it's never, my eyesight has never changed. And I assume because I get middle rate for stuff, it means I am not in the lower band of people. I assume. And because I have got it indefinitely. I think it shows, because if it was a fixed person it shows there's some ambiguity there, because I think I have got it indefinitely, it shows that I haven't, it's not going to change."

Some of the participants, at the time of the interview (October – December 2013), were also unconcerned about the changeover from DLA to PIP, as for them the changes were far away future.

"That's the thing, they send you a letter saying you will be reassessed in 2015, so like I said, most people will just put it aside and forget about it."

One person was quite anxious and asked the researcher for more detailed information on the changes, when he realised that the changes for him would not be imminent he relaxed and said, "Oh right, a couple of years – oh fine." Similarly a further participant said, "I'm not going to worry about it until it happens!"

One further concern of a couple of the participants was that the assessments were going to be carried out by those who do not understand the real life experience of a person with a disability:

"It is probably going to be ridiculous because it will probably be judged by people who have never met blind people before, and don't know what they are talking about. But that's probably me being very critical, and judgemental, and I hope it won't be like that."

"I think some of the criteria is very very stereotypical. Like I think a friend of mine was reading it, and she saw 'can you walk 10

metres', and it's just we are going back to the old school idea that to be disabled is to be in a wheelchair and can't walk, so I find it a bit ridiculous."

However one young person did feel supported by her doctor who she felt did understand her disability and its nuances and was confident that she would be able to 'prove' this to assessors:

"I hope my doctor can put it in a way that... I'm not allowed to drive, I can't use… the only thing I can use is public transport, and it's very expensive. And I need large print text books, I need all this stuff because I can't see smaller than that for periods of time… I assume because I am reassessed my doctor will have to send in new things. He is good at kind of phrasing things… He doesn't ever lie, he just says it as it is. He makes the clear distinction between, just because you can see this on the best day, it doesn't mean you can see well on the worst day."

7 CONCLUSIONS

Longitudinal Study

We have now been following this group of young people for approaching four years, and as mentioned in our previous technical report, it is encouraging to see so many of the original participants still engaged within the project. We take this as an indicator of how important they view the issues being addressed by the project to be.

Over the past twelve months, we have seen many successful transition outcomes for the participants. Almost all of the participants who made the transition to university in the academic year 2012-2013 successfully completed the first year. Unfortunately there are concerns for one participant who had severe problems with accessing his course (this will be explored further in a forthcoming report, which will focus specifically on the participants who are pursuing the university pathway) and another participant who dropped out of university after one semester, and has been NEET ever since.

At the time of the summer 2013 interviews, there were six participants who were looking for employment/apprenticeships, and positively one of these young people had secured employment by the time of the autumn interviews. From this, and previous waves of interviews, there are some indications that there are not as many apprenticeship opportunities available as the young people may have been led to believe, or at least, they are struggling to locate them.

There were some causes of concern when talking with this group of young people. In particular, one young man who had been feeling very positive after being offered a casual contract with a local charity for blind people. As a result of this job offer he had stopped looking for other work opportunities and was waiting until his CRB check was approved. However, in reality he has only been offered work on one occasion, and this has proved to be very demoralising for him. There were also concerns for a participant who completed special college for students with VI, but since returning home had not seemed to have engaged in searching for work, or to have had a strategy in mind. Instead he appears to have concluded that there was nothing suitable available for him. In both cases there were indications that the young people were at least approaching the point where they had given up on finding

something suitable for them to do. Not just as a young person who was NEET, but as a young person with a severe visual impairment.

In contrast, there have been several participants who have successfully made the transition into employment/apprenticeships. In addition to this, we have also observed some who are progressing in their roles – for example, moving from apprenticeships into permanent employment, or starting to work towards a supervisory role. In our focused analysis, it will be important to start investigating the relationship between these successful transition experiences, and some of the factors which have been identified as indicators of successful transitions by previous research studies.

Despite the fact that we have identified eleven participants who are in employment/apprenticeships, none of them had made contact with Access to Work. In some ways, this is to be expected, as many of those who have made this transition are also those who have described being able to cope simply by making their own adaptations in the work place, just as they have described doing in a classroom environment. In other cases however, particularly one participant who does need to use specialist software but looked to his employer to provide it, it could be argued that at least a discussion with an Access to Work advisor to see what support was available would have been beneficial.

To get a clear picture of how well Access to Work is supporting young people with visual impairments into employment, instead it will be necessary to wait for more of our participants to enter the labour market. We note that those participants with more severe visual impairments, who are more likely to need the support of Access to Work, tended to be the ones who have moved on to university, and therefore they will not be making the transition into employment for another two-four years. This highlights the importance of continuing this longitudinal research further, to ensure that we get a complete overview of the experiences of these young people.

