UNIVERSITY OF
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Support and Information received by Young People with Visual Impairments

Technical report of findings October 2014 to February 2015

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Glossary

DLA	Disabled Living Allowance
DSA	Disabled Students' Allowance
LVA	Low vision aid
LVC	Low vision clinic
QTV	Qualified teacher of visually impaired children
RNIB	Royal National Institute of Blind People
SENCo	Special Educational Needs Coordinator
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 report presents findings from the research project: “A longitudinal study of blind and partially sighted young people in the UK”. The project has surveyed a sample of young people about their circumstances and views since 2010 when they were aged between 14 and 16 years old.

This report draws upon interviews with 61 young people. The interviews took place in autumn 2014 / spring 2015 when the young people were aged between 19 and 21 years old. The data presented here relates to these young people’s recollections and understandings of:

- medical support relating to their eye condition and engagement with low vision clinics;
- their eye conditions and (often changing) level of vision;
- initial diagnosis and understanding of their eye condition;
- their general health; and
- emotional support and counselling.

Medical support relating to eye condition and low vision clinics

Just under half of the participants still attend a hospital eye clinic, and had either visited one in the previous 12 months, or had an upcoming appointment. The participants who did not attend an eye clinic gave a variety of explanations for this. Firstly, there were several participants who had been discharged from the clinic, sometimes at quite a young age, as their condition was considered stable and future treatment unlikely to be needed or appropriate. Others who reported not having attended an eye clinic in the previous 12 months appeared disengaged with the process – for example they were unsure which eye clinic they were registered with, if at all.

Those who did attend eye clinics spoke of either going for a regular check-up, or going only in response to problems. Five of the participants spoke of having to attend very regular appointments or of waiting for treatment which would require long periods of recovery.

Just over half of the participants had attended a low vision clinic in the past. This number was surprising as in previous interviews when discussing low vision aids, low vision clinics were mentioned very infrequently (although we also note that QTVIs were frequently identified as t4he main source of low vision aids). Those who had attended low vision clinics tended to view them positively, although very few currently attended them, or knew how to arrange for this to happen. Therefore whilst many had been to low vision clinics in the past, they were not necessarily something of consideration to the young people now. Sources of low vision aids (in order of frequency) include: low vision clinic; QTVI; specialist charity; SENCO; and local optician.

Eye conditions and level of vision

We have noted throughout the longitudinal study that many of the young people have eye conditions which mean that their level of sight loss has changed, and is likely to continue to change. Two participants whose registration changed from partially sighted/sight impaired to blind/severely sight impaired were both in further education at the time this occurred. They found that both they and their respective colleges struggled to adapt to their changing needs. This highlights the value of access to ongoing specialist education support. While education providers may be able to maintain provision for young people with stable sight conditions, for those with changing sight conditions more specialist support may be needed to help to provide both practical and psychological support.

Initial diagnosis and understanding

The participants were identified as having a sight condition at different ages: ranging from birth, to a baby/toddler, to primary school age, and older. They had a variety experiences in learning about their visual impairment (which in no small part reflects the range of ages at which their eye conditions were first identified and diagnosed). Just under half remembered a specific point in time when someone explained to them that they had a visual impairment, and what had caused it. Others recalled learning about their sight condition over time, sometimes through asking questions. There were also those who reported never having had their condition explained to them, or is some case sharing that no one was able to explain it to them because the medical professionals themselves did not understand it. Several other themes emerged from the accounts the young people offered, including:

- feeling their sight condition was difficult for them to understand;
- feeling that they had a lack of opportunity to find out more about their sight condition (for example, those who were discharged from the hospital eye clinic at a young age);
- finding that the period around diagnosis/learning the details of their sight conditions was an emotional time;

- not wanting to invest the time understanding it, but rather to ‘get on with life’ (although for some this changed as they got older);
- different reactions of their parents, ranging from those who were very open, to those who were reserved in discussing their child’s sight condition because they found it emotionally difficult to talk about;
- insufficient understanding of their visual impairment by both the young people and others (e.g. teachers), and how this had an impact on their education

People in a variety of roles had taken responsibility for explaining the visual impairment to the young person, including: family members; medical professionals; and QTVIs.

