# Early intervention support in eye clinics

An overview of emotional and practical support in UK eye clinics for the year 2012/13

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## Foreword

Providing emotional and practical support at the right time can help people who are losing their sight to retain their independence and access the support they need.

Experience in the eye clinic is very important. It is here that people will be given their diagnosis and prognosis. People go to the eye clinic for treatment and monitoring, and it is in the eye clinic that some will be told that they have permanently lost their vision and will go through the Certification of Vision Impairment process. People tell us how much they value support at all of these stages.

I am pleased to be able to present this report. It provides a timely overview of early intervention services throughout the UK based on data gathered by Eye Clinic Liaison Officers from the RNIB group of charities.

Colleagues working in the health, social care and voluntary sectors can use this evidence to speak with a unified voice to help improve the experiences of blind and partially sighted people and those at risk of sight loss.

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## Contents

[1. Introduction 5](#_Toc384043607)

[2. Executive summary 7](#_Toc384043611)

[3. Methodology 9](#_Toc384043617)

[4. Responding to the needs of service users – the role of early intervention 10](#_Toc384043620)

[4.1 Development of the ECLO role 10](#_Toc384043621)

[4.2. Further evidence 10](#_Toc384043622)

[4.3 Case studies 11](#_Toc384043623)

[5. Location and type of support 15](#_Toc384043624)

[5.1 Location of support 15](#_Toc384043625)

[5.2 Type of support 16](#_Toc384043626)

[5.3 Support provider 17](#_Toc384043627)

[5.4 Provision of support by trained staff and volunteers 17](#_Toc384043628)

[6. Demographics and characteristics of service users 19](#_Toc384043629)

[6.1 New and repeat service users 19](#_Toc384043630)

[6.2 Age 19](#_Toc384043631)

[6.3 Gender 21](#_Toc384043632)

[6.4 Ethnicity 22](#_Toc384043633)

[6.5 Sight loss 22](#_Toc384043634)

[6.6 Eye conditions 23](#_Toc384043635)

[6.7 Living arrangements 24](#_Toc384043636)

[6.8 Additional disabilities 25](#_Toc384043637)

[6.9 Risk of falls 26](#_Toc384043638)

[7. Support and services provided 27](#_Toc384043639)

[7.1 Where service took place 27](#_Toc384043640)

[7.2 Referral source 27](#_Toc384043641)

[7.3 Information and advice provided 28](#_Toc384043642)

[7.4 Onward referrals 29](#_Toc384043643)

[7.5 Time to first contact 30](#_Toc384043644)

[7.6 Length of contact 30](#_Toc384043645)

[8. Summary 31](#_Toc384043646)

[8.1 Recommendations 31](#_Toc384043647)

[Appendix A: List of table, charts and maps 33](#_Toc384043648)

[Appendix B: References 34](#_Toc384043649)

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## 1. Introduction

This is the first report that RNIB has published on early intervention services in the UK since 2007/08. At that time there were only six RNIB Eye Clinic Liaison Officers (ECLOs) and we had a limited understanding of locations with and without support. Since then the provision of early intervention services has become a strategic priority for the RNIB group of charities. In the intervening five years, the number of RNIB group ECLOs has dramatically increased and we have started to build a picture of the other types of early intervention support that are in place throughout the UK.

### Content of this report

Early intervention services managed by the RNIB group of charities support over 16,000 people each year who are in need of emotional and practical support. A range of data is routinely collected as part of these services, including information on demographics, the range of services provided and identification of potential risk factors such as living alone and falls.

We have undertaken work to map early intervention support in eye clinics across the UK; where it is provided, who is providing it and whether or not those providing support have attended one of the early intervention support training courses. By building this picture of provision we have the potential to identify gaps and can start to prioritise areas of the country for future investment or development.

Finally, there are a number of research studies that highlight the role that early intervention services play in supporting blind and partially sighted people and those at risk of sight loss. We also have a number of case studies to highlight the experiences of individual service users. A short summary of this work has been provided here to help put the data in context.

This report provides:

* a brief summary of research which provides evidence of the needs of service users and the role of early intervention services in eye clinics
* some case studies from service users who have received early intervention services
* location and gaps of early intervention services and providers
* an overview of data collected by early intervention services in 2012/13 provided by the RNIB group of charities.

### Early Intervention Support Network

RNIB Early Intervention Support Network (EISN) has been established to support staff working within eye clinic settings, providing services to newly-diagnosed blind and partially sighted people including those diagnosed with a sight threatening condition. The aim of the network is to create a community of those working within eye clinics across the UK, which offers peer support, development and dissemination of best practice, problem solving, sharing ideas, experiences and resources.

To find out more and subscribe visit [www.rnib.org.uk/eisn](file:///C:\Users\RHedley\AppData\Local\Packages\Microsoft.MicrosoftEdge_8wekyb3d8bbwe\RHedley\AppData\Local\Microsoft\Windows\Temporary%20Internet%20Files\Content.Outlook\AppData\Local\Microsoft\jslade\AppData\Roaming\Microsoft\Word\www.rnib.org.uk\eisn) or email us at [eisnetwork@rnib.org.uk](file:///C:\Users\RHedley\AppData\Local\Packages\Microsoft.MicrosoftEdge_8wekyb3d8bbwe\RHedley\AppData\Local\Microsoft\Windows\Temporary%20Internet%20Files\Content.Outlook\AppData\Local\Microsoft\jslade\AppData\Roaming\Microsoft\Word\eisnetwork@rnib.org.uk).

