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wsun
Wiltshire and Swindon Users' Network

Overcoming Barriers To Health and Social Care for People with a Visual Impairment in Wiltshire

WILTSHIRE AND SWINDON USER'S NETWORK

2016

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ACKNOWLEDGEMENTS

I must start by saying a very special thank you to all of the Visually Impaired Service Users (VI's) and organisations which helped and supported the research for this project, by giving up their valuable time to provide feedback and information which has been used in the preparation of this report. Without their help and assistance, this report could not have been completed.

I would especially like to thank the support groups (as listed in the Methodology section) which invited me to engage with all of their members, The Wessex Sight Centre, Action for Blind People, The Macular Society and the Hearing and Vision Team.

Debbie Furnell

Wiltshire and Swindon Users Network (WSUN)

January 2016.

INTRODUCTION

The Wiltshire and Swindon Users' Network (WSUN) are supporting people who use Health and Social Care services in the demographic area of Wiltshire to have their say about the way the services are run. This report concentrates only on how Visually Impaired Service Users feel about the Health and Social Care they receive and highlights the main issues faced by the Visually Impaired Service Users across the county of Wiltshire (not including Swindon which was not researched during the preparation of this report), when accessing these services.

The Wiltshire and Swindon Users' Network (WSUN) have prepared this report to highlight the needs and issues faced by Visually Impaired Service Users who access Health and Social Care services in Wiltshire, following discussions during previously held forums and workshops.

AUTHORS NOTE

For the purpose of this report the term ' Visually Impaired Service Users' has been used, however this includes blind and partially sighted people who may also be affected by dual sensory impairment and additional complex health needs.

Where direct quotes have been used within this report they will feature in "speech marks". * Denotes a term which is explained in more detail in the Glossary Appendix.

METHODOLOGY

It was clear from the outset of this project that the most appropriate way to engage with participants and collate the information required to complete this report would be through fieldwork and outreaching to visit established groups.

Additionally, as the project aimed to gain an insight into Visually Impaired Service Users experiences and requirements, it was decided that a questionnaire should be used (Appendix 1). However, it was vital to ensure that the form was planned specifically with these people in mind. Therefore, the form was designed with the following adjustments.

1) The form was prepared using Microsoft Word and designed in a text-only format to enable the users to read and complete the forms using their assistive technology and screen readers.

2) The font type Arial was used in size 16 to make the document as clear and easy to read as possible, enabling people to use any residual vision and their magnifiers.

3) The form incorporated large spaces to enable people to answer the questions as fully as possible and to complete it using marker pens, where required.

4) Once completed, the form was printed on both white and yellow paper to enable users to make a choice.

Some eye conditions may mean that the contrast of the black text on a yellow background improves the contrast and makes text easier to read.

An extensive Internet search was then carried out to locate established support groups and known relevant organisations. The Hearing and Vision Team, Action for Blind People and the Wessex Sight Centre were also contacted and provided some significant contact details. Wiltshire Sight declined to take part in the project. Each group and individual contact was then initially telephoned to introduce the Wiltshire and Swindon Users' Network (WSUN), explain the projects aims and objectives and request a visit.

To promote a person-centred approach, to best suit the groups and individuals taking part, numerous different techniques were devised. From one-to-one face-to -face consultations, telephone interviews, distributing of questionnaires via email, post and focus groups.

It must be mentioned that participation in the project was entirely voluntary and this was made clear to all of the individuals, groups and organisations contacted. However, the importance of the project and the information collated was stressed to all participants.

Following the initial contact by telephone, appointments were arranged to visit individuals, support groups and organisations, as listed below. For each support group and organisation that agreed to participate in the project, a variety of ways were used, depending on the support groups and organisations particular needs and requirements.

Over 80 Visually Impaired people between the ages of 21 and 98 were contacted during the research process of this report. 66 of those invited to take part, chose to participate by completing and returning questionnaires. This report has been based on the information collated through the completed questionnaires and through notes taken at the face-to-face interview consultations.

LIST OF ORGANISATIONS AND SUPPORT GROUPS IN WILTSHIRE WHO PARTICIPATED IN THIS CONSULTATION

1. Hearing and Vision

“Hearing and Vision” is the name given to a department within Wiltshire Council which offers statutory services to people with sight-loss. They are based in the Wiltshire town of Devizes. Hearing and Vision aim to actively promote independent living by carrying out home and mobility assessments, by providing information on benefit entitlements, assistance with completing claim forms and teaching new skills, kitchen skills, cane training, reading Braille and how to use text phones. They provide information and demonstrations relating to assistive technology products through their resource centre.

2. Action for Blind People

Now working with the Royal National Institute for the Blind (RNIB), Action for Blind People is a National Charity. It can assist with support and guidance to help people live a safe and independent life, by providing information and assistance with independent living skills, employment, training and benefits, assistive technology and children and family services. The RNIB run a telephone service called “Talk and Support”. Representatives from Action for Blind People were contacted and information relating to the project and a copy of the questionnaire was sent electronically via email. The questionnaires were then distributed by the representative to the Service Users who agreed to participate in the project.

3. The Wessex Sight Centre

A low vision clinic located at the Salisbury District Hospital run by the company Optima who have the contract for Wiltshire. Assessments are carried out after a referral has been received from the client's eye care professionals or GP. These assessments enable the assessor to find out the clients' needs and requirements and in the majority of cases provide low vision aids in the form of magnifiers or lights to help people live a more independent life at home.

Once in the system, 6 monthly follow up appointments are given to people so they have the opportunity to highlight any changes in their eye condition and to update the low vision aid they have been given. This service is free and allows people to access the low vision aids given on a free-hire basis.

Information was collected during a clinic, by shadowing the assessor for the day and taking notes during each client's appointment. One-to-one, face-to-face interviews were then carried out with each client and questionnaires were completed on their behalf following the consultation.