When asked to rate their understanding of their visual impairment on a scale of 1 to 6 (where 1 is ‘very well’ and 6 is ‘very poor’), the participants’ responses were mixed, although over two thirds responded with 1 or 2. Of particular concern were nine participants who rated their understanding as 4, 5 or 6. Of note, two of these participants reported that they would not know where to go to find out more about their visual impairment and six said that they would like to have a better understanding. Of those who were more satisfied with their level of understanding, many of them spoke of a sufficient enough understanding to get by in life.

General health

In previous interviews we have noted that several of the young people have additional health problems or disabilities which have had an additional impact upon their educational and life experiences, and so this was explored further. Sixteen of the participants (approximately a quarter) reported that they do have an additional health problem or disability, and provided further information about this:

- three of the young people spoke of having syndromes which affect multiple parts of their body, including their vision
- nine have other health problems/disabilities which are commonly associated with visual impairment
- four reported having medical conditions which they did not associate with their visual impairment.

Emotional support/counselling

Just over 20% (12 out of 61) of the participants reported having received some form of emotional support or counselling in relation to their visual impairment. A variety of explanations were given for this, including: challenges when in education; difficulties relating to the treatment that they received for their sight condition; support for general anxiety during which their visual impairment was discussed; a change in their level of vision; and concerns about the future. Those who had received such support spoke of it positively. A small number of participants had been offered support of this nature but rejected it, whilst just over half of the participants could not recall it being offered. On reflection, ten of the participants believed they would have benefited from some support, either now or at some point in the past. Often the difficulties described by either those who had benefited from counselling or by those who felt they would have benefited from counselling, coincided with transition points.

1 Introduction

The research project is entitled “A longitudinal study of blind and partially sighted young people in the UK”. This project was designed in 2009 by a team from RNIB and the Visual Impairment Centre for Teaching and Research (VICTAR) at the University of Birmingham in response to the research brief prepared by RNIB.

The key objectives of the project were:

1. To track the process of transition for blind and partially sighted young people from age 14 for [initially] 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.

Phase 1 of the study involved the recruitment of an original sample of approximately 80 young people to the longitudinal study and carrying out several surveys of their views and circumstances. This took place between autumn 2009 – March 2012 and was funded by RNIB. The phase of research resulted in a number of reports (e.g. Hewett and Douglas, 2011a; Hewett and Douglas, 2011b, Hewett, Douglas, Ramli, and Keil, 2012).

Phase 2 of the study has been funded by the Nuffield Foundation, and centred on follow-up surveys of the sample of young people with visual impairment. By autumn 2014/spring 2015 there were 73 participants actively involved in the research, 61 of whom were available for interviews which are presented in this report.

This report focuses upon data collected between October 2014 and February 2015 through semi-structured telephone interviews (“autumn 2014 interviews”). A more comprehensive overview of the data collection of the study as a whole is presented in an accompanying report “Longitudinal Transitions Study of Young People with Visual Impairments: Methodology Summary, June 2015” (Hewett et al, 2015a). This wave of interviews aimed to: explore the concept of wellbeing; look at the young people’s friendship networks; investigate the young people’s perceptions of how well prepared they consider themselves to be for independent living; and ask some more questions around support for and information about their eye condition. The findings from these interviews are presented in a series of accompanying themed reports:

- Longitudinal transitions study of young people with visual impairments: methodology summary (Hewett et al, 2015a)

- The transition experiences of young people with visual impairments aged 17-21 (Hewett et al, 2015b)
- Wellbeing of young people with visual impairments (Hewett et al, 2015c)
- Support and information received by young people with visual impairments (this report)
- Young people with visual impairments transitioning into independent living (Hewett et al, 2015e)

These reports are part of a series of technical reports which present all findings in the project since 2010.

2 Ongoing medical support relating to eye condition

2.1 Medical support relating to the young person's eye condition

Table 1: Are you visiting an eye clinic at the moment?

	Total (N)	Total (%)
Yes	26	42.6%
No	35	57.4%
Don't know	0	0.0%
Total	61	100.0%

The participants were asked if they were currently visiting an eye clinic (that is, a visit in the past twelve months or one planned for the future): 26 (43%) said yes, whilst 35 (57%) said no. The participants gave a range of explanations for their responses which have been grouped into four categories:

2.1.1 Discharged

Thirteen of the participants explained that they did not go to an eye clinic anymore as they had been discharged. This tended to be because their condition was stable, and therefore it was decided that there was no need for them to continue attending appointments.