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For the latest RNIB research reports, please visit [www.rnib.org.uk/research](http://www.rnib.org.uk/research)

## 2. Executive summary

### Role of early intervention

* The emotional and psychological impact of sight loss is profound. Depression is significantly higher amongst people with sight problems and wellbeing is considerably lower when compared to people without sight loss.
* Early intervention services in eye clinics play a key role in helping people adjust to sight loss.
* Having the right support in eye clinics can bring clear benefits such as: innovative and cost effective care; improved staff efficiency; provision of accessible information; completing Certificates of Vision Impairment; and improved onward referrals (Boyce, 2011).

### Location and type of support

* We estimate that there are over 400 hospitals in the UK that are providing outpatient ophthalmology appointments.
* 218 of these (53 per cent) have some form of early intervention support available to service users.
* There is significant variation between UK countries and regions in the proportion of hospitals with early intervention services.
* Over half (55 per cent) of support is provided by Eye Clinic Liaison Officers, and a further 12 per cent is being provided by ECLO-type roles.
* Around half of locations with support in place are staffed by people who have attended RNIB's accredited Eye Clinic Support Studies course.
* The largest group of organisations managing these services are local societies for the blind. These local charities manage nearly half (49 per cent) of early intervention services in the UK. The largest single organisation managing early intervention services is the RNIB group of charities.

### Service users

* Over 16,000 people were supported by early intervention services provided by the RNIB group of charities in 2012/13.
* Three-quarters of service users supported by RNIB group ECLOs were aged 65 and over. From data collected in Wales, we can estimate that around one-quarter were aged 85 and over.
* 96 per cent of service users were from White ethnic groups (White British, White Irish or White Other), with 4 per cent being from any other ethnic group.
* 71 per cent of service users were blind or partially sighted.
* 33 per cent were living alone.
* 43 per cent were recorded as having an additional disability.
* 18 per cent of service users in Scotland were recorded as having a history of falls.

### Service provision

* The majority (around 80 per cent) of service users were referred to early intervention services via the eye clinic. A further 10 per cent were self-referrals.
* ECLOs frequently provide information and advice on local and national services, eye conditions, equipment, registration and benefits.
* The most frequent onward referral was to social services (31 per cent). Other common referrals were for a Low Vision Assessment, other RNIB Group services and to local organisations.
* Around three-quarters of service users were offered support on the same day as the referral; whilst 15 per cent had to wait longer than a week to be contacted.
* Over three-quarters of interactions with service users lasted under 30 minutes; whilst 5 per cent were an hour or more.

### Key recommendations

* Data from across the UK is vital to support the development of early intervention services and a core dataset should be agreed.
* Knowledge of where early intervention services are offered and gaps in provision are important to planning and development. Further developments of this mapping work should be considered.
* Other organisations managing early intervention services should consider feeding data to RNIB to help build a more detailed picture of early intervention support in the UK.

## 3. Methodology

This section provides a short overview of the methodology used to gather data on the location of early intervention services and the information routinely collected by ECLOs employed by the RNIB group of charities.

### 3.1 Location data

Desk research was undertaken to identify hospital locations providing outpatient ophthalmology appointments. In Wales, Scotland and Northern Ireland this is straightforward because health providers in these countries publish annual reports on outpatient activity by speciality and hospital. In England this information is only published to NHS Trust level, not individual hospitals.

Each location providing outpatient ophthalmology appointments was contacted by telephone to enquire about the support in place. We have used contacts gained through our Eye Clinic Support Services course and the Early Intervention Support Network to keep this information up-to-date.

Further details, along with a range of other data related to blind and partially sighted people and those at risk of sight loss can be accessed via RNIB’s [Sight Loss Data Tool](http://www.rnib.org.uk/datatool).

### 3.2 Activity data

RNIB early intervention services in Scotland, Wales and Northern Ireland and Action for Blind People in England all record routine data. The majority of this management information is consistent, although there is some variation and additional information is collected in some areas. All data for the year 2012/13 has been collated into a single Excel spreadsheet and is reported here.

## 4. Responding to the needs of service users – the role of early intervention

This section provides a brief overview of the needs of service users in eye clinics and evidence on the role of early intervention services, in particular Eye Clinic Liaison Officers, in supporting blind and partially sighted people and those at risk of sight loss.

### 4.1 Development of the ECLO role

In 2001 RNIB commissioned a report which looked at the personal experiences of people with sight loss.

A common thread was the shock people with sight loss feel when medical treatment has nothing more to offer. People spoke out about the failure of health and social care services to give them the personal support that they needed at this devastating time. They were dissatisfied with how ophthalmologists or other staff communicated the news that nothing more clinically could be done to help them.