4. The Monday Club (Devizes & District Blind Club)

A self-funded volunteer-led group which enables people to meet every Monday for social interaction and support. For £3 a week the group provides the members with tea or coffee, a home cooked two course meal, trips out and a chance to meet with like-minded people.

The Chairman also provides transport for those who are unable to travel independently to the group. The group are actively looking for new members and volunteers. One-to-one, face-to-face interviews were carried out with individual members and questionnaires were completed on behalf of each member who responded during the consultations.

5. Warminster & Westbury Visually Handicapped Club

A large and very active, self-funded volunteer led group of users with varying degrees of sight loss. The group meets once a month for social interaction and support. There are many friendships which have been formed through the group and there seems to be a friendly atmosphere which is very supportive.

The members pay £3 a month to cover such costs as the venue, meals and activities. There is an active programme of events for the members to enjoy such as craft, art and poetry and many talks and trips are organised for the members to enjoy. The organiser also assists the members with signposting to relevant organisations to assist with independent living. A focus group was held, which was followed by individual one to one face-to-face interviews. Questionnaires were completed on behalf of each member during the consultations.

6. Salisbury Macular Society

A volunteer led support group for Visually Impaired Service Users with varying degrees of sight loss, principally due to Macular Degeneration*. The group has an active membership which meets once a month for support and social interaction. In the winter months the group finds that member numbers drop, so to save funds they hold their meetings in the Salisbury Playhouse, which is an informal venue for chatting and catching up. Trips and lunches are sometimes organised for members to attend.

Individual one-to-one face-to-face interviews were carried out with individual members and questionnaires were completed during the consultation.

7. Marlborough Macular Society

A self-funded volunteer led group which has a very active membership of Visually Impaired Service Users with varying sight loss due principally to the effects of Macular Degeneration*. The organiser of the group is Visually impaired and seems to have a good understanding of how her members feel and of the issues they may have.

The venue is funded by the local Specsavers Opticians and the group find that they need to look for sponsorship from local businesses to cover the costs of activities. The group meets once a month for support and have an active programme of events including talks, trips, craft activities and performances from entertainers. The group also provides their members with lunch, coffee and cake.

A focus group was held to explain the project and its aims which were then followed by individual one-to-one face-to-face interviews. Questionnaires were completed on behalf of the members where they were not able to complete the form for themselves during the consultation.

8. Trowbridge Macular Society

A volunteer led, self-funded support group, for Visually Impaired Service Users, principally affected by Macular Degeneration*. Unfortunately, the researcher was unable to attend this group due to the time constraints.
However, a telephone interview was carried out with the organiser of the

group who was able to confirm that the group has an active membership, with a full programme of events and activities for the members to enjoy. The organiser of the group has vast experience of sight loss and therefore provides a great support and signposting service for her members.

As face-to-face interviews were not possible, questionnaires and information explaining the project, its aims and objectives were sent by post to enable members to respond.

9. Devizes Coffee Club for the Blind

An informal volunteer led coffee club which meets on the first Friday of every month at the Castle Hotel in Devizes. Following problems with finding a venue, the group have now chosen to use the Castle Hotel as their venue. It is easily accessible and has no overheads. They have previously enjoyed trips out to venues such as the Salisbury Cathedral, but due to organisational challenges, the group now just enjoy meeting socially for coffee.

Questionnaires were handed out to members who were able to complete their own forms and where this was not possible individual face-to-face interviews were held and questionnaires completed on their behalf during the consultation.

10. Chippenham Coffee Club for the Blind

An informal volunteer led group which meets up on the second Thursday of every month for social interaction and support. Membership is very diverse with a large age range and members living with various eye conditions.

Individual face-to-face interviews were held with each member and questionnaires were completed on their behalf during the consultation.

11. Salisbury & District Guide Dog Group

A volunteer led group for people with guide dogs or those affected by sight loss. The group receive quarterly information newsletters, organise events, provide My Guide training to businesses and organisations, and attend talking engagements to promote the guide dog services. My Guide aims to support blind and partially sighted people to get out and about and do the things they want to do. The group are also active campaigners on issues affecting blind and partially sighted people. The membership of this particular group and their way of life meant that numerous styles of collecting information was used including face-to-face interviews and telephone interviews. There were also requests for information explaining the projects, aims and objectives and questionnaires to be sent electronically via email.

FINDINGS

1. NATIONAL HEALTH SERVICE (NHS) CARE SERVICES

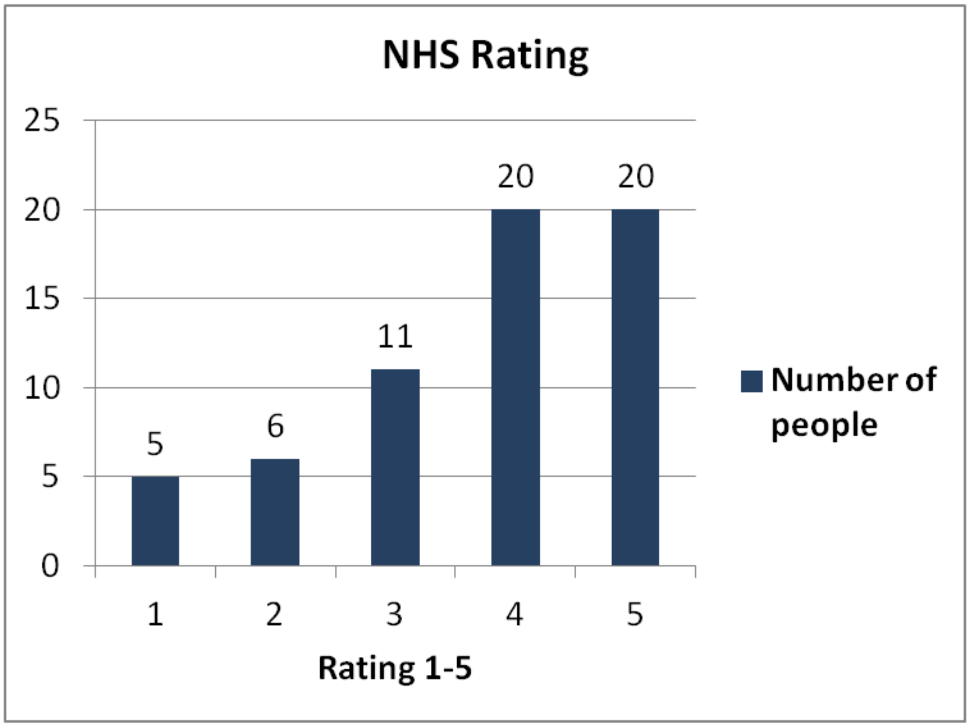
This section concentrates on the issues that people had experienced when accessing NHS care in Wiltshire. The Visually Impaired Service Users who participated, were asked to rate how they felt about the NHS care they receive in Wiltshire.