> "No I was discharged when I was 14, maybe 15"

One participant reported being discharged at the same time as his local eye clinic closed down, and had not found a replacement:

> "No, I have got discharged from hospital I think. It was quite a while back, because the department closed down…"

One participant who was discharged from the eye clinic described having infrequent problems and if she needed to get treatment relating to her eye condition had to attend accident and emergency (A&E):

> "…if I have things like conjunctivitis I end up having to go to A&E for it. I feel like I am wasting their time, but there is nothing I can do, if no one knows the eye condition I am kind of stuck…I wish the NHS had never discharged me in

> a way, because I would never have had problems then in going back”

In a previous interview, another participant who had been discharged spoke of problems in getting the medical evidence needed for her Disabled Students Allowance (DSA) application because she was not sure who to make contact with. This resulted in problems with her application and a delay in receiving her DSA support.

2.1.2Regular check up

Six of the participants spoke of attending regular check-ups and these would often be quite a distance apart, for example one to two years. In these cases the participants’ eye conditions had been stable.

> “I think that’s every two years, where I get a check-up regarding my visual impairment”

> “I usually go for sort of yearly check-ups, because they don’t reckon my sight is going to change that drastically…It’s just a look around at my eye”

2.1.3Response to problems

Five of the participants would only go to the eye clinic if they were experiencing problems.

> “…it’s just a case of wander in if something goes wrong”

2.1.4Lack of engagement

In previous interviews we have noted a lack of engagement by some of the young people in relation to their visual impairment. For example, some of the participants did not know if they were registered as sight impaired, or if they did know then they were unsure of the type of registration. Others were unaware whether they received Disability Living Allowance or not. These findings were mirrored in the case of eye clinics, with two of the participants not knowing which eye clinic they were registered with (if at all).

> Researcher: “Are you still registered anywhere?”
> Participant: “I think so, but I’m not entirely sure. I haven’t been to a check-up for a long time, mainly because I have been very busy.”

> “To be honest I don’t even know what [my eye clinic] is at the minute”

Table 2: What are the visits to the eye clinic for?

	Total (N)
To see the eye doctor/ophthalmologist	8
For a check up	27
Low vision clinic, e.g. to get advice about Low Vision Aids, to see optometrist or orthoptist	6
For treatment relating to your eye condition	8
Other	1

The participants attended their eye clinic for a variety of reasons. In twenty seven cases it was for a check-up (although as noted above, in some cases they would wait two years or more between check-ups). Eight would go to see the eye doctor/ophthalmologist, six to attend a low vision clinic and eight for treatment relating to their eye condition. One participant had also attended an eye clinic due to participation in a research study.

Five of the participants spoke of having to attend very regular appointments, or of waiting for treatment, which was disruptive to their everyday lives. For example, one participant would go for check-ups at two different hospitals, sometimes as often as once a month. Another participant had to travel a substantial distance to his eye clinic every three months. Two participants were due to receive surgery on their eyes. One of these participants was delaying applying for work as she did not want to start a new job and then have to take time off to recover. Another was due to have surgery during the winter break from his third year at university, therefore disrupting his revision and dissertation preparations:

> “…you literally need three weeks to recover, and then I will start my work. I am not sure how to go about getting extensions and things like that. I am aware that it is a complicated process”

These responses show that when considering how their sight conditions may impact on young people with visual impairments transitioning into work it is necessary to think beyond simply their vision, and also to consider the implications for those who have to attend medical appointments, or who are receiving medical treatment. Once these young people look for employment we will observe how accommodating their employers are of these appointments, and how the young people themselves manage the situation.

2.2 Changing sight conditions

We have noted throughout the longitudinal study to date that many of the young people have sight conditions which mean that their level of vision has changed over the course of the research. For example, two participants who were registered as partially sighted/sight impaired at the start of the research have experienced a change in their sight loss, and now they are eligible to be registered as blind (or severely sight impaired). Another participant who had an operation on her eyes during the study, which meant that her sight vastly improved, has since reported that her sight has deteriorated again (although not to the same degree as before). Additionally, a further participant was recently diagnosed with a second sight condition, which is likely to mean that her sight will gradually worsen over time. The two participants whose registration changed to blind/SSI were both in education at the time, and found that both they and their respective colleges struggled to adapt to their changing needs.

2.3 Attendance at low vision clinics

Table 3: Have you visited a low vision clinic in the past?

