Time To Move:
A Review Of Habilitation For Children And Young People With Sight Loss In England
Executive Summary

In England approximately 25,700 children and young people with sight loss receive support from their local authority. Blind Children UK is the leading charity for children with vision impairment in England (and the UK as a whole). It provides advice, support and a range of services to help children enjoy their childhood and reach their potential as adults.

One of the vital services provided by Blind Children UK is habilitation. Habilitation involves training children and young people, aged between 0 and 25, who have a vision impairment. They are helped to develop their personal mobility, navigation and independent living skills which can have a significant positive impact on their learning, confidence and wellbeing.

Blind Children UK conducted research with local authorities to find out how many children and young people with sight loss are accessing habilitation, the range of services offered and the factors that affect local authorities’ ability to deliver a comprehensive habilitation service. A Freedom of Information (FOI) request was sent to 152 local authorities, and 15 local authorities were interviewed verbally, asking them about provision in the preceding six months.

The research revealed that there is a patchwork of habilitation provision across England. Only 17% of children with sight loss received habilitation in the six months covered by the research. This is a figure that varies dramatically across the country, with some local authorities providing habilitation to as much as 64% of their local population of children with sight loss, and others to as little as 2%. We are concerned that with such low percentages of children receiving habilitation provision in many areas this indicates that there is unmet need.

Interviews with council officials revealed the same concerns with one commenting:

"There is a difference though between what we are obliged to do, which we are able to do, and what we would like to do."

(Borough Council)

We discovered that there is a dearth of services for children outside of school age with just 3.5% of children aged 0-5 years old receiving habilitation in the previous six months and only one third of local authorities holding information about habilitation services for young people over 19. Habilitation for both these age groups is vital to enable children and young people with sight loss to access the same opportunities as their sighted peers.

Local authorities explained the key factors behind a lack of provision. They told us that funding challenges are threatening service provision, forcing some local authorities to have strict eligibility criteria to prioritise which children should receive services. We were told that even a small increase in demand could make it very challenging for their habilitation service to meet local need in some areas.

Compounding this, nearly all local authority representatives’ interviewed said that recruitment of Habilitation Specialists is difficult due to lack of trained staff, training opportunities and knowledge within local authorities on what habilitation is. One local authority explained:

1 Vision 2020 UK, Key Facts About Vision Impairment in Children and Young People
3 Children and young people aged 0 - 19
4 As a proportion of children and young people aged 0 - 19
To improve the habilitation service offered to children and young people living with sight loss in England we propose the following recommendations:

1. Funding from central government to support habilitation

The impact of relatively small increases in funding has the potential to drive future savings in other services if children and young people gain independence through habilitation training. The report shows that funding constitutes a problem in the provision of habilitation. As habilitation is not available to all children who need it through their local authorities, the Government should provide funding to support habilitation services.

2. Focused campaign by the Department for Education and Department of Health to promote habilitation

Habilitation is still a relatively new term and there is a lack of understanding about it in the medical profession, schools and some local authorities. Some of the debates around the issue relate to whether habilitation falls under education, health or social care provision, which in turn leads to confusion around who should provide funding for the training. The Department for Education and the Department of Health should work to increase understanding of habilitation and the benefits it brings to local authorities, healthcare professionals, schools, children and young people and families.

3. Health Education England to increase the number of training places for habilitation specialists

The overwhelming majority of respondents reported that recruiting habilitation staff was a significant challenge. The qualifications are not well understood and habilitation training remains a very niche specialism. To overcome this issue, Health Education England should increase the number of training places available for people to train and retrain to become Habilitation Specialists.
Methodology

In March 2015 Blind Children UK submitted Freedom of Information (FOI) requests to 152 local authorities in England to discover how many children with sight loss have accessed habilitation in the previous six months. 149 local authorities responded to the request. 40 local authorities did not provide complete responses to the questions and so the data throughout is based on the responses of 112 local authorities. The full list of questions asked can be found in Appendix 1.

Secondary research was carried out by external researchers commissioned by Blind Children UK who approached by letter 35 local authorities approved by Blind Children UK. Interviews were secured with 15 representatives from five county councils, two London Borough Councils and six metropolitan or city councils. Councillors and officers were invited to take part in this project on an anonymous basis. An example of the questions asked can be found in Appendix 2.

The response rate to the secondary research was low and repeated efforts to secure calls with representatives from local authorities proved challenging. On that basis, the respondents who took part are self-selecting and very likely to be local authorities which are confident that they are meeting demand for their habilitation services. The secondary data should therefore, not be seen as representative of all local authorities in England, however it is useful in providing further insight to the findings of the FOI.