This predominantly referred to the care they had received in relationship to their sight loss. For the purpose of this project it was clarified to participants that NHS care may relate to care received through hospitals, eye care specialists or consultants and GP'S,

The respondents were asked to rate the services using a scale of 1 - 5, 1 being totally dissatisfied and 5 being very satisfied with the care received.

Chart 1:

Graph demonstrating how respondents rated the NHS care they have received in Wiltshire.



92% of respondents were able to provide an informed rating, (as the remaining 8% felt they were unable to give a rating). This was principally due to receiving private health care and care from health providers outside of the area of Wiltshire.

The majority of Visually Impaired Service Users involved in this research were satisfied with the medical treatment they received from their care providers in Wiltshire, with 77% of respondents rating the NHS care they received a 3 or above. We asked people who scored the service below a 3, why they had chosen this score. The issues highlighted were as follows:

1.1

An elderly service user affected by Macular Degeneration* was heavily encouraged by an NHS Eye Care Consultant to have his eye care referred to a private Health Clinic despite the patient explaining he would prefer to remain at the NHS run clinic he had been attending.

This left the respondent very confused and angry, as he had been totally satisfied with the care that he had received and was not interested in or able to pay for private health care.

1.2

10% of the respondents felt that hospital appointment waiting times are far too long and, when the appointment was received it was difficult for respondents to attend. This was principally due to the following reasons:

a. A lack of accessible public transport available across the rural demographic areas of Wiltshire.

b. Appointments are sent for hospitals which are not local, which makes it difficult for patients to attend. The Royal United Hospital in Bath was highlighted to be one of the most difficult hospitals to travel to for respondents. 8% of respondents rely on family to support them with travel to hospital and doctors appointments, due to the lack of public transport and the cost of taxis.

c. During a group session one service user reported that they found it difficult to attend late afternoon appointments due to the nature of their eye condition. A further 9 people agreed that peoples’ mobility and ability to travel independently is greatly affected by dim light and they have a fear of travelling in the dark.

1.3

7% of respondents felt that appointments booked with their GP or eye care specialists were not long enough (usually restricted to 10-15 minutes), meaning that they could not discuss their eye condition, their concerns and / or worries fully. They often left appointments feeling uninformed about their eye condition, treatments available and the future diagnosis in relation to their sight loss.

1.4

10% of respondents were finding it difficult to book an appointment with their GP, often being told that they would have to wait at least two weeks for an appointment. One patient was told that she would have to wait two weeks for a telephone consultation with her own GP.

1.5

A Service User with dual sensory loss was not told that his GP had moved to a new location. He therefore went to the old surgery to find it closed. There were signs, but due to his sight loss he was unable to read them, but luckily a passer-by was able to read the sign on his behalf.

The person was left not knowing where the new surgery was or how to get there. When he made a complaint to his GP he was told "That the CCG had advised the surgery that they did not have to write to individual patients as they had put up posters in the Waiting Room informing everyone of the move". The service user had been a long term patient of this surgery and all staff were aware of his dual sensory impairment.

1.6

13% of participants who responded felt that their GP or eye specialist did not show any empathy or compassion for them. In some cases the respondents felt that their GP had shown a lack of understanding of their eye condition and its impact on them, leaving them feeling like they were wasting their health care provider's time.

1.7

Respondents found it difficult to make contact with their own doctor, often meaning that they would have to duplicate their medical history numerous times to different medical professionals.

1.8

One person had requested a home visit from their GP following an eye operation. The procedure left her unable to leave her home as she had no residual vision and no support to take her to the doctor's surgery.

Her GP refused to provide a home visit due to a busy schedule, meaning the patient had to wait until she had recovered from her procedure to attend an appointment at the surgery, assisted by a member of her family.

1.9

7% of respondents commented that they had received correspondence from health care providers which had been sent to them in a format which was not accessible, stating that they had received letters which they could not read. These respondents also strongly felt that they had not been given the opportunity throughout their care to choose which format they would like appointments and other correspondence to be prepared and sent to them in. Letters informing people for Eye Clinic Outpatient appointments had been received in text using a small font and could therefore not be accessed without assistance.

1.10

10% of respondents felt unsupported following consultations with their eye specialists, having received information that their sight loss was irreversible and that there was nothing more that the medical professionals could do. These respondents commented that they had been left to go home with no emotional support, no after-care provision and no information on where to receive help and assistance. This left many feeling isolated and frightened.

1.11

8% of respondents stated that their Eye Consultants did not offer enough information about their eye condition or the treatments available. This had left them with a lack of understanding about their own eye condition and what to expect in the future, in turn resulting in the respondents not knowing how the eye condition would impact on both their own and their families' lives.