	Total (N)	Total (%)
Yes	27	51.9%
No	21	40.4%
Don’t know	4	7.7%
Total	52	100.0%

Table 4:Have you ever been presented with different options of low vision aids at a low vision clinic?

	Total (N)	Total (%)
Yes	25	56.8%
No	17	38.6%
Don’t know	2	4.5%
Total	44	100.0%

In previous interviews we have discussed with the participants there use of low vision aids (LVAs) (see Hewett et al, 2014). Whilst some of the young people had previously spoken positively of the use of LVAs, there were several who spoke quite negatively of their experiences of using them. There appeared to be some link between negative perceptions of LVAs and who had introduced LVAs to them (i.e. whether it had been a specialist or not), including a few participants who spoke of positive experiences of receiving LVAs through a low vision clinic (LVC). For this reason we investigated this further.

Twenty seven of the participants had visited a LVC in the past, and twenty five had been presented with different options of LVAs at a LVC. We asked all 52 of the young people who might have benefited from LVAs (i.e. excluding those with very little or no vision) if they had ever been given the opportunity to look at LVAs, and if so, where this took place. Their responses are presented in the table below:

Table 5:In the past, who has presented you with different options of low vision aids?

	Total (N)	Total (%)
Low vision clinic	18	54.5%
QTVI	11	35.5%
Specialist charity	1	3.0%
SENCO	1	3.0%
Local optician	1	3.0%
Unknown	1	3.0%
Total	33	100.0%

Thirty three of the participants reported having been either given LVAs in the past or the opportunity to experiment in using them. We therefore investigated further the initial source of the LVAs they were given. Just over half of these were through low vision clinics, and just over a third through a QTVI. Individual participants also reported receiving a LVA through their school special educational needs co-ordinator (SENCO), a local charity for people with vision impairment and their local optician. One participant said she received her LVA via her parents, but she was not sure who had originally given it to them.

We also sought to ascertain how long ago it was that the participants had last visited a LVC. The responses were very mixed, with some who had been very recently, whilst others had not been since they were much younger.

> “Oh it was ages ago, absolutely ages ago. I think it was Year 8 [age 13], something like that”

One participant who had attended a LVC recently had described in previous interviews how he was not aware of LVAs until he moved to a specialist school, and observed other young people using them. He subsequently visited a LVC, and has found LVAs to be very beneficial to him.

We also discussed with some of the participants who had not been to a LVC for a long time, or those who were initially given their LVAs by a source other than a LVC, whether they would know where to go now if they wanted to look at LVAs. One participant reported that he would know who to ask, whilst four other participants were unsure of where they would go:

> Researcher: “If you did think that you might need something else…would you know where to go to look at options that might be available?”
> Participant: “No, not really.”

Another participant reported that no one had ever told them about LVCs:

> “No one has really told me about low vision clinics. In fact I don’t know if there is one where I live”

Finally, we asked those participants who had been given LVAs if they could share more of their initial experience of being given them. The young people who were given LVAs through LVCs tended to have tests on their vision first before aids were recommended to them, whilst those who received LVAs through their QTVI spoke of the teacher bringing in a selection of aids, and then trying out using them.

> “I would basically go and they would ask me to read the letters on the board, and the one where they have the different fonts and the sizes, and then they would ask me to read it without a light and with a light, and with a magnifier and without. And then they would check my vision on the board, and then they would ask me to do that with binoculars and without binoculars”

> “They brought a load in, and we worked out which was best.”

Those who attended assessments at low vision clinics generally spoke about them very positively:

> “I found it brilliant, excellent, yeah”
>
> “I remember it was really nice, they let me try loads out and I picked out which ones I wanted. I remember going it was really nice, I used to go quite a lot”

One participant, once he was aware of LVAs found the assessment process very helpful, but he was unsure why he had not been made aware of them before:

> Participant: “I’m not sure, I don’t know, maybe because I was in a mainstream setting and it wasn’t very specialised, so when I did go to low vision…because I was using just normal stuff at school, they may not have thought that I needed it”
> Researcher: “Has it made much of an impact since you did get the low vision aids?”
> Participant: “A massive impact”

What has been particularly interesting from this round of data collection is that more young people attended LVCs than was previously thought. This is because in previous interviews when asking them to share their experience of LVAs very few of them spoke of having attended a clinic. Whilst it is encouraging that more young people had the opportunity to receive LVAs in this way than previously thought, it does indicate a lack of disengagement with the young people in considering this type of service. For a more comprehensive overview of the young people’s experiences of using low vision aids, this section should be read in parallel with the 2014 technical report (Hewett et al, 2014).