Registration and DLA/PIP

After speaking with the young people about their knowledge of the registration process and the associated benefits of registration, there are some concerns over the lack of engagement that 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 and personal independence payments. It is

understandable that the young people's parents will have taken responsibility for things like these when their children were younger. However, now these participants are young adults, and it could be argued that they would benefit by starting to take more responsibility and interest in these more formal aspects of having a visual impairment.

Accessing Information and Equipment

A key factor for the young people in looking to make the transition into employment will be their ability to access information. The autumn 2013 interviews have raised a number of concerns about the young people, and just how well prepared some of them are.

Firstly, there is some indication of a rather 'patchy' approach in the provision of low vision aids for the young people. Only six of the participants spoke of attending some form of low vision clinic, and having the opportunity to experiment with low vision aids and see which would suit them best. Others spoke of their experiences of being given low vision aids by people presumably unqualified to do so (such as parents and school SENCo), only to conclude that low vision aids were impractical for them, and discounting them altogether.

Secondly, there is some evidence of a gap in training for the young people who use specialist accessibility software. This particularly seems to be the case for participants who have attended special secondary schools. Very few of these participants attended these specialist schools throughout their secondary education. For example, one participant attended mainstream school until their GCSE exams and then changed to special residential school/college, whilst another participant attended from the first year of secondary school, completed her GCSEs, before then moving to a mainstream college. Whilst speculative, it does appear that this creates some difficulties in ensuring that the students receive the necessary training in the specialist software which they use. This was highlighted in the case of one participant who initially used magnification software, but as her eyesight deteriorated moved to using Jaws screen reader. She had received training previously in using magnification software, but during the course of the interview had the realisation that during school she had never received any tuition in using any type of screen reader software. She received training in Jaws as part of her DSA, and during this training became aware of large gaps in her knowledge. This meant that she was taking a lot longer in navigating through documents than was necessary. For a person with a visual impairment needing to be competitive in the job market, being able to

access information and use a computer at a fast pace, is an important skill.

Finally, we have particular concerns for two of the participants who realistically soon may not be equipped to access information at all. In both cases, the nature of their respective eye conditions means that their visual impairment is getting gradually worse, and eventually they will not be able to use print (currently their only means of reading). They described half-hearted attempts to teach them braille, but neither have received sufficient tuition for it to be a viable method of reading for them. In addition, neither have received sufficient training in be able to use screen reading software, and do not appear to have access to it to start learning now. Both participants seem very aware of their changing condition, and have concerns about how this is going to impact on them. They both report that it was known that their conditions would change like this, although it is unclear whether it was expected that their visual impairment would be so severe at this stage in their lives. Nevertheless, it does raise the question of whether the educational system should have been working in anticipation of their conditions, ensuring that they would be fully equipped in these skills, even if they did not need them immediately in completing their courses. Part of the post-14 transition process involves transition planning where agencies meet together to discuss what needs to be put in place to ensure a successful transition from school. It could be argued that simply putting plans in place which would ensure that the young person will be able to read once they get to employment age should be a priority item on the transition agenda. Both young people do appear to be victims of the fact that their eye conditions are progressive. Whilst we only have a limited sample and it is important not to generalise, it raises a question of whether the services around them were designed to meet only immediate needs, and not to anticipate future ones.

Within the field there have been suggestions that braille will soon be made redundant and replaced by using specialist speech software. It is interesting to see how the young people who use braille still generally really value it. They may not use it as extensively as in the past, but were clear that there are some tasks where braille is preferable to using speech software. This was particularly the case for those students who are at university. Perhaps it would be more appropriate to suggest that hard copy braille is seen by them as being redundant, with many explaining how instead they benefit from using a form of electronic, refreshable braille. In several cases the participants who use electronic refreshable braille did not have access to a device until it was provided

as part of their disabled student allowance. Therefore it is possible that there are other visually impaired young people who may benefit from using braille this way, but have not had an opportunity to try.

A final focus of this report has been the young people's use of mainstream technology as assistive tools to help them with their visual impairment. The participants gave an extensive list of examples of ways in which they use mainstream technology both as low vision aids, and also as ways to help them access information. Whilst historically touch screen technology has been seen as a barrier for people with visual impairments, the introduction of inbuilt screen reading software has opened up new opportunities for this group. For young people with visual impairments in school who have struggled with feeling 'different' when using specialist low vision aids in the classroom, the fact that this mainstream technology is becoming both more accessible for them, and also has the potential to act as a form of low vision aid, will be particularly welcome.