1.12

One person reported that there seems to be a very worrying trend across the entire demographic area of Wiltshire that there is a lack of registration* of ' Severely Sight Impaired ' or ' Sight Impaired' by eye care professionals. Service Users are being duly discharged from hospital care without the registration* process being explained and its vital importance (fully covered in Appendix 2 Social Care Service). Once the patients have been discharged from the Eye Hospital, it appears that respondents and their families are not signposted to any further organisations for support or information.

CASE STUDY: 1

Mrs R was keen to tell her story despite it being emotional for her to relive her experiences. She was adamant that the case study should be used in this research project so that the issues she experienced during her sight loss journey were highlighted and lessons could be learnt in the hope that improvements to the way Visually Impaired Patients are treated when receiving Health Care can be made.

"I had been an ongoing patient of the Eye Out Patient Department of the Salisbury District Hospital for many years. I noticed a recent deterioration in my sight and simple things like reading books and watching television had become increasingly difficult for me. I had been forced to finish my work as a teacher and leave a career which I loved due to the changes in my sight loss and although heavily supported at home by my husband I felt that I was becoming more isolated.

I requested an appointment with my Eye Consultant, who sent me an appointment for a check-up. I had very little vision in either eye and was not very confident; I really had started to rely on my husband and my best friend. I attended my appointment, which took place at the Salisbury District Hospital, with my friend who was able to take me. I was taken from the waiting room into a smaller room but no one was with me to explain how the room was set out or what was going to happen during the examination process. I was told to sit down by a man, which I later found out was my consultant, and told to sit in the chair but no guidance or assistance was given or offered to help me find it. I felt so helpless; why anyone wasn’t willing to help me?

Without explanation or warning the Consultant proceeded with his examination on me. He did not pre-warn me that he was going to touch my face and just took my forehead and pushed it back into the chair. I was so shocked to feel a hand on my face. He continued with the eye examination without any explanation or confirmation of what was going to happen during the rest of my appointment. I felt so upset by the whole experience and so shocked that I couldn't say anything to the Consultant. I was then duly told to wait in the room outside.

The consultant returned to inform me that there was no more that could be done with my vision to improve the sight and that I would be discharged from his clinic. There was no explanation to what my eye condition was or why no further treatment could be given. There was "no holistic" approach to my care. I felt that I was being treated like a commodity and that he was glad to get rid of me.

My notes had been left on a chair in the waiting room, by the Consultant, so I asked my friend to read the notes which had been written. To my shock my friend read that I had been showing signs of Retinitis Pigmentosa (RP*). No one had ever mentioned or informed me about this diagnosis at any of my previous appointments and I had never received any information or medication for this condition.

After a couple of days I contacted my local high street Optician who confirmed that I was indeed showing the later stages of RP*. The Optician then promptly referred me to my GP who sent a referral letter to a specialist at Moorfields Hospital in London for an emergency appointment. After a short wait I was sent to Moorfields Hospital to attend a specialist clinic to receive the shocking diagnosis that I was indeed suffering from a very rare form of RP*. The Eye Specialist fully explained the condition and its affects. Sadly, my eye condition would mean that at some point my vision would be totally lost, as there was no treatment available. I was devastated and both my husband and I could not quite believe what was happening to us.

The staff at Moorfields Hospital were able to equip me with various strategies to help me deal with the future changes that were going to be forced upon me by this eye condition. They provided practical coping mechanisms to help me with things like sleeping as I had been struggling to get to sleep as I had been left with no reaction to light in either eye and could not tell what time of day it was. It was like retraining my body and learning to live again.

Despite, the practical help I received through Moorfields Hospital I have never been offered any emotional support from any health care professionals or organisations. I know this has left me psychologically and emotionally scarred and I can often find myself crying over simple things. Sight loss for me is like suffering bereavement, I feel like I lost part of myself when I lost my sight, I had to learn how to live all over again, I can't even remember what I look like anymore".

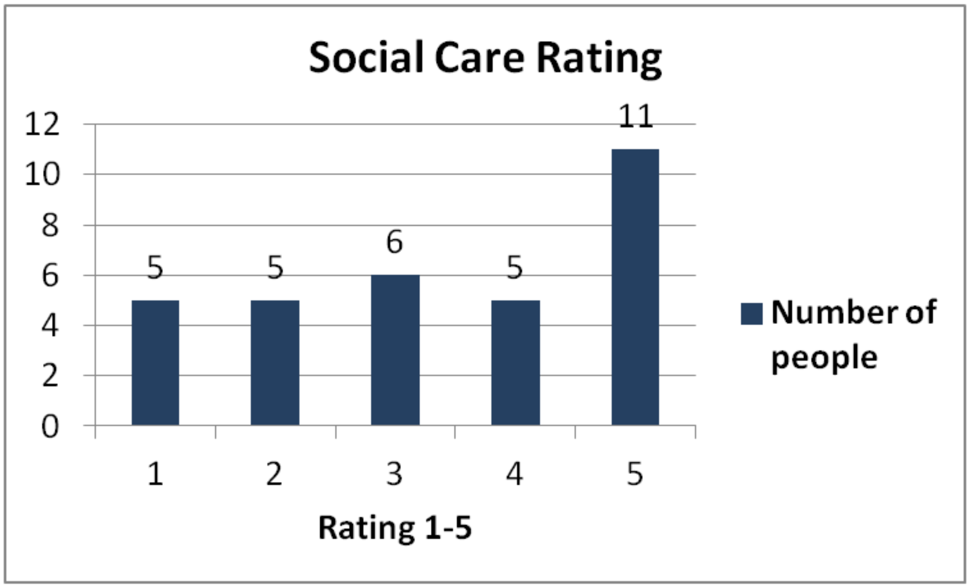
2. ISSUES WITH SOCIAL CARE

This section concentrates on the issues that people have experienced when accessing Social Care support services in Wiltshire. Participants were asked to rate how they felt about the service they have received from the Social Care support system in relationship primarily to their sight loss. For the purpose of this project it was clarified to the participants that Social Care Support services may include specialised sight loss services such as the Hearing and Vision Team, Housing and Benefit support.