3 Initial diagnosis and understanding

Table 6: How old were you when your sight problem was identified?

	Total (N)	Total (%)
At birth	13	21.7%
Baby/toddler (under 2)	11	18.3%
2-4	11	18.3%
5-11	18	30.0%
12+	2	3.3%
Doesn’t know	5	8.3%
Total	60	100.0%

The participants reported that their eye condition was identified at a range of ages. In thirteen cases the eye conditions were identified at birth, and in a further eleven they were identified as a baby:

> “I was born with it. I was born with a bubble in my eye, so I think the first or second day old they checked it out, and came back to my mum and dad with it, and it’s been since then.”
>
> “I was very young, no older than one year old. I have a picture of me maybe five or six months old, and I had massive glasses on back then!”

Eleven participants described having their sight condition identified between the ages of two and four (pre-school), and eighteen between five and eleven (primary-age). In some of these cases the young people had other medical difficulties which resulted in their sight loss, whilst in other cases their sight condition had not been detected until that point:

> Participant: “…quite far on in schooling, I think about year 3 or 4.”
> Researcher: “Did you have it before then, or was it something that developed later?”
> Participant: “It was something that opticians picked up.”

Two of the participants were not diagnosed as having a visual impairment until they were teenagers. This inevitably has meant less opportunity for them whilst in education to learn to use assistive technology and to receive specialist support and guidance:

> “I think it was detected when I was 16, maybe 17. I knew myself that something was wrong at 15, I’d say. So about three or four years ago, because I am turning 21 this year, so…It’s hard to tell really because you don’t know whether it’s just because you are tired, or I don’t know, you don’t really take notice unless you go to a doctor and say there’s something wrong with me. So around 15/16 I think I kind of knew.”

Table 7: When you were younger, did anyone sit down with you to explain your visual impairment to you?

	Total (N)	Total (%)
Yes	28	47.5%
Gradual understanding/questioning	10	16.9%
No – never had it explained	10	16.9%
No – explained when older	6	10.2%
Unsure	3	5.1%
No – medics don’t understand condition	2	3.4%
Total	59	100.0%

Twenty eight of the participants could remember a specific time when their visual impairment was explained to them. A further ten reported having had opportunities to learn about their visual impairment, but it was over a period of time and often as a result of their own curiosity. Six participants reported that their visual impairment was explained to them, but not until they were older.

> “Yeah, my Mum. She had a lot of conversations about it when I could first talk.”

> “I think it was more of a process, because obviously, like so when I was in primary school, as the years went on, I had different people coming in and out who were there to support me. So I had a person, like a TA [teaching assistant], who was my support worker and touch typing lessons and stuff like that. So I think sometimes, when I have that, I guess I was, they would explain to me a little bit. But I don’t remember ever having a sit-down conversation with somebody. It was just something that I gradually asked. When I was maybe more a teenager I would ask my Mum and Dad what was going on, in a more scientific way, like what biological things was wrong with them. It was more of a process of several conversations,

> which grew in depth, as I became older and able to process more information.”
>
> “I can remember the first time that I asked the doctors about my eyesight, but I can’t remember anybody coming up to me, and telling me ‘oh you can’t see as well as a normal person’. I don’t think anyone came up to me at that point. But I think when I was 12 or 11, that’s when I started asking the doctors at my check-ups. That’s when I first fully understood.”

Ten of the participants felt that no one had really explained their visual impairment to them, whilst two felt that no one could really explain their condition to them, as the medical professionals themselves did not understand it.

> “I kind of grew up with it, so no one really explained it to me.”
>
> “Not that I remember, only the things that mum mentioned, I just knew that things weren’t right with my eyes. I knew that I had to wear glasses, but never realised it was different to anyone else. It was only when I got older that I realised that it wasn’t right.”
>
> “Not really, I just lived with it to be honest.”
>
> “No, they are not really aware of what caused it. So I haven’t had anyone to explain it to me, because no one really knows.”

Several other themes emerged in the participants’ response to this question. These are addressed in turn.

3.1 Difficult to understand

Some of the participants spoke of how difficult their conditions were to understand – especially at a younger age. They benefited from having family support around, to help explain their visual impairment as they got older, and also to help simplify what the medical professionals had said.