8 FUTURE PLANS

This report is part of a series of reports from a longitudinal study, which is following the transition experiences of 80 young people. The project commenced in autumn 2009, and is currently funded to continue until March 2015, with intentions to secure funding to extend this further. The overall objective of the project is to follow the experiences of these young people until they seek to enter the labour market.

During each year of the project, we plan to speak to the young people once in depth about particular issues relating to transition, along with shorter interviews which will help track their journey.

In summer 2013, we commenced case study work, looking at the experiences of several of the young people in more depth, and particularly focusing on the influences of people around them (for example family, support services, university disability support offices and Access to work). We are also conducting annual surveys of the support services that work with the young people whilst at school and to learn more about the role that they play, particularly in the context of changing legislation.

Future findings will be presented in technical reports similar to this one, focused reports and research briefings looking at particular themes, and papers in peer-reviewed journals. A conference to present the findings of the longitudinal study is scheduled for spring 2015.

9 APPENDIX

9.1 Interview schedule

Nuffield Transitions Project
Autumn 2013 Interviews – Vision and DLA/PIPs

Name:

I am phoning from University of Birmingham in relation to the Transitions Project that you agreed to take part in. Are you still happy to take part in the project?

Yes [ ] No [ ]

We have an interview that we would like to conduct with you. This will be particularly focusing on your vision, and the tools, tactics and equipment that you use. We are also interested in asking you some questions about any benefits you may receive in relation to your visual impairment, particularly in the context of the changes which have been made to the benefit system recently. The interview will take approximately 45 minutes. Is this a suitable time?

This interview asks some more personal questions than we have used in the past. If there are any questions that you would prefer not to answer, please say and we can move onto the next question.

I would like to remind you that this information will be treated confidentially and will not be passed onto anyone. We will ensure that no one is identifiable in any reports we will write.

We would like to record the interview to ensure that we record everything accurately, and also to help the interview flow better. Would you be happy with this?
Yes [ ] No [ ]

Contact details:

Before we start, can I just double check that we have your most up to date contact details? Do you know if you are planning to change address or telephone number in the next six months?

Are you a member of our Facebook page? [Give details if not]

This interview has four/five main sections:
1. **Catch up on what you are currently doing**
2. **Your vision**
3. **How you see and access information**
4. **(If relevant) Your vision in different contexts**
5. **Disabled Living Allowance (DLA) and Personal Independence Payment (PIP)**

Section 1: Current Status

Last time we spoke with you, you said that you were studying. Is this still the case?

Yes [ ]
No [ ]

[If no] What are you doing now?

Details of changes:

Prompts:
- If left university: what was the reason; are they intending on going back; what are they doing now; what are their plans now?
- If now in employment/apprenticeship: details of the job, application procedure; responsibilities; access to work; adjustments
- If now seeking work/apprenticeship: type of role they are looking for; experience (and approach) of applying for jobs; details of any interviews; access to work
- If back in education: details of course; length; qualification type; plans after that

Section 2: Your vision

In this section I would like ask some questions to help us understand more about your visual impairment and how it affects you. Just to remind you, if there are some questions you do not feel comfortable answering, please say and we can skip them.

Registration of sight problems

The first few questions are about registration of sight problems with the Social Services.

1. As far as you know, are you registered as blind or partially sighted? (and if so, as what?)

    Severely sight impaired (blind) [ ]
    Sight impaired (partially sighted) [ ]
    Registered, but don't know which category [ ]
    Not registered [ ]
    Don't know [ ]

[If registered blind] Were you registered partially sighted before you were registered blind? **(Continue to question 2)**

    Yes [ ]
    No [ ]
    Can't remember [ ]

[If not registered] Do you know if you are eligible to be registered as Blind or Partially Sighted? ['registrable']

    Yes, I am eligible [ ] **(Continue below)**
    No, I am not eligible [ ] **(Continue to question 4)**
    Unsure if eligible or not [ ] **(Continue to question 4**

[If eligible] Could you share your reasons for choosing not to register? **(Continue to question 4)**

2. How long ago were you certified by an ophthalmologist? Do you remember much about the process? How did you find it? Support received? Specialist advice received?

3. What were your main reasons for choosing to become registered? Prompts: pros and cons of registration.
Would you advise other young people with a visual impairment to register? Why?

If the young person is interested in knowing more about registration, refer them to RNIB guidance notes/offer to forward on

Now I am going to ask some questions more specifically about your eyesight.