Part One: Habilitation Provision In England

Both the FOI request and secondary research asked local authorities about the provision of habilitation. Data from the FOI shows that an average of just 17% of children and young people with sight loss received habilitation in the six months previous.

Table 1: The percentages of children and young people ages 0-18/19 receiving habilitation

<table>
<thead>
<tr>
<th>Age range = 0-18/19</th>
<th>Local authorities that provide full data responses = 112</th>
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<tr>
<td>0 to 5</td>
<td>3.5%</td>
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<tr>
<td>6 to 11</td>
<td>6.6%</td>
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<tr>
<td>12 to 18/19</td>
<td>6.4%</td>
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The Quality Standards for Habilitation state that the introduction of habilitation during early years will enable children and young people to avoid bad habits which would potentially need modifying at a later stage. However the responses show that provision for children in the early years (0-5 years) is less than those in school age ranges, i.e. 6-18 years.

Roughly one third of local authorities included data for the older age range (19 – 25 years). Within those local authorities that provided data just 2% of young people (19 – 25 years) received habilitation in the previous six months. Data from the secondary research also showed that some of the local authorities did not provide habilitation for young people over the aged of 19.

In 2014, legislative reform extended support and services to those aged 19-25 years with special educational needs (SEN) meaning that this age group is also entitled to habilitation training. Whilst it is recognised that local authorities will have needed time to implement these changes, it is worrying that over 100 local authorities did not either provide habilitation for this age range or hold data for this age range, or chose not to provide it in their response to us.

5 Respondents either gave information about young people up to age of 18 or 19

6 Dr Olga Miller, Dr Karl Wall and Dr Malcolm Garner, Quality Standards on the Delivery of Habilitation Training (Mobility and Independent Living Skills) for Children and Young People with Visual Impairment, January 2011
Eligibility criteria

The FOI request asked local authorities what eligibility criteria they apply in their local area. The results show that there is substantial variation across the country in terms of what the criteria for assessment are. The Quality Standards advise that the initial assessment of the habilitation needs of a child or young person is made by a qualified Habilitation Specialist working in partnership with parents and the Qualified Specialist Teacher of VI (QTVI).7

Of the 148 local authorities that answered this question, only 8 mentioned that they used the Quality Standards criteria. 35 stated that they used National Sensory Impairment Partnership (NATSIP) criteria, NATSIP is a partnership of organisations that work together to improve outcomes for children and young people with sensory impairment.

The remaining two thirds of local authorities (109) either did not hold information about criteria or gave one of a variety of answers including:

- Any child with a visual impairment can access vision impairment services. 
  (Borough Council)

- Based on need and urgency. 
  (Borough Council)

- There is no formal criteria, Individual assessment and professional judgement of a habilitation specialist. 
  (Borough Council)

7 Dr Olga Miller, Dr Karl Wall and Dr Malcolm Garner, (January 2011) Quality Standards on the Delivery of Habilitation Training (Mobility and Independent Living Skills) for Children and Young People with Visual Impairment
The fact that so many local authorities do not follow set criteria is particularly concerning as it infers a lack of understanding of what habilitation is, of the requirements set out in the Quality Standards and the level of training a child or young person may need.

It is concerning that some councils may operate very strict eligibility criteria, which excludes some children who would benefit from habilitation. Examples include local authorities that say that only children with “a significant visual impairment” or whose vision is “6/18 or less” are eligible.

Part Two: Why Is Habilitation Provision So Low?

Demand

The FOI data demonstrated that provision is low in some areas, with just under one fifth of children and young people receiving training. Whilst it is likely that during the time period of the research not all children and young people with sight loss would have needed habilitation, the very low rates likely mean that some children who would benefit from habilitation are not accessing it. Some councils were only providing habilitation to as few as 2% of children and young people with sight loss living in their area. One London Borough had 140 children living with a vision impairment, yet only 3 children received habilitation in the last 6 months.

The issue of demand and need for the training is therefore key. One borough council interviewed stated that demand is significant and rising:

“We would say that demand is great and the need for habilitation is going up.
(Borough Council)

The FOI data also showed variation in provision and this is likely to indicate a variation in unmet demand. For example one metropolitan council provided habilitation to 64% of the children and young people in the past six months so we can expect unmet demand to be much lower there than in the previously mentioned London Borough.