> “My mum did try, but it’s one of those conditions, it’s not the easiest to explain when you are young. So it’s really only

> the past couple of years that I have started to look into it myself, and things like that. I still can’t get my head round it like. It is really tricky to understand.”
>
> “Yeah, but I didn’t really understand, my mum took it all in.”
>
> “I think that’s why my Dad told me, because he could tell me in relatable terms. That was the best for me, because that simplified things”

3.2 Lack of opportunity

In the previous section we noted how thirteen of the participants had been discharged from the eye clinic, meaning that they had limited opportunity to find out more about their visual impairment. For one participant this posed a barrier as she was discharged at a young age:

> Participant: “No. I just kind of grew up with it.
> Researcher: “Did you ever get much opportunity when you were young to ask people questions about it?”
> Participant: “Well, my parents, but that’s about it.”
> Researcher: “Do you know how old you were when you were discharged from the eye clinic?”
> Participant: “I guess about 10/11”
> Researcher: “Since then have you had any professionals you could talk to, to ask questions?”
> Participant: “It’s just the case of going to the GP.”

3.3 Emotional response

Another participant whose eye condition was not diagnosed until she was 14 spoke of her relief of having her eye condition explained to her. It had taken approximately five years for her to get a diagnosis:

> Participant: “Yeah, a couple of things were explained. But it took a while for that to be done.”
> Researcher: “Was that done by a consultant, the ophthalmologist?”
> Participant: “Yeah, but basically saying what the specific problem could mean, and things like that.”
> Researcher: “And how did you find that?”
> Participant: “Kind of a relief at the time just to know.”

In contrast, another participant despite having been aware that there was a problem in relation to her eyes found it quite a shock when she was diagnosed:

> “I can’t remember, I think it was just my parents. [..] It came as a shock, it was unexpected. I can kind of remember bits of it myself.”

3.4 Getting on with it

Several of the participants spoke of not having the opportunity to get to really understand their visual impairment, but just wanting to “get on with life”.

> “Not really, I just lived with it to be honest”

> “Well, no, not really. It was only like you have got to wear glasses because your eyes aren’t great, like. I just kind of got on with it”

3.5 Parents’ reaction

Several participants also spoke of different experiences according to their parents’ reaction to their visual impairment. Some participants spoke of their parents being very open to discussing their eye condition, whilst another participant found that it was difficult to discuss their visual impairment as their parents would get upset about it.

> “Yeah, I had yearly appointments at [the eye clinic], and everyone there was really nice. If I had any questions they would answer them. It’s difficult to talk to my parents because they get upset and stuff.”

> “Oh yeah, my parents were really open about that.”

> “…they are very honest with the facts with me. They were very sort of clear at the beginning when I was a child, so I imagine they probably did sit me down and explain.”

3.6 Insufficient understanding

One participant in reflecting back felt that he did not have sufficient information given in order to understand his eye condition, and this in turn had had an impact on his time in education:

> "Not to the extent that I needed really, that's been why education has always been a bit of a struggle. It's only been in the last maybe year and a half that I really understood what I had to do about it."

3.7 Not wanting to understand

Finally, there were those who had not wanted to know about their visual impairment:

> "Yeah, I think the opportunity was there, but I just never really wanted to."

In the case of one participant, this changed as she got older and her visual impairment changed:

> "Yeah, I started asking questions when my sight deteriorated drastically when I was 14. Before then I hadn't really been interested, I didn't want to know."

Table 8: Who explained your visual impairment to you?

	Total (N)	Total (%)
Family	26	52.0%
Medical person	9	18.0%
QTVI	6	12.0%
N/A Visual impairment had not been explained	9	18.0%
Total	50	100.0%

It was most common for the young people to have their visual impairment explained to them by a family member. This tended to be as they had got older so were able to understand their sight condition better. Several of the participants were not diagnosed until they were older, and they tended to have their visual impairment explained to them by a medical professional. Additionally, six of the participants had their visual impairment explained to them by a QTVI who worked alongside them in school.

Table 9: On a scale of 1 to 6, where 1 is ‘very well’, and 6 is ‘very poor’, how would you rate your understanding of your visual impairment?