4. Do you know the medical name of the eye condition that causes your eyesight problem? (Do not prompt, then prompt)

Macular degeneration	
Congenital Glaucoma	
Cataract	
Diabetic eye disease	
Diabetic retinopathy	
Retinitis Pigmentosa	
Injury	
Detached retina	
Other – specify:	
Don't know	
Prefer not to say	

Prompt required:

Yes [ ]
No [ ]

4b. I am not asking for it now, but do you know your visual acuity and visual field, or how to get it?
Yes [ ]
No, but know how to get it [ ]
No [ ]

5. Can you tell me in your own words what is wrong with your eyesight?

6. Put another way, can you explain to me what can you see?

Note to researcher: if established from previous questions that visual impairment is minimal (e.g. stated that not eligible for registration, or demonstrated in description of what they can see), start from number 3 in list.

7. Assuming comfortable lighting conditions, can you see well enough to:
(we want to know about their sight wearing glasses/contact lenses)

	Yes	No
1. Can I check, in a room during daytime, can you tell by the light where the windows are?		
2. Can you see the shapes of the furniture in a room? (If participant uncertain, ask can you see the furniture, or do you just know where it is by habit)		
3. Can you see well enough to recognise a friend if you get close to his or her face? (If participant uncertain, ask can you actually see the person, or do you just recognise their voice)		
4. Can you see well enough to recognise a friend who is at arm's length away? (If participant uncertain, ask can you actually see who the person is or do you know because you recognise their voice?)		
5. Can you see well enough to recognise a friend across the room? (average size) (If participant uncertain, ask can you actually see who the person is or do you know because you recognise their voice?)		
6. Can you see well enough to recognise a friend across a road? (If participant uncertain, ask can you actually see who the person is or do you know because you recognise their voice?) (An average 2-lane road)		

(If established they are unable to read any print at all, move to question 9)

8. Can you see well enough to, (and if relevant to you, wearing glasses or contact lenses)?

	Yes	No
Can you see well enough to read ordinary newspaper print, without a LVA?		
Can you see well enough to read a large print book (N14), without a LVA?		
Can you see well enough to read a newspaper headline, without a LVA?		

9. How much of the time do you worry about your eyesight? Would you say it's:

> None of the time [ ]
> A little of the time [ ]
> Some of the time [ ]
> Most of the time [ ]
> All of the time [ ]
> Don't know [ ]

10. Do you have how much pain or discomfort in and around your eyes (for example, burning, itching or aching)?

> None [ ]
> Mild [ ]
> Moderate [ ]
> Severe [ ]
> Very severe [ ]
> Don't know [ ]

11. Is the difficulty you have your with sight greater or less than it was a year ago, or is it about the same?

> Greater than a year ago [ ]
> Less than a year ago [ ]
> About the same [ ]

12. Does your eye condition mean that your level of vision can vary from day to day? Could you tell me more about this?

13. Do you ever suffer with eye strain/fatigue when reading, or perhaps when using a computer? Could you tell me more about this?

14. **[If not answered by question above]** Do you have difficulties with glare when using screens, e.g. computer or tablet computer? Could you tell me more about this?

Note to be sensitive for these questions, be aware of potential difficult experiences

15. Have you had any operations on your eyes in the past that have changed your vision? Could you tell me about these?

16. Do you have any operations planned for eyes, that are likely to change your vision? Could you tell me about these?

[   ]

Section 3: How you see and access information
This next set of questions look more at the tools, tactics and equipment that you use, in relation to your vision and everyday life.

17. Do you wear glasses or contact lenses (this could include tints/dark glasses):
 All of the time [ ]
 Most of the time [ ]
 Some of the time [ ]
 Not at all [ ] **(Continue to question 19)**

18. What do you wear your glasses or contact lenses for?
 Reading at near distance [ ]
 Other close-up uses, e.g. sewing (not TV) [ ]
 Distance vision, e.g. TV, walking around [ ]
 To shield against bright lights [ ]
 To protect your eyes [ ]
 Cosmetic reasons [ ]

I am now going to ask you about how you read and any aids you may use to help you read.

19. I'd now like you to think about all the different ways in which people can read. Do you read using: [Tick all that are relevant]
 Ordinary print (with or without a magnifier) [ ]
 Large print (with or without a magnifier) [ ]
 Braille [ ]
 Moon [ ]
 Audio material [ ]
 Someone who reads to you [ ]
 Electronically (without speech output)[ ]
 Electronically (with speech output) [ ]
 E-reader [ ]
 Other
 _____
 None of these [ ]

If would not access print at all, continue to question 24

20. Do you use magnifiers for reading, for example reading newspaper or magazine articles, headlines, labels or packets, your post, or instructions?