Amongst the councils who contributed to the secondary research interviews the overall sense was that they felt that they were meeting current demand. However, the strong impression was that should demand increase – if, for example, referrals increased – councils would struggle to meet that demand. In addition, the FOI shows that in many councils who didn’t take part in the secondary research demand was simply not being met.
Resource

When asked about why councils were not meeting demand, some councils raised the challenge of finding qualified habilitation officers and stated that a small increase in demand for habilitation would overwhelm them. Councils also raised concerns about the implications of the 2014 legislation which places obligations on councils to work with young people up to the age of 25:

“At the moment we are well resourced but there could be implications in the future... we have been well preserved.”

(Borough Council)

Another council was content that demand was being met but recognised meeting demand and providing a comprehensive service are not always seen as the same thing:

“I think we can meet demand – it depends on your vulnerability. There is a difference though between what we are obliged to do - which we are able to do - and what we would like to do.”

(Borough Council)

This shows potential concerns with the quality of provision; this is an issue that should be addressed to ensure that children and young people are receiving quality habilitation.

Prioritisation

As part of the secondary research, respondents were asked if limited resources and high demand meant that they had to prioritise certain services at the expense of others. In most cases councils responded that they did not feel that they had to prioritise certain types of provision over others, however the FOI data showed low levels of provision, which suggests that in those councils who did not choose to take part in the telephone interviews the case may be otherwise. Additionally some of the comments from councils suggested that provision was prioritised to a degree.

One borough council said that it has had to prioritise services due to high demand. They told us that children are assessed on a scale of 1-7, where the higher the number the higher the need for support. Provision for children ranging between 1-3 on the scale rests with the local schools. The Council’s visual impairment support services focus their support on children in the higher ranges:
It is interesting to note that none of the local authorities mentioned the Quality Standards when asked about how they prioritise services. It may be that they are aware of the Standards, Blind Children UK have produced a summary of the Standards and is encouraging supporters to share this with local habilitation commissioners.

**Funding arrangements**

Since 2010, local authority budgets have been significantly tightened. Respondents seemed to understand this and appreciate that their budgets were under constant scrutiny and review; however there will always be a need for funding for the service. The following comments were indicative:

> We are prioritising children with the most needs”.
> There are some children the council cannot support: “There are some we would like to work with who don’t meet the threshold for support but those are children with mild needs.
>  
> (Borough Council)

One of the respondents alighted on funding issues when young people are at a point of transition. As we have already stated, this is a key stage at which habilitation training should take place:

> I would like more money – none of us go into local politics without wanting more funds. Every time we look at an area, we then look at another area which is important. The simple answer is that we would welcome more resource.
>  
> (Borough Council)

> When we have both [officers] working we are just about ok but more can always be done.
>  
> (Borough Council)
Given the lack of provision for young people aged 19-25 years, it is encouraging to see that the above local authorities are recognising that there are issues with the service for this age range and are hopeful that the new regulations can deliver improvements. If young people are becoming isolated then this is a real problem and goes against the aims of providing habilitation.

Funding for habilitation comes from a range of sources. In some cases funding comes from the Department for Education’s dedicated schools grant, in some cases from health funding and in some cases from the local authority’s education budget – or from a mixture:

> If a young person with a visual impairment leaves school then we can no longer support them – that is a gap. If they go to sixth form or further education they still need mobility. The college would have to provide it at that point. 16-year olds are expected to travel independently and whereas for school-age children there might be transport available and there are shorter school days, for over-16s there is no school transport and they can become isolated. This is a hangover from how things were funded in the past. The 0-25 agenda may make it something the authority needs to fund.
> (Borough Council)

Another respondent recognised that it is not always easy to categorise a young person’s needs and so allocate a budget. For example:

> We are unusual in our local authority in that we have joined-up provision but the budgets come from different strands.
> (Borough Council)

It is clear that there is some confusion around budgets; councils are not clear where money should come from, an issue which may arise from the different routes which children are referred for habilitation support from.
Staffing

The FOI data tells us that there was a large variety in the types of qualifications that people who provide habilitation possess. 148 local authorities provided information about whether the people who deliver habilitation have specialist qualifications specifically in habilitation. A high proportion of local authorities employed specific habilitation staff, however only 5 explicitly mentioned that their staff have a habilitation qualification. The habilitation qualification has only been available for around five years, we therefore think that due to the limited number of Habilitation Specialists who would have graduated in this time that the data provided by local authorities for this may not be accurate.

Instead, habilitation training is delivered by a wide range of staff, in addition to Habilitation Specialists, including QTVIs, rehabilitation workers and mobility officers. The Quality Standards recommend that staff who are employed to carry out habilitation should have a relevant qualification, or be in the process of gaining their qualification. It is concerning that so few local authorities are employing qualified staff, or are unsure on the type of qualification that their staff have. We hope this is something that central government can seek to address.