	Total (N)	Total (%)
1 – Very well	24	39.3%
2	19	31.1%
3	9	14.8%
4	4	6.6%
5	5	8.2%
6 – Very poor	0	0.0%
Total	61	100.0%

When asked to rate their understanding of their visual impairment on a scale of 1 to 6 (where 1 is ‘very well’ and 6 is ‘very poor’), the participants’ responses were mixed. Positively, over two thirds responded with 1 or 2. Of concern however were nine participants who rated their understanding as 4, 5 or 6. Of note, two of these participants reported that they would not know where to go to find out more about their visual impairment and six said that they would like to have a better understanding.

Of those who were more satisfied with their level of understanding, many of them spoke of having a sufficient enough understanding to ‘get by’ in life.

> “Yeah. I know the bare things you need to know. Don’t ask me the scientific names, I can describe it, I find no need for them. They are written down somewhere”

4 General health

Table 10: Do you have any long term health problems or disabilities (other than your visual impairment)?

	Total (N)	Total (%)
Yes	16	27.6%
No	42	72.4%
Total	58	100.0%

In previous interviews we have noted that several of the young people have additional health problems or disabilities which have had an additional impact upon their educational and life experiences to date. We therefore asked an additional question about participants' general health to confirm the number with additional difficulties and to ascertain whether it was possible that these additional health problems or disabilities could impact upon their long term transition into employment.

Sixteen of the participants reported that they do have an additional health problem or disability, and provided further information about this. Three of the young people spoke of having syndromes which affect multiple parts of their body, including their vision.

In future interviews we will explore this topic further, to ascertain the effect that these additional long term health problems or disabilities have on the young people's lives.

5 Emotional support/counselling

5.1 Young people who have received emotional support/counselling

Table 11: Has the participant ever received emotional support/counselling in relation to their visual impairment?

	Total (N)	Total (%)
Yes	13	21.7%
No	47	78.3%
Total	60	100.0%

The participants were asked whether they had ever received support relating to their emotional rather than practical needs. It was explained that this could be described as counselling, but not necessarily on a formal basis. Just over 20% reported that they had received support of this nature. Those participants who answered ‘yes’ were asked to give more of an explanation.

5.1.1Explanation of reasons for emotional support

The participants who had received emotional support/counselling gave a range of explanations for this. These included:

- Having difficulties when in education in wanting to be like everyone else
- Having difficulties relating to the treatment being received for their eye condition
- Having received counselling for general anxiety issues, but their visual impairment had been discussed
- Having support following a sudden and dramatic change in their eye condition
- Having experienced problems when at school linked to their visual impairment
- Having experienced difficulties at university linked to their visual impairment
- Having anxieties about how their visual impairment would impact upon their future

5.1.2 Evaluation of support

The majority of the 13 participants who had received support of this nature spoke of it positively. Three of the participants had been receiving counselling over a period of time, whilst in other cases they only had one or two appointments, but found those to be beneficial and sufficient:

> “I only went there once, I never went back, but I do think it really helped”
>
> “Yeah, it’s helped me get a better outlook, sort of be a bit more positive I think, they have changed my way of thinking. So I have come back in September with a better sort of outlook and that has helped me be more positive about other things.”

One participant reported finding counselling difficult, and felt that they benefited more from speaking with friends. However it is worth noting that the person in question was still at primary school at the time, so it is possible with added maturity they would have benefited from it more.

All of the participants who had received support were satisfied with the support that they had received.

5.2 Support offered to the young people

The 45 participants who had not received emotional support/counselling in the past were asked whether it was something that they had ever been offered, and also if it’s something that they think they may have benefited from:

Table 12: Were you ever offered emotional support/counselling and declined it?

	Total (N)	Total (%)
Offered	7	15.6%
Not offered	32	71.1%
Unsure	6	13.3%
Total	45	100.0%

Seven of the participants reported that they had previously been offered emotional support/counselling, 32 reported that they had not, and six were unsure. Those young people who had declined this support were asked to give further explanation. Their responses included:

- Already having support from friends and their class teachers
- Knowing that support was available to access, but not feeling they needed to draw on it

Table 13: If never received counselling, do you think that this is something that you might have benefited from?

	Total (N)	Total (%)
Not needed	32	76.2%
Would like/would have liked	10	23.8%
Total	42	100.0%

Ten of the young people felt they may have benefited (or could benefit) from some form of counselling/emotional support.