The respondents were asked to rate the Social Care services received using a scale of 1 - 5, 1 being totally dissatisfied to 5 being very satisfied with the service or care provided.

Chart 2:

A graph demonstrating how respondents rated the Social Care services received in Wiltshire.



It must be mentioned for the purpose of this project that only 48% of respondents were able to provide an informed rating, due to only 32 out of the 66 respondents who participated in this project having ever received any support from this particular service. It must be noted that some Service Users, although having a sight impairment may not have a certificate of visual impairment. Only those people who have been registered* as Sight Impaired will have been offered a Statutory Care Needs Assessment.

2.1

This project has highlighted a very worrying trend amongst participants, across the demographic area of Wiltshire of a lack of Registration* of Blindness (Severe Sight Impaired) or Partial Sight Loss (Sight Impaired). Appendix 2. Despite a large number of respondents having very limited vision, it became apparent that many of the respondents had been discharged from Eye Hospital Clinics by their Eye Care Professionals without any registration* process being put in place.

This seemed to be especially high amongst the Visually Impaired Service Users affected by Macular Degeneration*, predominantly those suffering with Dry Macular Disease. During discussions respondents felt that they could not register because they had some vision left, but this is simply not the case as 9 out of 10 of those registered have some remaining vision. *Source: Royal National Institute for the Blind 2016 (RNIB)*

Registration* would help the Visually Impaired Service Users who participated in this project with accessing support with independent living, assistance with mobility, assistance to remain in work and look for employment and support with training courses and further education. This subject is discussed further in Appendix 2 Registration and its benefits.

2.2

17% of respondents commented that the waiting time for their initial home visits from a Rehabilitation Officer of Visual Impairment (ROVI*) from the Hearing and Vision Team was too long. They also felt the visits were too infrequent and difficult to arrange, leaving respondents feeling abandoned. However, it was commented by respondents that these initial home visits when carried out by the ROVI* had been valuable.

They had provided assistance in the form of aids, such as bumpon's* and mobility canes* as well as providing them with cane training to promote independent living. The ROVI* had been able to recommend adjustments to respondents' homes, such as adding hand rails into bathrooms and to doorways, which had helped respondents to remain living independently in their own homes.

2.3

45% of respondents stated that although an initial home visit had been made by a Rehabilitation Officer of Visual Impairment (ROVI*) from the Hearing and Vision Team, no further contact was made. Respondents commented that they had to contact the Local Authority themselves to arrange a follow up visit. People felt that it was not made clear that a further home visit would not be made.

This left some respondents and their families feeling like they had been forgotten. In many cases the service user's sight may deteriorate over time and their needs and requirements change. One respondent told how they had received their initial home assessment and was then booked in to receive a mobility assessment for cane training to enable them to go out and about in their local community.

Despite making numerous telephone calls to the Hearing and Vision Team the respondent had still not received their mobility assessment over 4 months later and was therefore unable to go out independently.

2.4

17% of participants had never been offered independent living skills from any organisation including the statutory services of the Hearing and Vision team since losing their sight. They did not feel confident doing basic living skills such as preparing and cooking food, using their white goods, such as washing machines or their microwaves. Many respondents were reliant on either family members or services such as home delivered meals.

CASE STUDY: 2

Ms J an elderly female living in sheltered accommodation had recently lost her self-confidence, following a home visit by a Social Worker and wanted to tell her story.

"I have lived in the same sheltered accommodation for a few years, since my husband passed away. My flat is lovely and has a little kitchen, bedroom and bathroom. They even hold coffee mornings and Christmas dinners downstairs where I live. A Social Worker recently came out to visit me at my flat. She told me that due to my sight loss I wasn't allowed to cook anymore. She said that I wasn't safe and should really be having meals delivered. She told me that she would arrange to have my cooker disconnected and a microwave delivered. She was also going to arrange meals to be delivered to me. A man then came out to turn off my cooker and they arranged meals on wheels to be delivered for me. They are nice but they're not the same as fresh vegetables. I used to enjoy cooking and really loved spending time baking cakes with my Grandchildren when they visit but we can’t do that anymore, I can only ever offer a biscuit or toast. I don't know why they stopped me cooking I have been cooking for years. Everyone else cooks where I live.”

2.5

One respondent reported that the Hearing and Vision team made their interview accessible by the use of information technology.

CASE STUDY: 3

The Local Authority (Hearing and Vision Team) carried out an assessment to claim Direct Payments for a Visually Impaired Service User who has dual sensory loss. To assist him they communicated via his iPad and through signing on his hand. This meant that he felt included during the assessment and was able to contribute fully. His claim was successful and has helped him fund someone to help him with shopping and attending appointments.

2.6

28% of respondents stated that due to a lack of any support being offered or provided by any Social Care Support provider they were reliant on close family members for much of their care needs. Respondents confirmed that their family member, predominantly their spouse or child visited them on a daily basis to carry out all of their care needs such as shopping, driving them to appointments, cooking and bathing. Although the family members were indeed the primary carers of the respondents none of them were registered as their principal carers or in receipt of any type of support or funding for the care they were providing (Carers Allowance).

Many of these family members were carrying out their caring role in addition to having their own families to look after and working. In one respondent's case her son had been forced to leave his full time job and take on a part time role to enable him to care for his mother as her care needs had become more demanding on his time. The older age demographic who participated in this research project had a genuine fear for their future as their spouse was acting as their principal carer since losing their sight and they were concerned that if anything happened to their partner they would have no one left to look after them.