One council stated that their staff do not hold the habilitation qualification, and mentioned budgets being one of the reasons:

> Staff have specialist qualifications in visual impairment rehabilitation and wide experience in delivering programmes of mobility and independent living skills to children and young people. Staff are on the provisional register of Habilitation VI UK and are keen to work towards full registration as Habilitation Specialist with Habilitation VI UK. As funding for the only currently available top up training has not been made available, we are awaiting details of other top up training which fulfils the requirements of registration e.g. programme of courses in development at Institute of Education in London.
> (Borough Council)

With one exception all local authorities who took part in the secondary research were concerned about recruitment. The very specialist nature of habilitation, the limited understanding around what habilitation is and the obscurity of the qualification all make recruitment a challenge.

Some local authorities interviewed said that the challenge has been where to advertise to find a suitable candidate:

> Because it is such a specialised area we have to think about where we are advertising. We have to publish our adverts online and put them on our website but anything beyond that has to be approved...and we did not find a recruit. This time round we will ensure that the advert includes a lot more information so we connect to the right people and we are going to have to look further afield. A portal, a platform to connect qualified habilitation officers and local authorities would be great.
> (Borough Council)

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8 Since the Quality Standards were written, Habilitation VI UK has become the professional body for Habilitation Specialists. Registration with Habilitation VI UK is becoming the standard expected of local authorities.
Referral routes and assessments

As referred to previously in this report, the Quality Standards advise that the initial assessment of a child or young person’s habilitation needs is conducted by a Habilitation Specialist working in partnership with parents and the QTVI.

A number of local authorities said that they receive referrals from medical professionals and directly from parents. However, some say they won’t accept referrals from groups such as parents, and one council expressed concern that too few referrals are coming from medical professionals.

This again shows the need for local authorities to promote their habilitation services clearly on their websites and amongst professionals. It also highlights the absolute need for a standardised system for referring children and young people to avoid patchwork provision across the country.


Local political support

None of the local authorities who took part in the secondary research felt that there was a lack of local political support for the work that they are doing, however given that these councils were self-selecting this is not surprising. Some respondents proactively said that there was very strong political support. Others noted that they have never had an issue with elected councillors and concluded that political support was forthcoming, if not very vocal.

A number also cited that the provision of habilitation services was not a high-level political issue in their local authority. In one borough the limited level of engagement with councillors was cited:

"I don’t think habilitation has crossed the desks of the elected councillors."

(Borough Council)
Central government support

Unsurprisingly, a number of local authorities would welcome additional government funding and for some councils additional central government funding would be transformational:

“Lack of provision can limit opportunities for a young person – a lot of the young people in our area are taken to and from school so there has been the argument that this is providing mobility. But habilitation is more than getting from A to B.”
(Borough Council)

“Realistically the answer is money from central government – not much more they could do. We are all strapped for cash, hopefully as things get better money will come. We are fortunate that we are starting to move down the devolution route and we will have greater autonomy.”
(Borough Council)

As previously discussed, a lack of funding for some councils is not only causing staffing issues and therefore provision issues, but also causing them to create strict eligibility criteria. Additional funding, or at least no further budget reductions is vital in addressing these issues and ensure that children and young people access the habilitation training they are entitled to.

Some local authorities mentioned that their “ask” of Government is for more work to promote habilitation and increase awareness of the benefits of habilitation training. Specifically, some felt that a greater understanding of the distinction between mobility and habilitation and the broader benefits offered by habilitation training in terms of life skills would be really helpful. Raising the profile of habilitation was cited as being particularly important:

“It is not about money...it is about raising the profile and being more aware of the needs and the additional things that need to happen. Habilitation is being more widely understood here – and people were like ‘What is that? [habilitation]’...but now that is the service and it is accepted.”
(Borough Council)
Another council also raised the issue of terminology:

“The term habilitation is not well-known. If you explain it [habilitation] then they get it. They can also think it is only about travelling to and from school – there are misunderstandings. I think central government think this is matter for transport or someone else.”
(Borough Council)

The need to distinguish between habilitation and mobility is also seen as an important issue:

“The perception is that it is just about mobility and getting from A to B but it is about skills for life.”
(Borough Council)

For this council it would also be helpful if government recognised the challenges presented by the low number of qualified staff:

“It’s not always clear that government recognises that despite the low-incidence the demand in terms of equipment and staff can still be high.”
(Borough Council)

These points highlight that central Government needs to take a role in communicating with local authorities about what habilitation is and how they can ensure that they are delivering a service in line with the Quality Standards. For example addressing issues such as how the service should be funded and who has responsibility for the provision of the service, including recruiting new staff.
Conclusion

Many local authorities are providing good quality habilitation to children with a vision impairment living in their local area. However it is clear that there is a patchwork of provision across England, meaning that some children are not receiving habilitation at the stages and settings that would most benefit them. It is particularly concerning that so few children in the early years and post 19 years are receiving habilitation training.