        Yes [ ]
        No [ ]
        N/A as do not read at all [ ]

21. What low vision aids do you have?

        Magnifier - hand held without a built in light [ ]
        Hand held magnifier with a built in light [ ]
        Pocket magnifier (often used for 'outdoor' tasks such as shopping) [ ]
        Magnifier - on a stand with light [ ]
        Magnifier - on a stand without light [ ]
        Magnifier - attached to glasses? [ ]
        Magnifier mounted in/on spectacles glasses? [ ]
        Binoculars - monocular or hand-held telescope [ ]
        CCTV [ ]
        Other – SPECIFY [ ]

[If do not use low vision aids]. Have you ever tried using low vision aids, for example magnifying glasses, lights, telescopes or CCTVs?

        Yes [ ]
        No [ ]
        Don't know / Can't remember [ ]

22. Could you tell me a bit more about the low vision aids you use?
- When did you first start using them?
- Who taught you how to use them?
- How do you find using them?
- What type of things would you use your low vision aids for?

23. How do you find using low vision aids?
- Do you have any difficulties in using them?
- Would you use magnifiers at home?
- How about outside of the house?
- How did you find using them in school/college?

24. If you were to receive written documents to read, what font size would you request:

    a) If you were not using any low vision aids _____

    b) If you were using a low vision aid _____

How do you communicate in writing with sighted people? [Select all that are relevant]

    Pen (writing) [ ]

    Electronic document (e.g. word/PDF) [ ]

    Email [ ]

    Social media (e.g. Facebook/Twitter) [ ]

    Text message [ ]

    Some other way [ ]

    _____

    None of these – I don't communicate in writing [ ]

IT SKILLS (FOR ALL)

The following set of questions are looking at how you use computers. Initially we are talking about desktop and/or laptop computers (e.g. a PC or Apple Mac)

25. In what ways are you able to access a computer? [Select all that apply]

    Computer with no adjustments [ ]

    Computer with basic adjustments (e.g. enlarged icons; mouse pointer [ ] Computer with specialist magnification software [ ]

    Computer with specialist speech software [ ]

    Computer with specialist speech & magnification [ ]

    Other [ ] Details:

    _____

In which way would you prefer to access a computer?

    Computer with no adjustments [ ]

    Computer with basic adjustments (e.g. enlarged icons; mouse pointer [ ] **(Continue to question 26.)**

    Computer with specialist magnification software [ ] **Continue to question 27**

    Computer with specialist speech software [ ] **Continue to question 27**

    Computer with specialist speech & magnification [ ] **Continue to question 27**

Other [ ] Details:

_____

(Continue to most appropriate question)

26. We are particularly interested in the way in which you use a computer, and the training that you have received in the past. Could you tell me more about the adjustments you make and how you learned to make them (prompts: training received, who from)? Are you able to make these adjustments yourself if you were to access a new computer? **(Continue to question 29)**

┌───┐
│   │
└───┘

27. We are particularly interested in the way in which you use a computer, and the training that you have received in the past. Could you tell me more about the software you use, who trained you to use it, and the training you have received? Are you able to use this software independently (i.e. set it up yourself)?

┌───┐
│   │
└───┘

28. How confident do you feel in using specialist accessibility software?
Very confident [ ]
Confident [ ]
Not very confident [ ]
Not at all confident [ ]
Unsure [ ]

29. What has helped you in improving your confidence? **OR** What has restricted you in gaining confidence?

┌───┐
│   │
└───┘

30. We are also interested in any other electronic devices that you may use and what you might use them for. Examples could include, but not exclusively, tablet computers, E-readers, mobile phones/smartphones. Could you tell us more about any devices you use that might be relevant, and also what you would use them for?

Prompt: We are also particularly interested in how young people with visual impairments are using mainstream technology, for example iPads and smartphones, as assistive tools to help them with their visual impairment.
• Is this something that you personally would do?
• Can you think of any examples?

How did you find out that it was possible to use the devices in this way – for example, was it something you discovered yourself, read about, or were shown by friends?

31 How important is ICT to you in your everyday life? Could you explain?
Essential [ ]
Important [ ]
Fairly important [ ]
Fairly unimportant [ ]
Not very important [ ]
Not at all important [ ]

ONLY FOR BRAILLE USERS, PRINT USERS CONTINUE STRAIGHT TO S4

I would now like to ask you some questions about your use of Braille.

B1. At what age did you start learning to use Braille?

B2. Do you recall whose decision it was for you to start learning Braille?