RNIB and other organisations including local societies, piloted the role of Eye Clinic Liaison Officer (ECLOs), based in eye clinics. Their job was to give people the emotional and practical support they need when their sight loss first became a problem. They made sure that patients did not leave without getting information on the local and national services available. They referred people to the services they needed and acted as a bridge between Health and Social care. Perhaps most importantly, these support staff stayed in touch with people to check that services were provided and they were not left alone. Lessons from the pilot were adopted and the ECLO role has developed, supported by a qualification accredited by City University.

### 4.2. Further evidence

The emotional and psychological impact of sight loss is profound (Burmedi and Becker et al, 2002), and sight is the sense that people fear losing the most (College of Optometrists, 2011). Depression is significantly higher amongst people with sight problems (Evans, Fletcher and Wormald, 2007), and feelings of wellbeing are significantly lower when compared to people without sight loss (McManus and Lord, 2012). Patient experience in the eye clinic is crucial. It is here that people receive their diagnosis, undergo treatment and potentially go through the process of receiving a Certificate of Vision Impairment. Support at any of these stages can be invaluable to someone experiencing sight loss (Boyce, 2011; and Douglas et al, 2008).

Evidence shows that these early intervention services play a key role in:

* providing innovative and cost efficient care
* improving staff efficiency
* providing accessible information
* completing Certificates of Vision Impairment
* improving referrals.

Key sources of evidence are:

* Boyce, 2011
* Subramanian, Conway and Gillespie-Gallery, 2011
* Boyce 2012

All of these reports can be found on the RNIB website [www.rnib.org.uk/research](http://www.rnib.org.uk/research).

### 4.3 Case studies

#### Carl, 63 years old

In September 2012 Carl experienced a stroke that left him with permanent sight loss. In the first instance he was referred to the Stroke Association. After six months they referred him onto the ECLO in Rotherham, which was, in Carl’s words “a bit later than I would’ve liked”. Carl added: “The Stroke Association weren’t able to do one-to-one support, and the hospital didn’t help very much. I had no one to talk to, about what I felt and what I wanted to do”.

The ECLO was able to link him with social services, helped him to engage his employers to retain his job, and helped with finding ways to travel after his driver’s license was taken away. In particular the ECLO was able to secure Carl appointments in the hospital after he found out that they had lost his records and therefore had lost track of him. After 10 months of work with the ECLO, Carl was finally registered partially sighted.

Life for Carl still isn’t easy. He is still very depressed about his sight loss, and his job is still at risk, but with the ECLO he “wouldn’t have known where to go, and certainly wouldn’t have gotten back into the hospital”.

#### Elsie, 74 years old

Elsie went blind in one eye in 1994 and had been gradually losing sight in the other. In the seven years following her diagnosis she received no help at all to adapt to her sight loss and struggled through alone. “I was a prisoner, and it took a lot of self-talking to get me out of that door” she says.

However in 2011 her husband was diagnosed with AMD and was referred to the ECLO at the eye clinic. The ECLO was so helpful that Elsie asked for help also. Summarising the impact the ECLO had on her, Elsie simply said “I’ll be forever grateful to her for my whole life”.

The ECLO was someone to talk to about the challenges Elsie and her husband now faced, was able to answer Elsie’s questions and to check everything was progressing with Elsie and her husband. The ECLO referred Elsie to internal NHS and external services. Before long a rehab worker came to make changes to their kitchen. This enabled Elsie to remain independent and safe whilst cooking, as well as giving her a second contact point for support. The ECLO referred Elsie to Age UK for help applying for Attendance Allowance, and got independence aids like magnifying glasses and a new stick. The ECLO put Elsie in touch with Guide Dogs and gave her an accessible route to Directory Enquiries, now that the phonebook wasn’t available to her. Elsie can also now get out and about thanks to either a buddy scheme or the door to door bus.

In Elsie’s own words, “everything comes back to the ECLO”. Her only regret is those seven years she lived with sight loss but without advice and support, “I wish I’d have had her when my eyes went”.

#### John, 51 years old

John began having problems with his sight in 2007. At first he was diagnosed with glaucoma, but more recently he has been told he has macular degeneration. For John, an ECLO supported him from the very beginning, talking him through what the diagnoses meant and the process he was going through. Importantly, the ECLO was able to ensure John continued to receive timely hospital care throughout the confusion over his diagnosis. At one point the hospital had discharged John, however after a sudden change in his vision, the ECLO ensured he was referred back into the hospital again to be re-assessed.

Whilst John was losing his sight the ECLO was also working to help him maintain his independence by learning new skills. The ECLO was able to link him in with Blind Veterans UK and Guide Dogs, and now Dawson, his guide dog, is able to help him travel independently. The ECLO also arranged for the local authority sensory team to assess his flat, resulting in the installation of increased lighting and adaptations to ensure he can remain in his own home and is able to look after himself.

Overall John credits the ECLO with being able “to help a lot more than the hospital about my condition, and help me in my own time”. John’s condition is on-going and therefore a point of contact with the hospital gives him hope and reassurance that he’s not disconnected. John states the impact of the ECLO on his life in no uncertain terms: “without her I wouldn’t be here today”.