2.7

28% of respondents stated that they had faced difficulties in accessing benefits. The key issues were with respondents knowing their benefit entitlement and with completing application claim forms. The most frequently mentioned forms were those for Disability Living Allowance (DLA) and Personal Independence Payments (PIP). Respondents commented that the forms were very difficult to access using assistive technology and were very hard to understand. In the case of the PIP application forms, respondents felt that the questions did not always relate to them or their own personal circumstances.

It must be mentioned that none of the respondents who participated in this project were able to complete the application forms independently. Indeed, in some cases this had meant that some of the people had decided that it was too difficult to make a claim and they were therefore receiving no form of benefit. It was mentioned by one of the respondents that he had contacted the DWP directly by telephone to ask for assistance with claiming his benefits, but they only left him more confused with what his benefit entitlement was and how he should make his claim. The respondent, however, was able to get advice and assistance with making his claim and application by a member of staff from Action for Blind People based in Salisbury.

2.8

The local “Housing Department” has been very supportive to some of the people who participated in this project, by providing adaptations to make their housing more accessible. However, the respondents mentioned that they had to then wait up to 4 months for the relevant adaptations and alterations to be made on the premises to fully meet their needs.

This section must be closed with a direct quote from one of our respondents.

> *"It feels as though*
> *when you strive to be independent*
> *you are penalised."*

RECOMMENDATIONS

These recommendations are based on the guidelines as set out in the Adult Sight Loss Pathway. The Adult UK Sight Loss Pathway offers Commissioners and Practitioners the opportunity to provide people with sight loss the correct care and support at the right time, clarifying the pathway between health and social care, promoting better partnership working and a smoother transition for the person with sight loss.

The Adult Sight Loss Pathway has been approved by the Strategic Agency Group of the UK Vision Strategy and it is therefore being urged that Local Authorities, GP's, Optometrists, Ophthalmologists and all health care professionals work together to implement the Pathway fully.

The Pathway is set out as follows:

1. Early intervention to address a person's needs

2. Visually Impaired Rehabilitation as an early intervention to be supplied by a specialist qualified professional

3. Interventions to help maximise functioning vision

4. Provision of Care Assessment of eligibility for Social Care Services, if there are unmet needs for care following early intervention

It must be highlighted that a person may enter the Pathway at many different levels and through various referral procedures, depending on the receipt of the Certificate of Visual Impairment (CVI). People with sight loss will also experience very different Pathways depending on how they lose their sight and whether this is through a diagnosis of an eye condition or through a secondary cause, such as a stroke or accident.

ISSUE	RECOMMENDATION 1
Transport 1.2b	Wiltshire Council to work in partnership with all local bus companies to ensure that an accessible bus service is provided to enable blind and partially sighted people to attend local hospitals. Where an accessible bus service is not readily available ensure that a Community Funded travel scheme such as the Link Project is promoted and made available to people with sight loss. Actively raise awareness of the concessionary bus pass available for people with sight loss by local bus companies, entitling the companion or carer of a blind or partially sighted passenger to travel with them free of charge. Disability Awareness Training to be provided to all bus drivers and front line staff to ensure safe bus travel for all passengers with sight loss.
ISSUE	**RECOMMENDATION 2**
Accessible Appointments 1.2c	Health Care Providers to reserve easily accessible morning appointments as a priority for patients with complex medical, physical and mental health issues, who request them. To provide a timely telephone consultation if these high priority appointments are not readily available.
ISSUE	**RECOMMENDATION 3**
Appointments to short 1.3	Ensure that patients are fully aware of the availability of booking double appointments when discussing complex health issues with their GP. To ensure that a fully qualified Eye Care Liaison Officer (ECLO)* with a working space to enable patients to discuss their eye condition and queries in confidentiality is available

	at all hospitals where eye clinics are taking place. To ensure that GP's, Opticians, Ophthalmologists and other health care professionals have access to information relating to relevant organisations and support groups.
ISSUE	**RECOMMENDATION 4**
Availability of GP appointments 1.4 1.8	Rating system to be put in place by GPs to ensure high risk patients (patients with complex medical, physical and mental health issues) are given priority appointments.
ISSUE	**RECOMMENDATION 5**
Accessible Formats 1.5 1.9	Develop and deliver a multimedia campaign to promote the new NHS Information Standard approved by the Standards Committee for Care in July 2015. Health Care Providers are required to have these new standards implemented by the 1st of July 2016. By the 1st of April 2016 Health Care providers must identify and record how their patients are to be communicated with, whether existing or new patients to their care. By 31st July 2016 Health Care providers records must be in place and all correspondence must be supplied in a format that can be read by patients. GPs have to be formally notified by patients of their preferred formats. Develop and deliver a campaign using a variety of media accessible by blind and partially sighted patients in Wiltshire, to include talking newspapers, local radio stations and social media, highlighting the need for them to contact their health care providers to confirm their preferred formats. Work in partnership with Local Authority, Adult Social Care to include the Hearing and Vision Team, charities and health care professionals to promote the campaign to inform blind and partially sighted people of the need to inform their health care provider of their preferred formats.