B3. Who taught you Braille? Could you share with me some of your experience? (Setting; method (e.g. one-on-one, group); how they found it)

B4. What would you use Braille for? (Prompts: work/education; around the home; leisure activities)
Reading a novel
Studying
Labelling (e.g. CDs, filing)
Short note taking
Long texts (essays)
Revising
Other

B5. In what ways are you able to access Braille?

Paper (hard copy) Braille [ ]
Electronic Braille note-taker [ ]
Braille Display [ ]

How would you most often access Braille?
Paper (hard copy) Braille [ ]
Electronic Braille note-taker [ ]
Braille Display [ ]

B6. How much opportunity do you get to use Braille? (Prompts: work/education; around the home; leisure activities)

B7. Do you have a preference between using Braille or electronic material? Why?

B8. Could you describe the importance of Braille to you in your everyday life?

If participant is not a print reader, move to Section 5

Section 4: Your vision in different contexts

The next set of questions are designed to help us understand your visual ability, and to help us understand the type of tasks that you might find particularly difficult, and those which you find easier.

I'm going to read you some questions that ask about how what you can see affects what you can do. After each question I will read you a list of possible answers. Please choose the answer that best describes your situation.

Please answer all the questions as if you are wearing your glasses or contact lenses or using low vision devices like Magnifiers, CCTV, Light, Tints etc. (if any).

Please take as much time as you need to answer each question. I won't pass your answers to anyone. Your answers must be as accurate as possible so that we can understand what you can see, what you can do or can't do and how this affects your life. Remember, if you wear glasses or contact lenses or using low vision decides for a particular activity, answer all of the following questions as thought you were wearing or using them.

V1. Education:

For this first section, I would like you to think about when you were in school and taking your GCSEs.

(1= very easy, 2 = easy, 3 = difficult, 4 = very difficult, 5 = don't do for other reason or not interested in doing this)

Categories	1	2	3	4	5
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult did you find your maths lessons?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult did you find your science lessons?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult did you find your geography lessons?					
Because of your eyesight and with your glasses and low vision aids if you use them,					

how difficult did you find your language lessons?					

V2. Near vision:

(1= very easy, 2 = easy, 3 = difficult, 4 = very difficult, 5 = don't do for other reason or not interested in doing this)

Categories	1	2	3	4	5
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult did you find reading text books and work sheets you were given in school?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult did you find reading the smallest print in your text books?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult did you find drawing, colouring or painting?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find reading text messages on your mobile phone?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find it to read restaurant menus?					

V3. Distance vision:

(1= very easy, 2 = easy, 3 = difficult, 4 = very difficult, 5 = don't do for other reason or not interested in doing this)

Categories	1	2	3	4	5
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult did you find reading the board in your class room?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find it to watch television?					

	1	2	3	4	5
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find it to watch film at the cinema?					

V4. Getting around:

(1= very easy, 2 = easy, 3 = difficult, 4 = very difficult, 5 = don't do for other reason or not interested in doing this)

Categories	1	2	3	4	5
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find it going out alone in the day light?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find it to walk in a crowded place?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find using public transport (bus/train)?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find reading bus or train time tables on a screen at a station?					

V5. Social interaction:

(1= very easy, 2 = easy, 3 = difficult, 4 = very difficult, 5 = don't do for other reason or not interested in doing this)

Categories	1	2	3	4	5
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find it to chat with your friends?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find recognizing faces or identifying your friends sitting close by or at your arm length?					

Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find seeing your friends in a playground?					

V6. Entertainment
(1= very easy, 2 = easy, 3 = difficult, 4 = very difficult, 5 = don't do for other reason or not interested in doing this)

Categories	1	2	3	4	5
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find it to use a Playstation?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find it to play computer games?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find using your iPod/phone for playing music?					

V7. Sports
(1= very easy, 2 = easy, 3 = difficult, 4 = very difficult, 5 = don't do for other reason or not interested in doing this)

Categories	1	2	3	4	5
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find swimming?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find it to take part in athletics?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find it to play ball games?					

Section 5: Disabled Living Allowance (DLA) and Personal Independence Payment (PIP)

In this final section, we would like to ask you some questions about Disabled Living Allowance, particularly in the context of the change in benefits system and the introduction of Personal Independence Payment, or PIPs.