#### Rachel, 26 years old

Rachel began losing her sight in her early twenties and has been attending the hospital eye clinic ever since. In 2007 Rachel began working with the ECLO, and perhaps most importantly for Rachel the ECLO has been instrumental in helping her access training courses and employment support.

Rachel’s own perspective is that without the ECLO, “there’s not a lot of support out there. I would probably have given up working and gone onto benefits”. In addition, the ECLO was able to help Rachel understand her tax situation, and her DLA entitlement, increasing her level of income on both counts.

The ECLO has been able to help across a range of other areas of independence, including referrals to Action for Blind People and the low vision clinic, as well as mobility training, accessibility products and disability cards for leisure discounts.

With encouragement from the ECLO, and the result of her increased confidence and adaptation to her sight loss, Rachel has been able to offer her learning and knowledge to others she meets living with sight loss, especially younger people.

## 5. Location and type of support

This chapter provides a summary of the location of early intervention support in hospitals throughout the UK, the type of support provided and whether or not those providing it have attended one of RNIB's eye clinic support courses.

### 5.1 Location of support

As of April 2013, we estimate that there are over 400 hospitals in the UK providing outpatient ophthalmology appointments. The nature of these locations varies considerably. Some are very large specialist eye hospitals providing care for tens of thousands of people each year across multiple clinics. Other locations will be small treatment centres with a single clinic providing care for a couple of thousand people each year.

We have evidence that 218 hospitals have some form of early intervention support. This means that around half of hospitals have some type of support in place, and half do not.

There is variation between UK countries on the proportion of hospitals with early intervention services in place:

* Northern Ireland – 91 per cent
* Wales – 77 per cent
* England – 50 per cent
* Scotland – 47 per cent

There is also variation between the nine English regions. The East region has the highest proportion of early reach support (20 of 29 locations). The region with the lowest proportion of support available is the South West (17 of 53 locations).

We see similar variation within local authorities. The local areas with the highest proportion of early intervention support in place are Lancashire, Cornwall and Isles of Scilly and Glasgow. The local areas with the lowest proportion of support are Devon, North Yorkshire and Lincolnshire.

A summary of early intervention support by local area can be accessed in RNIB’s sight loss data tool: [www.rnib.org.uk/datatool](http://www.rnib.org.uk/datatool).

##### Table 5.1: Location of support, by UK country

|  |  |  |  |
| --- | --- | --- | --- |
| Area | Total number of locations | Locations with some form of early intervention support | Proportion |
| **UK** | 409 | 218 | 53% |
| **Scotland** | 37 | 17 | 46% |
| **Wales** | 22 | 17 | 77% |
| **Northern Ireland** | 22 | 20 | 91% |
| **England** | 328 | 164 | 50% |

Base: Estimated number of hospital locations that are providing outpatient ophthalmology appointments in the UK (n=409)

### 5.2 Type of support

Over half (55 per cent) of early intervention support is provided by Eye Clinic Liaison Officers. A further 12 per cent of support is being provided by ECLO-type roles. This group includes professionals with a range of different job titles, including: Clinical Support Workers, Low Vision Support Workers, Patient Support Officers, Sight Loss Advisors and Vision Support Officers. Other types of support included: Information Officers or Information Desks (11 per cent); volunteers (10 per cent); nurses who have an element of patient support built into their role (5 per cent); and Hospital Co-ordinators (3 per cent).

We also have evidence that 18 hospitals have some additional form of support. For example, an ECLO recruiting and managing volunteers, additional ECLOs in a large specialist eye hospital and additional support provided by nurses.

##### Table 5.2: Type of support available

|  |  |  |
| --- | --- | --- |
| Type of support | Number | Proportion |
| Eye Clinic Liaison Officers | 120 | 55% |
| ECLO-type roles | 26 | 12% |
| Information Desk or Information Officers | 24 | 11% |
| Volunteers | 22 | 10% |
| Nurses | 10 | 5% |
| Hospital Co-ordinators | 6 | 3% |
| Telephone service | 3 | 1% |
| Rehab Officer | 3 | 1% |
| Orthoptist | 1 | 1% |
| Other | 3 | 1% |

Base: Estimated number of hospital locations that are providing outpatient ophthalmology appointments in the UK which have some form of early intervention service in place (n=218)

### 5.3 Support provider

The largest group providing early intervention support services are local voluntary organisations, responsible for nearly half of the early intervention support. This group is made up primarily of local societies for the blind, and there are over 50 organisations involved in providing this support.

The single largest organisation providing early intervention services is the RNIB group of charities. Services provided by RNIB Cymru, RNIB Scotland, RNIB Northern Ireland and Action for Blind People in England account for 36 per cent of all early intervention support.

##### Table 5.3: Provider of support

|  |  |  |
| --- | --- | --- |
| Provider of support | Number | Proportion |
| Voluntary organisation | 106 | 49% |
| RNIB Group | 79 | 36% |
| Unknown | 2 | 1% |
| Joint | 1 | 1% |
| Other | 30 | 14% |

Base: Estimated number of hospital locations that are providing outpatient ophthalmology appointments in the UK which have some form of early intervention service in place (n=218)

### 5.4 Provision of support by trained staff and volunteers

Some hospitals provide support through staff or volunteers who have been accredited and trained to provide high quality emotional and practical support. We estimate that of the 218 hospital locations with support, 109 are covered by staff or volunteers who have attended the accredited Eye Clinic Support Studies course. That means that only 27 per cent (109 out of 409) of hospitals in the UK providing ophthalmology outpatient appointments have staff in place who are qualified and accredited to deliver this support.