ISSUE	RECOMMENDATION 6
Post consultation care and support 1.6 1.10	Work in partnership with GPs and Eye care professionals to ensure that health care providers are aware of specialist support groups for patients with sight loss. Ensure information relating to relevant support groups is readily available in accessible formats in key locations such as GP surgeries, eye clinics and hospitals. Provide additional funding to encourage peer support groups. Form a ' buddy' or ' befriending' scheme, to be run by an individual who has experience with assisting people living with sight loss.
ISSUE	**RECOMMENDATION 7**
Accessing Services and Benefits 1.11 2.1 2.4 2.6	Production of ' TOP TIPS' handouts providing easy to read up to date information on important issues experienced by people with sight loss in Wiltshire, predominantly. Registration* and its benefits Employment and sight loss Entitlement to Benefit and how to claim Independent Living The TOP Tips handouts should be available in a variety of accessible formats and easily accessible on the Wiltshire Council website. Work in partnership with Health and Social Care Providers to raise awareness of the importance of Registration* and its benefits.
ISSUE	**RECOMMENDATION 8**
Rehabilitation 2.2	To measure how many Rehabilitation Officers of Visual Impairment (ROVI’s*) are needed in Wiltshire, to cut down waiting times for initial assessments.

	Run an active recruitment strategy to ensure there is an adequate number of Rehabilitation Officers of Visual Impairment (ROVI*) to ensure that waiting times for initial assessments is set at an acceptable level. Continue to ensure that despite a long waiting time for an initial assessment, contact is made by telephone to reassure the person with sight loss that their need has been acknowledged and an estimated time for their assessment can be given.
ISSUE	**RECOMMENDATION 9**
Independent Living 2.3 2.4	Follow up procedure to be put in place by Local Authority (Hearing and Vision Team). ROVI* to offer a further follow up appointment, to discuss additional needs and changes in vision. The services of the Local Authority (Hearing and Vision Team) should be promoted clearly at hospital eye clinics, GP surgery's and easily accessible on the Wiltshire Council's "Your Care, Your Support" website. Ensure that information is readily available in accessible formats at eye clinics informing service users of the services available to aid independent living, including contact detail cards for the Hearing and Vision Team. Ensure that users and their families are aware of the ability to self-refer for a home visit by a ROVI*. Ensure that newly diagnosed people are fully aware of the courses available such as the community based ' Living with Sight Loss' 1, 2 or 6 day course provided by Action for Blind People (Salisbury) to assist them with independent living. Promote the services of Low Vision Centres, such as the Wessex Sight Centre, based at the Salisbury District Hospital to assist Visually Impaired Service Users with aids

	such as magnifiers and lights. Actively promote the variety of mobility services available, such as the My Guide programme (provided by the Guide Dogs for the Blind Association) or the cane training, provided as part of assessments carried out by ROVI's* to enable people with sight loss to remain as independently mobile as possible.
ISSUE	**RECOMMENDATION 10**
Carers and support 2.6	Production of TOP TIP handouts, see recommendation 7. The TOP TIP handout will include important information for the people with sight loss, including benefit entitlement, how to claim and contact details of organisations who can assist with completing the claim. Adult Social Care to provide information relating to benefit entitlement, financial practical assistance to family members who provide care for people with sight loss. Adult Social Care to provide information about emotional support for both the service user and family members. ROVI's* to recognise when carrying out initial assessments the caring relationship between family members and provide relevant information and refer family member to the relevant support. Wiltshire Council to provide accessible information on how to obtain financial and emotional support for carers.
ISSUE	**RECOMMENDATION 11**
Entitlement to benefits 2.7	Production of TOP TIPS handouts see recommendation 7. Promote community based courses such as ' Living with Sight Loss' provided by Action for Blind People to newly diagnosed Visually Impaired Service Users, which covers benefit entitlement and how to claim.

APPENDIX 1

wsun

Wiltshire and Swindon Users' Network

QUESTIONNAIRE: HELPING TO GIVE BLIND AND PARTIALLY SIGHTED PEOPLE THEIR SAY ON HOW SERVICES ARE RUN IN WILTSHIRE

Using a scale of 1 to 5 (1 being **unsatisfied** and 5 being **very satisfied)**:

1. Please specify the type of service(s) you have received from your local Health Authority (i.e. GP, NHS hospital care) and rate how you feel about the service(s) you received. If below 3 please state why.

1	2	3	4	5

SERVICE(S) RECEIVED:

WHY (BELOW 3):

2. Please specify the type of service(s) you have received from your local Social Services (i.e. housing, benefits, social care support), and rate how you feel about the service(s) you received. If below 3 please state why.

1	2	3	4	5

SERVICE(S) RECEIVED:

WHY (BELOW 3):

3. Please specify the type of service(s) you have received from other organisations (i.e. Charitable or Voluntary, National or Local) and rate how you feel about the service(s) you received. If below 3 please state why.

1	2	3	4	5

SERVICE(S) RECEIVED:

WHY (BELOW 3):

4. What type of social support group or activity do you feel would be most beneficial to you in Wiltshire?

5. What are the main issues for you living in Wiltshire and how could this be changed to make life easier for you?

6. We would like to know how you correspond with friends and family. Do you have access to any of the following? (Please circle the relevant social media):

Home Telephone	Mobile Telephone	Email	Facebook
Twitter	Large Printed Correspondence	Braille	Other (please specify):

7. We would like to contact you with future correspondence and information from the Wiltshire and Swindon Users Network (WSUN). If you would like to hear from us could you please let us know below which format(s) would be most accessible for you and please provide your contact details. Every effort will be made

to contact you in your desired format.

I, …..………………………… give permission for future contact

NAME:

ADDRESS:

CONTACT TELEPHONE NUMBER:
EMAIL ADDRESS:

FORMAT(S):
If you are happy to provide us with your age range, please circle:

U18 19 – 30 31 – 4546 – 55 55 – 70

71 – 85 Over 85

Please return the completed questionnaire in the provided pre-stamped and addressed envelope. Wiltshire and Swindon Users Network, The Independent Living Centre, St Georges Road, Semington, Wiltshire, BA14 6JQ

If you require assistance to complete this questionnaire, please contact our office on **01380 871800** and we would be happy to help. **If you have any further comments, please write on the back page of this document.** WSUN is an inclusive organisation which supports and empowers people to have a voice. We aim to promote peoples' wellbeing and independence.