32. Do you get Disability Living Allowance or Personal Independence Payment?
      Yes [ ]
      No [ ] **(Continue to question 33)**
      Don't know [ ] **(Continue to question 47)**
      Refused [ ] **(Continue to question 47)**

[If Yes] Which do you receive?
DLA [ ] **(Continue to question 34)**
PIP [ ] **(Continue to question 40)**

33. **[If no, don't receive DLA or PIP]** Have you ever applied for this?
      Yes [ ]
      No [ ]
      Don't know [ ] **(Continue to question 47)**

[If no, never applied] Do you know if you would be eligible for DLA or PIP? What are the reasons why you have not applied for these before? **(Continue to question 47)**

[If applied and unsuccessful] Were you expecting to have been eligible? Did you consider appealing the decision? Experience with process; help from anyone else; specialist advice received **(Continue to question 47)**

For those receiving Disability Living Allowance

34. Do you know if your DLA is for a fixed term with review date, or indefinite?
Fixed award [ ]
Indefinite award [ ]
Don't know [ ]
Prefer not to say [ ]

Do you get the care component of the Disability Living Allowance?
Yes [ ]
No [ ] **(Continue to question 37)**
Don't know [ ] **(Continue to question 37)**
Refused [ ] **(Continue to question 37)**

35. And which rate of the care component do you get?
Highest rate (£79.15) [ ]
Middle rate (£53) [ ]
Lowest rate (21) [ ]
Don't know [ ]
Refused [ ]

36. Did you get this rate on your first application or did you have to appeal?
First application [ ]
Appeal [ ]
Don't know [ ]
Refused [ ]

37. Do you get the mobility component of the Disability Living Allowance?
Yes [ ]
No [ ] **(Continue to question 39)**
Don't know [ ] **(Continue to question 39)**
Refused [ ] **(Continue to question 39)**

38. And which rate of the mobility component do you get?
Higher rate (£55.25) [ ]
Lower rate (£21) [ ]
Don't know [ ]
Refused [ ]

39. What do you use the DLA money for? How important to you is the contribution that you receive through DLA?

Can you recall your experience of applying for DLA? Prompts: Application procedure; help from anyone else; specialist advice received. **(Researcher note: Interested in application as a child, but particularly at/after 16 years)**

Continue to question 47.

For those receiving PIP

40. Do you get the care component of the Personal Independence Payment (PIP)?
      Yes [ ]
      No [ ] **(Continue to question 43)**
      Don't know [ ] **(Continue to question 43)**
      Refused [ ] **(Continue to question 43)**

41. And which rate of the care component do you get?
      Standard (£53) [ ]
      Enhanced (£79.15) [ ]

42. Did you get this rate on your first application or did you have to appeal?
      First application [ ]
      Appeal [ ]
      Don't know [ ]
      Refused [ ]

43. Do you get the mobility component of the Personal Independence Payment (PIP)?
      Yes [ ]
      No [ ] **(Continue to question 45)**
      Don't know [ ] **(Continue to question 45)**
      Refused [ ] **(Continue to question 45)**

44. And which rate of the mobility component do you get?
      Standard (£21) [ ]
      Enhanced (£55.25) [ ]
      Don't know [ ]
      Refused [ ]

45. Could you take some time to tell me more about your experience in applying for PIP? Prompts: did they receive DSA before; how they found completing the forms; assessment process; administration; specialist support received

46. How important to you is the contribution that you receive through PIP? Prompts: anything in particular that it is used for that they would struggle without?

End of interview – continue to final question

All those not receiving PIP

47. Are you aware that people on Disabled Living Allowance are going to be gradually switched over to the new benefits system Personal Independence Payment (PIP), and anyone applying for this type of benefit for the first time would be required to apply for PIPs rather than DLA? (If yes) Could you share with me what have you heard about this?

48. From October 2015, everyone who is still getting DLA will have to make a claim for PIPs. Could you share with me your thoughts on the significance to you of this policy change to introduce PIPs? Is this something that you have been thinking about before this interview?

End of interview

That is all of the questions that I had to ask. Is there anything else you would like to share? Maybe about something related to the interview we have just completed, or maybe something more general that you think is relevant to the project?

9.2 Exploring vision in different contexts

As part of the interview schedule, we incorporated the 25-item Cardiff Visual Ability Questionnaire for Children. This is a measure which was developed by researchers at Cardiff University with the original aim being "to develop and validate a short questionnaire to assess self-reported visual ability in children and young people with a visual impairment" (Khadka et al, 2010).

The instrument involved 25 statements relating to everyday tasks that a young person may face. Those answering the questions were advised to answer the questions as though they were wearing glasses, contact lenses or using low vision aids, as appropriate to them.

The original inclusion criteria for participants involved in developing the original measure included that the young person is able to access print, converse in English, and have no other physical, sensory or severe cognitive impairment. Therefore these questions were only asked of those participants who could meet these inclusion criteria (i.e. those who were not print readers were excluded).

It should also be noted that as some of these questions related specifically to situations that the young person would face in a school environment, we asked the participants to answer the questions retrospectively.