RNIB also supports volunteers who are providing early intervention support in eye clinics. The Search Project, funded by the Department for Health, offers a one-day training course, supplemented by additional learning, personal development and networking opportunities.

##### Table 5.4: Locations with qualified early intervention support

|  |  |  |
| --- | --- | --- |
| Locations supported by staff who have attended RNIB's Eye Clinic Support Studies course | Number | Proportion |
| Yes | 109 | 50% |
| No | 109 | 50% |

Base: Estimated number of hospital locations that are providing outpatient ophthalmology appointments in the UK which have some form of early intervention service in place (n=218)

## 6. Demographics and characteristics of service users

This chapter provides a summary of the profile of users of early intervention services. RNIB Group ECLOs record details of who they are supporting, their age, ethnicity, additional disabilities, sight loss, falls risks and living arrangements.

### 6.1 New and repeat service users

In 2012/13, data on 16,121 service users was recorded by the RNIB group of charities early intervention services in England, Scotland, Wales and Northern Ireland. Of this total, 72 per cent were new service users who had not used early intervention services before, and 15 per cent were existing or repeat service users. Details for the remaining 14 per cent were not recorded.

#### Table 6.1: Type of service user

|  |  |
| --- | --- |
| Type of service user | Proportion |
| New | 71.7% |
| Existing | 14.7% |
| Not recorded | 13.6% |

Base: All people supported by RNIB Group early intervention services in the UK (n=16,121)

### 6.2 Age

Three-quarters of early intervention support service users were aged 65 years or over. A further 22 per cent were of working age, and 3 per cent were children aged 18 or under.

Due to slightly different age banding, we cannot directly compare with the age profiles of adults and children issued with a Certification of Vision Impairment (CVI) in 2011/12. In England, 5 per cent of CVIs were issued to children aged 0–17 (RNIB, 2013); while 2.7 per cent of early intervention service users were aged 0–18. This suggests that children and families may be slightly less likely to access early intervention services, or it could be an administrative issue with parents or guardians being recorded as the service user rather than the young person.

ECLOs in Wales collect more detailed information on age, which allows us to breakdown the "65 and over" group. Of the 4,389 early intervention service users in Wales: 18 per cent were aged 65-74; 34 per cent were aged 75-84; and 25 per cent were aged 85 and over.

##### Chart 6.2a: Age



##### Table 6.2a: Age

|  |  |
| --- | --- |
| Age range | Proportion |
| 0-18\* | 2.7% |
| 19-49\* | 9.8% |
| 50-64 | 12.6% |
| 65+ | 75.0% |

Base: People supported by RNIB Group early intervention services in the UK who had their age recorded (n=14,196)

\*Note: Data for Wales is in the age bands 0-16 and 17-49

##### Chart 6.2b: Detailed age



##### Table 6.2b: Detailed age

|  |  |
| --- | --- |
| Age range | Proportion |
| 0-5 | 0.4% |
| 6-16 | 0.9% |
| 17-24 | 1.6% |
| 25-39 | 3.2% |
| 40-49 | 4.5% |
| 50-59 | 6.8% |
| 60-64 | 5.0% |
| 65-69 | 6.9% |
| 70-74 | 11.3% |
| 75-79 | 14.8% |
| 80-84 | 19.5% |
| 85-90 | 16.7% |
| Over 90 | 8.4% |

Base: People supported by RNIB Group early intervention services in Wales who had their age recorded (n=4,389)

### 6.3 Gender

More women were supported by early intervention services than men. In 2012/13, 60 per cent were female and 40 per cent were male.

Sight loss is linked to age, and women have a higher life expectancy than men. As a result, around 63 per cent of people with sight loss are female, 37 per cent are male (Access Economics, 2009).

##### Table 6.3: Gender

|  |  |
| --- | --- |
| Gender | Proportion |
| Male | 39.7% |
| Female | 60.3% |

Base: People supported by RNIB Group early intervention services in the UK who had their gender recorded (n=15,969)

### 6.4 Ethnicity

Around 96 per cent of people supported with early intervention services were recorded as one of the White ethic groups (White British, White Irish or White Other). The remainder (4 per cent) were recorded as being from any other ethnic group.

The proportion of people from black and minority ethnicity backgrounds varies considerably by UK country. However, on the basis of the recorded information it does appear as though there is an under-representation of other ethnic groups amongst early intervention service users. Further research should be considered into the uptake of early intervention services by ethnic minority groups, along with identification of any barriers that may exist to accessing services.

##### Table 6.4: Ethnicity

|  |  |
| --- | --- |
| Gender | Proportion |
| White (British, Irish or White Other) | 96.4% |
| Black and Minority Ethnic | 3.6% |

Base: People supported by RNIB Group early intervention services in the UK who had their ethnicity recorded (n=13,423)

### 6.5 Sight loss

Overall, 77 per cent of people supported by early intervention services were recorded as blind or partially sighted: 27 per cent were blind; 32 per cent were partially sighted; and 18 per cent did not have their level of sight loss recorded. The remaining 24 per cent of service users were either not registered as blind or partially sighted, did not have sight loss or their sight loss was unknown.