There are several factors which have led to this situation including the relatively small population of children with sight loss, the limited number of staff with a habilitation qualification, confusion on referral routes and which agencies fund habilitation, and lack of awareness on habilitation and its benefits.

Many local authorities are moving away from a ‘local’ approach of dealing with habilitation – pooling resources with neighbouring local authorities to ensure that they are able to deliver quality services. To build on this and to enable the habilitation sector to develop this further, the Government needs to provide support through:

- Raising awareness about what habilitation is and its benefits
- Working with Health Education England to supporting more Habilitation Specialist training places
- Providing financial support to local authorities to deliver habilitation training

Through taking these steps more children with sight loss will be able to access this vital support resulting in a generation of young people with sight loss who are equipped to lead independent lives, fulfilling their potential.
Appendix 1

1. How many children with a vision impairment live in (local authority)?

2. Are habilitation (mobility and independence) services available to children and young people with vision impairments living in (local authority)
   a) yes
   b) only in certain cases – please give details
   c) no

The following questions are only relevant if you responded a or b to the above question:

3. In the last 6 months how many children and young people have accessed habilitation services, broken down into the following age groups?
   0-5
   6-11
   12-18
   18-25

4. Does your habilitation service include the teaching of:
   a) early movement skills
   b) sensory, spatial and body concepts
   c) cane training
   d) route learning
   e) independent living skills?

5. What eligibility criteria do you operate for habilitation in your local area?

6. Do the people who deliver habilitation have specialist qualifications specifically in habilitation?
   a) Yes - all
   b) yes - some
   c) no
   d) staff are working towards their registration as a Habilitation Specialist with Habilitation VI UK (the professional body)

7. Is your habilitation service available to children and young people in the following settings:
   a) home,
   b) school
   c) community settings
   d) during school holidays

8. Do children and young people with vision impairment in your area receive habilitation assessments as a matter of course at key stages, such as when transferring between schools or settings?
   a) yes
   b) no
   c) only in certain cases – please give details
Appendix 2 – Examples of questions asked in telephone interviews to local authorities

Background

Can you give a brief summary of the process you went through to develop the Local Offer (as required by the SEND Code of Practice 0-25 years)?

Are you aware of concerns that the Local Offer is not always easy to locate on local authority websites?

Are you in a position to share some of the challenges of drafting the Local Offer?

Are there any services in your local offer which have been prioritised?

Understanding of habilitation services

What is your understanding of the term “habilitation”?

Do you have an understanding of local demand for habilitation services? Do you think that provision of habilitation services meets local demand?

How are habilitation services delivered by your local authority?

How do you ensure that those young people who need habilitation services are able to access local provision?

How do you ensure awareness of the habilitation services which are available?

What is your assessment of funding for habilitation (and other services in the Local Offer)?

Is there political support for your department in the delivery of the Local Offer and of habilitation services?

How could the government support you in delivering habilitation services?

Further questions

Are you able to describe the eligibility criteria for access to habilitation services? Are these set out in the Local Offer?

Can you talk about the qualifications you require of those who deliver habilitation services? Do you have a minimum required standard?

Are you aware of where children can access habilitation training? (E.g. at home, school etc.)

What is the process for a child to be assessed for habilitation? How is this promoted to families who might need an assessment?
## Appendix 3

### Glossary

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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td><strong>CYP</strong></td>
<td>Children and young people</td>
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<tr>
<td><strong>Habilitation</strong></td>
<td>Habilitation involves training children and young people with a vision impairment in personal mobility, navigation and independent living skills.</td>
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<td><strong>NATSIP</strong></td>
<td>National Sensory Impairment Partnership. A partnership of organisations working together to improve outcomes for children and young people with sensory impairment.</td>
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<td><strong>QTVI</strong></td>
<td>Qualified teacher of the visually impaired</td>
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<td><strong>SEN</strong></td>
<td>Special Educational Needs. The term applies to children who have learning difficulties or disabilities that make it significantly harder for them to learn or access education than most other children of their ages.</td>
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