- 3 participants felt they needed support at the time of interview, and were provided with the contact details for RNIB emotional support service
- 2 participants felt they would have benefited from support at specific time points in education
- 1 participant would have benefited from support in relation to specific limitations that their visual impairment caused them, for example in not being able to drive
- 1 participant felt they could have benefited from support when they were younger but did not specify the reason
- 1 participant felt that they would have benefited from support as they had got older but did not specify the reason
- 1 participant felt they would have benefited from support once they left their specialist school and re-entered the ‘sighted world’
- 1 participant felt they would have benefited from support when they were being bullied in relation to their visual impairment.

6 Conclusions

It is interesting to note how many of the young people reported that they had been discharged from eye clinics. For many this was at a young age, and while from a clinical perspective this may have been a logical decision for those with stable conditions that are unlikely to require further health input, it has meant that the young people have had limited opportunity as they have got older to find out more about their visual impairment or access allied services such as low vision clinics. Being discharged from an eye clinic has also caused some complications for the participants. For example, one participant who was out of the 'eye clinic system' went to A&E with an infected eye; another participant had difficulties getting the necessary evidence for her Disabled Student Allowance application. Additionally we observe some lack of engagement with services such as low vision clinics, with very few of the participants knowing how they would go about setting up an appointment for a low vision assessment.

A number of obstacles have been identified by the young people in developing their understanding of their visual impairment. Many were diagnosed as having a visual impairment at a young age, and often before they would have had the maturity to be able to understand the full extent of their eye condition. Whilst they may have been able to draw upon child-friendly books which have been produced by charities to explain specific sight conditions, none of the participants referred to having used one of these. For those who no longer had the chance to meet with a medical professional in an eye clinic, this meant limited opportunity to ask further questions about their condition. Additionally, one participant spoke of how he felt unable to ask his parents about his visual impairment, as his parents became upset when discussing it. It is possible that the way in which the news of diagnosis is first presented to the parents could have a long-term impact on their own attitude to their child's visual impairment. In our case study work we asked the participant's parents to share their stories of when their child was first diagnosed as having a visual impairment. When reviewing these interviews, we can therefore explore further whether, and how, this might have affected the parents' attitude to their child's visual impairment.

We also note that some of the participants were required to have regular check ups for their sight conditions, and in some cases their associated health difficulties. Additionally, at the time of interview one participant who was in the third year of university was scheduled to have an operation on his eyes which would require several weeks' recovery. It is therefore important when considering the impact that a young person's visual impairment might have upon them during these challenging transition years, that a broader perspective is taken of the consequences of that condition, beyond simply how it affects their vision. We also observe how some of the young people have conditions which mean their level of vision has changed over time, so whilst they may have received appropriate training at that point in their education, more and different training may be required now.

The availability of counselling support to the young people (formal or otherwise) appears to have been mixed, and whilst many of those who were not offered such support did not feel they required it, there were still several who did. Those who did not require such support tended to explain that they had the support of their family instead. At this point it is worth highlighting how in our first questionnaire with these young people, we identified that we had recruited a group of young people who in general consider themselves to be well supported (above average when compared to the general population of young people of their age). Whilst this is typical of studies of this nature as well supported young people are more likely to be encouraged to participate in research studies, it raises the question of whether young people with visual impairments who feel less supported would be more likely to require counselling support. When discussing the points in their lives at which they received counselling/emotional support, or would have benefited from it, this often coincided with key transition times. In line with other literature, this offers a useful indication of when services should target their work.

7 Future plans

This publication is part of a series of reports from the Longitudinal Transitions Study, which is following the transition experiences of over 80 young people with visual impairments. The project commenced in autumn 2009, and we have working alongside the young people since 2010. Funding has been received in two phases:

- Phase 1: 2009-2011 - Royal National Institute of Blind People
- Phase 2: 2012-2015 the Nuffield Foundation

We are pleased to report that funding has been secured through Thomas Pocklington Trust to continue the research into a third phase. This comes about as the participants continue their transitions into adulthood and employment, and look to start living more independent lives. Thomas Pocklington Trust's interest in the research came about following their own scoping study (Blood, 2015) which found that the likelihood of success for a young person with visual impairment making a positive transition into living independently was strongly linked to their employment status - thus concluding that a key way to help young people with visual impairments to be able to start living independently is to help equip them for work. Such findings also serve as a reminder that in looking to support a young person with visual impairment into employment, we need to think simply beyond the skills that they need in education, and instead look to the broader skills that they are going to need to live independently.

As the project continues, we intend to keep speaking to the participants at regular intervals to continue tracking their transition experiences and in particular their experiences as they try to enter the labour market.

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