In 2012/13, 24 per cent of early intervention service users were newly registered as blind or partially sighted; 22 per cent were existing registrations; the date of registration of 13 per cent was unknown; the registration status of 18 per cent was unknown. The remaining 24 per cent of service users were either not registered as blind or partially sighted, did not have sight loss or their registration status was unknown.

##### Table 6.5a: Severity of sight loss

|  |  |
| --- | --- |
| Severity of sight loss | Proportion |
| Partially sighted | 32.1% |
| Blind | 26.7% |
| Blind or partially sighted, status unknown | 17.6% |
| Not registered or Other | 23.6% |

Base: People supported by RNIB Group early intervention services in the UK who had their level of sight loss recorded (n=9,973)

##### Table 6.5b: Time since registration

|  |  |
| --- | --- |
| Time since registration | Proportion |
| New registration | 23.9% |
| Existing registration | 21.9% |
| Time of registration unknown | 13.0% |
| Registration status unknown | 17.6% |
| Not registered or Other | 23.6% |

Base: People supported by RNIB Group early intervention services in the UK who had time since registration recorded (n=9,973)

### 6.6 Eye conditions

Based on data collected in Wales, by far the most common eye condition experienced by early intervention service users in Wales was age-related macular degeneration (47 per cent). Other common eye conditions were glaucoma (19 per cent), cataracts (8 per cent) and diabetic eye disease (6 per cent).

The proportion of eye intervention service users with age-related macular degeneration (AMD), glaucoma and diabetic retinopathy is similar to those recorded diagnoses on Certificates of Vision Impairment. In Wales for the period 2011/12:

* AMD was the cause of sight loss in approximately 47 per cent of all certifications.
* Glaucoma was the cause of sight loss in approximately 17 per cent of certifications.
* Diabetic eye disease was the cause of sight loss in approximately 6 per cent of certifications.

##### Table 6.6: Eye condition

|  |  |
| --- | --- |
| Eye condition | Proportion |
| Age-related macular degeneration | 47.2% |
| Glaucoma | 19.2% |
| Other eye conditions | 11.2% |
| Cataracts | 7.5% |
| Diabetic retinopathy | 5.9% |
| Retinal problems | 4.9% |
| Hemianopia | 1.7% |
| Vascular condition | 1.4% |
| Retinitis pigmentosa | 1.1% |

Base: People supported by RNIB Group early intervention services in Wales who had eye condition details recorded (n=4,853)

### 6.7 Living arrangements

One-third of people supported by early intervention services were living alone. The remainder were either living with someone else, their living arrangements were not recorded or were withheld.

Early intervention services in England collect more detailed information about living arrangements: 35 per cent of early intervention service users were living alone; 24 per cent were living with a partner; 5 per cent were living with others; 4 per cent were living with parents; 4 per cent were living with other family and 3 per cent were not recorded. A further 24 per cent of service users withheld their living arrangements.

##### Table 6.7a: Living arrangements

|  |  |
| --- | --- |
| Living arrangement | Proportion |
| Living alone | 32.9% |
| Living with family or other, not recorded or withheld | 67.1% |

Base: All people supported by RNIB Group early intervention services in the UK (n=16,121)

##### Table 6.7b: Detailed living arrangements

|  |  |
| --- | --- |
| Living arrangement | Proportion |
| Living alone | 35.1% |
| Living with partner | 23.8% |
| Living with others | 5.4% |
| Living with parents | 4.1% |
| Parent with family | 3.8% |
| Single parent | 0.2% |
| Not recorded | 3.1% |
| Withheld | 24.3% |

Base: People supported by RNIB Group early intervention services in England (n=6,613)

### 6.8 Additional disabilities

43 per cent of service users supported by early intervention services were recorded as having an additional disability. The remaining 57 per cent were either recorded as not having an additional disability, additional disability being unknown or not recorded.

In Wales, 2,024 out of 5,959 service users were recorded as having an additional disability (34 per cent). Of these 2,024 service users, 39 per cent had mobility problems; 18 per cent had hearing difficulties, 11 per cent had arthritis; 6 per cent had experienced a stroke; 6 per cent had heart problems; and 15 per cent had another type of additional disability.

##### Table 6.8a: Additional disabilities

|  |  |
| --- | --- |
| Additional disabilities | Proportion |
| Yes | 43.3% |
| No, not known or not recorded | 56.7% |

Base: All people supported by RNIB Group early intervention services in the UK (n=16,121)

#### Table 6.8b: Type of additional disability

|  |  |
| --- | --- |
| Type of additional disability | Proportion |
| Mobility problems | 39.1% |
| Hearing difficulties | 18.0% |
| Arthritis | 10.8% |
| Stroke | 6.1% |
| Heart problems | 6.0% |
| Cancer | 2.2% |
| Osteoporosis | 1.4% |
| Learning disability | 1.2% |
| Other | 15.2% |

Base: People supported by RNIB Group early intervention services in Wales who had details of an additional disability recorded (n=2,024)

### 6.9 Risk of falls

In Scotland, 18 per cent of all service users had a history of falls. However, other service users may have experienced a fall as around one-third of service users did not have this information recorded.