The table below presents the format of some of the questions asked. For further details of questions, please refer to Khadka et al, 2010.

Table 82: Example questions from Cardiff Visual Ability Questionnaire for Children

Statement	Very easy (1)	Easy (2)	Difficult (3)	Very difficult (4)	Don't do for other reason or not interested in doing this (5)
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find maths lessons?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find reading the smallest print in your textbooks?					
Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find reading the board in your class room?					

The Cardiff researchers used rasch analysis to create a score for each possible response the participants could give. These scores would then be averaged to give a measure of that young persons visual ability, i.e.:

The persons visual ability = sum of item measure / number of items answered (excluding items with missing data)

Using a scoring sheet provided by Cardiff University, responses given by the participants to each of the 25 statements were recoded in SPSS, and then visual ability scores calculated. The higher the visual ability score in negative sign, the higher the visual function or ability that is indicated, and vice versa. The table below provides a summary of a number of descriptive statistics calculated from this variable.

Table 83: Descriptive statistics for visual ability score of participants (N=47)

Descriptive statistics	Value
Range	3.50
Minimum score	-1.95
Maximum score	1.55
Mean score	-0.5498 (S.E. 120520
Standard deviation	.82621
Variance	.683

The scatterplot below shows each participants' visual ability score plotted against participant ID number:

Figure 1: Visual ability scores plotted against Participant ID

Number (N=47)
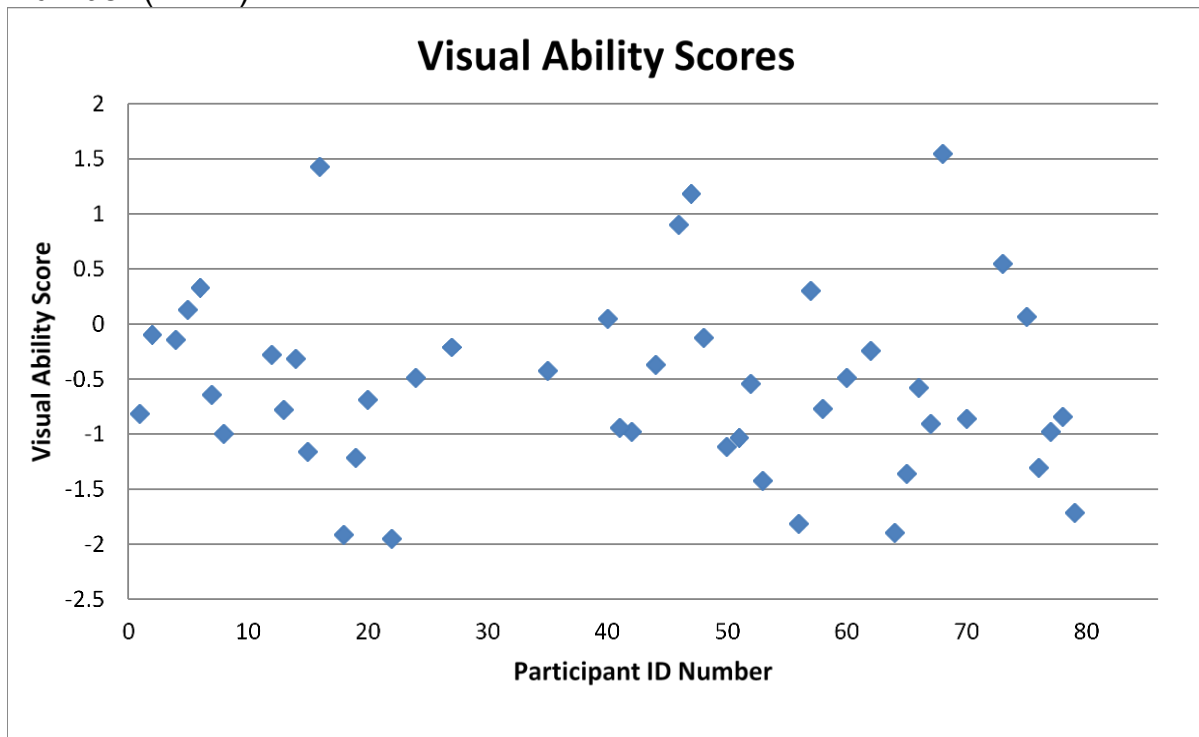
As a guide of reference, if a participant had answered very easy to all statements, their visual ability score would have been -2.966 whilst if they had answered very difficult to all statements, it would have been 2.8016. These visual ability scores will act as important dummy variables when conducting further analysis on the transition outcomes of the participants.

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