##### Table 6.9: History of falls

|  |  |
| --- | --- |
| Risk of falls | Proportion |
| Yes | 18% |
| No | 50% |
| Not known | 33% |

Base: People supported by RNIB early intervention services in Scotland (n=1,019)

## 7. Support and services provided

This chapter provides a summary of the support provided by ECLOs, what they talked to service users about and any onward referrals that were made as a result.

### 7.1 Where service took place

Details of where the early intervention support session took place are recorded in Scotland, Wales and Northern Ireland. Over one-third of sessions took place in the ECLO's office; 31 per cent were by telephone; 24 per cent in the waiting room; and 9 per cent took place in other locations.

##### Table 7.1: Where session took place

|  |  |
| --- | --- |
| Where session took place | Proportion |
| ECLO Office | 35.6% |
| Telephone | 30.8% |
| Waiting room | 24.4% |
| Other | 9.2% |

Base: People supported by RNIB Group early intervention services in Wales, Scotland and Northern Ireland who had the location of session recorded (n=9,286)

### 7.2 Referral source

As we might expect, the vast majority of referrals to early intervention services that are based in eye clinics come from other eye clinic staff (79 per cent). A further 10 per cent of service users were self-referrals; referrals from other hospital departments and health services accounted for 4 per cent of service users; and a further 7 per cent were referred from other sources.

##### Table 7.2: Referral source

|  |  |
| --- | --- |
| Referral source | Proportion |
| Eye Clinic | 79.4% |
| Self-referrals | 10.2% |
| Other hospital department or health service | 3.7% |
| Other | 6.7% |

Base: People supported by RNIB Group early intervention services who had details of the source of referral recorded (14,685)

### 7.3 Information and advice provided

The most common type of information and advice provided by Eye Clinic Liaison Officers was details about their role and their contact details. This basic information was supplied to 78 per cent of service users.

ECLOs also play a key role in raising awareness of available support, providing details of local organisations to 57 per cent of service users and details of national organisations to 37 per cent.

ECLOs have a role in helping people understand their eye condition or treatment. In 2012/13, ECLOs provided information and advice on eye conditions to nearly half of new service users (47 per cent), and information and advice on eye treatments to 15 per cent of new service users.

ECLOs help people to live independently through the provision of information and advice on equipment to 54 per cent of service users; benefits to 35 per cent; emotional support to 14 per cent; employment to 4 per cent; travel concessions to 3 per cent; and education to 2 per cent.

There is a link between ECLOs and social services. Over one-third of new service users were provided information and advice about registration as blind or partially sighted, and 12 per cent were given other information and advice about social services.

##### Table 7.3: Information and advice provided

|  |  |
| --- | --- |
| Advice provided | Proportion |
| ECLO role/contact details | 78.1% |
| Local information | 56.5% |
| Equipment | 53.6% |
| Eye condition | 46.7% |
| National information | 36.5% |
| Registration | 36.2% |
| Benefits | 35.0% |
| Eye treatment | 15.4% |
| Emotional support | 13.8% |
| Social services | 11.7% |
| Carer support | 5.7% |
| Employment | 4.4% |
| Falls prevention | 3.4% |
| Travel concessions | 3.3% |
| Education | 1.8% |
| Diet and nutrition | 0.8% |
| Other | 16.4% |

Base: New service users supported by RNIB Group early intervention services in 2012/13 (n=11,556)

### 7.4 Onward referrals

As well as providing information and advice to service users, ECLOs also provide referrals to other professionals and services. The most common type of referral is to social services, with nearly one-third (31 per cent) of new service users referred to local authority VI teams, duty social workers or rehab teams.

16 per cent of new service users were referred for a Low Vision Assessment, and 2 per cent were referred to an optometrist.

Other destinations for referrals included: 14 per cent referred on to other RNIB Group services, 9 per cent to other local organisations and 6 per cent for benefits advice.

##### Table 7.4: Onward referrals

|  |  |
| --- | --- |
| Referrals | Proportion |
| Social services | 30.8% |
| Low Vision Assessment | 16.2% |
| RNIB Group services | 13.8% |
| Local organisations | 9.0% |
| Benefits advice | 5.8% |
| Resource centre | 4.1% |
| Transport and mobility | 3.5% |
| Other health service | 2.4% |
| Optometrist | 2.2% |
| Employment | 2.0% |
| Carer support | 1.0% |
| Falls prevention | 0.9% |
| Counselling | 0.7% |
| Education | 0.7% |
| Occupational therapy | 0.7% |
| Other services | 17.7% |

Base: New service users supported by RNIB Group early intervention services in 2012/13 (n=11,556)

### 7.5 Time to first contact

Nearly three-quarters of interactions between ECLOs and service users occurred on the same day as the referral (72 per cent); 13 per cent of service users were contacted within a week; and 15 per cent of service users had to wait 6 days or longer to be contacted.

##### Table 7.5: Time to first contact

|  |  |
| --- | --- |
| Time to first contact | Proportion of interactions |
| Same day | 72.2% |
| 1–5 days | 13.1% |
| 6 or more days | 14.7% |

Base: Interactions with "Time to first contact" variable completed (n=9,487)

Note: This variable is not collected in Wales.

### 7.6 Length of contact

Over three-quarters of interactions took less than 30 minutes (78 per cent); 18 per cent were between 30–60 minutes; 4 per cent were between 1–2 hours; and 1 per cent of interactions were over 2 hours.

##### Table 7.6: Time spent on interaction

|  |  |
| --- | --- |
| Time spent on interaction | Proportion of interactions |
| Under 30 mins | 77.5% |
| 30–60 mins | 17.5% |
| 1–2 hours | 4.1% |
| Over 2 hours | 0.9% |

Base: Interactions with “Time spent on interaction” variable completed (n=19,609)

## 8. Summary

Early intervention services in eye clinics play a key role in helping service users adjust to sight loss. However, only half of hospitals in the UK with eye clinics have any form of support in place. An even smaller number have support available from staff and volunteers who have undertaken training to provide high quality emotional and practical support. There is also significant variation between countries, regions and local authorities in offering this vital support to service users who are experiencing sight loss.

ECLOs provide a wide range of information and advice to service users on local and national services, demonstration of aids and equipment, benefits and eye conditions. They also provide onward referrals, particularly to social services, low vision services and national or local organisation services.

### 8.1 Recommendations

Based on the evidence in this report, the top five recommendations are as follows:

#### Core data is collected

A core dataset and definitions should be agreed and collected consistently across the UK. This information will help provide an evidence base for early intervention services. Systems should be put in place to ensure that this recording is not too onerous a task for ECLOs.

#### Mapping of services is used to prioritise development

Currently mapping of eye clinic support does not take into account the size of the eye clinic. This is crucial information if we are to assess the coverage of these services and utilise it in our influencing work.

#### Recording level of sight loss and certification should be a priority

We have data on 16,121 people who were supported by RNIB early intervention services in 2012/13. Only 9,973 of these (62 per cent) had any details of their sight loss or certification/registration status recorded. Both of these variables are crucial data in planning early intervention services as they help us prioritise and estimate the potential need for these services.

#### Official statistics providers should make key data available

Data published in Wales, Scotland and Northern Ireland tells us which hospitals have eye clinics and how many people attend at each location. This type of data is invaluable when prioritising resources. This data is not available in England, where it is only available at NHS Trust level. There should be engagement with the NHS Information Centre to influence the availability of this information.

#### Other organisations managing early intervention services should consider feeding data to RNIB

There are a wide range of organisations managing early intervention services in the UK. One of the limitations of this report is that it relies only on data from ECLOs employed by the RNIB group of charities. These other providers should consider feeding data to RNIB so that we can give a more complete picture of early intervention services. This would support service support, agreement of development priorities and add to the business case of early intervention support services.

## Appendix A: List of tables, charts and maps

[Table 5.1: Location of support, by UK country 16](#_Toc377115642)

[Table 5.2: Type of support available 16](#_Toc377115643)

[Table 5.3: Provider of support 17](#_Toc377115644)

[Table 5.4: Locations with qualified early intervention support 18](#_Toc377115645)

Table 6.1: Type of service user……………………………………..19

[Chart 6.2a: Age 20](#_Toc377115646)

[Table 6.2a: Age 20](#_Toc377115647)

[Chart 6.2b: Detailed age 21](#_Toc377115648)

[Table 6.2b: Detailed age 21](#_Toc377115649)

[Table 6.3: Gender 22](#_Toc377115650)

[Table 6.4: Ethnicity 22](#_Toc377115651)

[Table 6.5a: Severity of sight loss 23](#_Toc377115652)

[Table 6.5b: Time since registration 23](#_Toc377115653)

[Table 6.6: Eye condition 24](#_Toc377115654)

[Table 6.7a: Living arrangements 24](#_Toc377115655)

[Table 6.7b: Detailed living arrangements 25](#_Toc377115656)

[Table 6.8a: Additional disabilities 25](#_Toc377115657)

Table 6.8b: Type of additional disability……………………………25

[Table 6.9: History of falls 26](#_Toc377115658)

[Table 7.1: Where session took place 27](#_Toc377115659)

[Table 7.2: Referral source 27](#_Toc377115660)

[Table 7.3: Information and advice provided 28](#_Toc377115661)

[Table 7.4: Onward referrals 29](#_Toc377115662)

[Table 7.5: Time to first contact 30](#_Toc377115663)

[Table 7.6: Time spent on interaction 30](#_Toc377115664)

## Appendix B: References

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### About RNIB’s research

RNIB is a leading source of information on sight loss and the issues affecting blind and partially sighted people. Our Research and Knowledge Hub contains key information and statistics about blind and partially sighted people including our Sight Loss Data Tool, which provides information about sight loss at a local level throughout the UK. You’ll also find research reports on a range of topics including employment, education, technology, accessibility and more. Visit our Knowledge and Research Hub at: **rnib.org.uk/research**