APPENDIX 2

REGISTRATION AND BENEFITS

Registration* can only be carried out by an Ophthalmologist who will check the patients distance vision and field of vision. If the criteria set out is then met, the Ophthalmologist can then confirm if the patient is eligible for registration* ' Severe Sight Impaired' (blind) or ' Sight Impaired (partially sighted) '. Your eye specialist will measure how good you are at seeing detail at a distance (your visual acuity) and how much you can see from the side of your eye when you are looking straight ahead (your field of vision).

The Ophthalmologist will then ask the patient to sign a form called the Certificate of Vision Impairment (CVI), previously known as a BD8 Form. One copy is then sent to the Local Authority Hearing and Vision Team and the other copy is sent to the patient’s own GP. The issue of this certificate doesn't mean that the person is automatically registered but simply means that the patient has given consent to pass on their eligibility to register.

The Wiltshire Community Service has a legal obligation to keep a record of all Visually Impaired Service Users registered in their area. Once a CVI has been received a Rehabilitation Worker of Visual Impairment (ROVI*), from the Local Authority's Hearing and Vision Team will contact the patient. They will discuss the services available and talk through any issues, concerns and offer practical assistance where required.

Registration* is voluntary and patient consent is needed for the Ophthalmologist to make the registration. Once this consent has been received by the Rehabilitation Worker ROVI*, they can then arrange the issue of a “Proof of Registration*” card.

The importance of Registration* must be stressed, now more than ever, as the entitlement to some benefits and support rely on the presence of the Proof of Registration*.

The main benefits of Registration* are as follows:

1) Entitlement to Personal Independence Payments (PIP) and Attendance Allowance for those over 65

2) Potential funding towards education and training courses

3) Concessions on public transport, Tax Credit Payments, entry into venues and events and television licence fees

4) Disabled Parking Permit

5) Blind Persons Tax Credits

6) Blind Persons Tax Allowance (transferable to spouse if earning more)

APPENDIX 3

GLOSSARY OF TERMS

ECLO - Eye Clinic Liaison Officer

An ECLO (Eye Clinic Liaison Officer), sometimes also known as a 'Sight Loss Advisor' or a ' Vision Support Officer' is a funded member of the Eye Clinic Staff who work closely with medical and nursing staff within the Eye Clinic and the Sensory Team.

They are able to provide recently diagnosed patients with information relating to their eye condition, practical advice and emotional support to help the patient understand their eye condition and the impact of their sight loss in turn assisting the patient maintain independent living.

Most importantly the ECLO can dedicate their time following consultations to discuss the impact of a diagnosis on a person's life. It is known that a person with sight loss is more likely to suffer some form of depression with nearly 1/4 (23%) of patients leaving an eye clinic without knowing the nature of their eye condition.

There are currently ECLO's in funded roles at both the Great Western Hospital and the Salisbury District Hospital.

ROVI - Rehabilitation Officer of Visual Impairment

The aim of a ROVI is to help Visually Impaired people remain or become as independent as possible.

A ROVI is able to advise recently diagnosed patients about the registration process and provide information relating to the Certificate of Visual Impairment (CVI). They are also able to provide assessments and advice to promote independent living including, teach new skills, suggest simple adaptations to homes and household goods, provide Mobility Assessments and cane training. ROVI's are also able to provide a link to other organisations and voluntary bodies by sign-posting.

Macular Degeneration (MD) and Age Related Macular Degeneration (AMD)

Macular Degeneration affects a tiny part of the Retina at the back of the eye called the Macular. AMD causes problems for the central vision but is not painful and alone does not lead to total blindness. The effects on a person's sight with AMD is with their central vision when looking directly at something such as when trying to read, look at pictures or watching television. It may cause the vision to look distorted or blurry and in the most severe cases cause a blank space. Macular Degeneration mainly affects people over the age of 65, however, the degeneration may start to form in people in their 40's or 50's. There are two forms of Macular Degeneration as described below.

Dry

The more common form of Macular Degeneration develops slowly and causes a gradual change in vision. At its most severe it can lead to a blank space in the central vision but will not affect a person's peripheral vision so total blindness does not occur. There is no known treatment for this type of Macular Disease.
Source: Royal National Institute for the Blind (RNIB)

Wet

This condition is caused by the growth of tiny blood vessels which are formed by the cells in the eye to repair damage caused by the Macular Disease. The new vessels grow in the wrong place and cause pressure and burst leaving scarring which damages the Macular leading to blank spaces in the central vision. There is treatment available through the NHS for this condition in the form of an injection into the eye, which deters the growth of the new vessels. Only 10% to 15% of people are affected by this form of Macular Disease.
Source: Royal National Institute for the Blind (RNIB)

RP - Retinitis Pigmentosa

Retinitis Pigmentosa (RP) is the name given to a collection of inherited eye disorders affecting the Retina.
RP causes permanent damage to a person's vision and can differ in the time taken for the affects to impact on a person's vision from patient to patient.

The retinal changes can affect the side vision which in turn makes it harder for a person to see in dim light or in the dark. It can also affect the central vision making detailed items very difficult to see and therefore things like reading and watching television become challenging. Most people affected by RP are able to retain some useful vision, however long term sufferers of the condition live with tunnel vision as a consequence of the disorder.

There is currently no treatment to control or delay the effects of this eye disorder.

Bumpon's or Tactile Markers

Can be used to mark and locate: - The on and off switch of an oven - Home telephone buttons - Areas of a keyboard - Other household and office appliances. Orange round bumpons are raised and have a dome-like shape to touch. Use the feel of the bumpon or bright orange contrast to highlight and mark everyday items effectively.
Source: Royal National Institute for the Blind (RNIB)

Canes

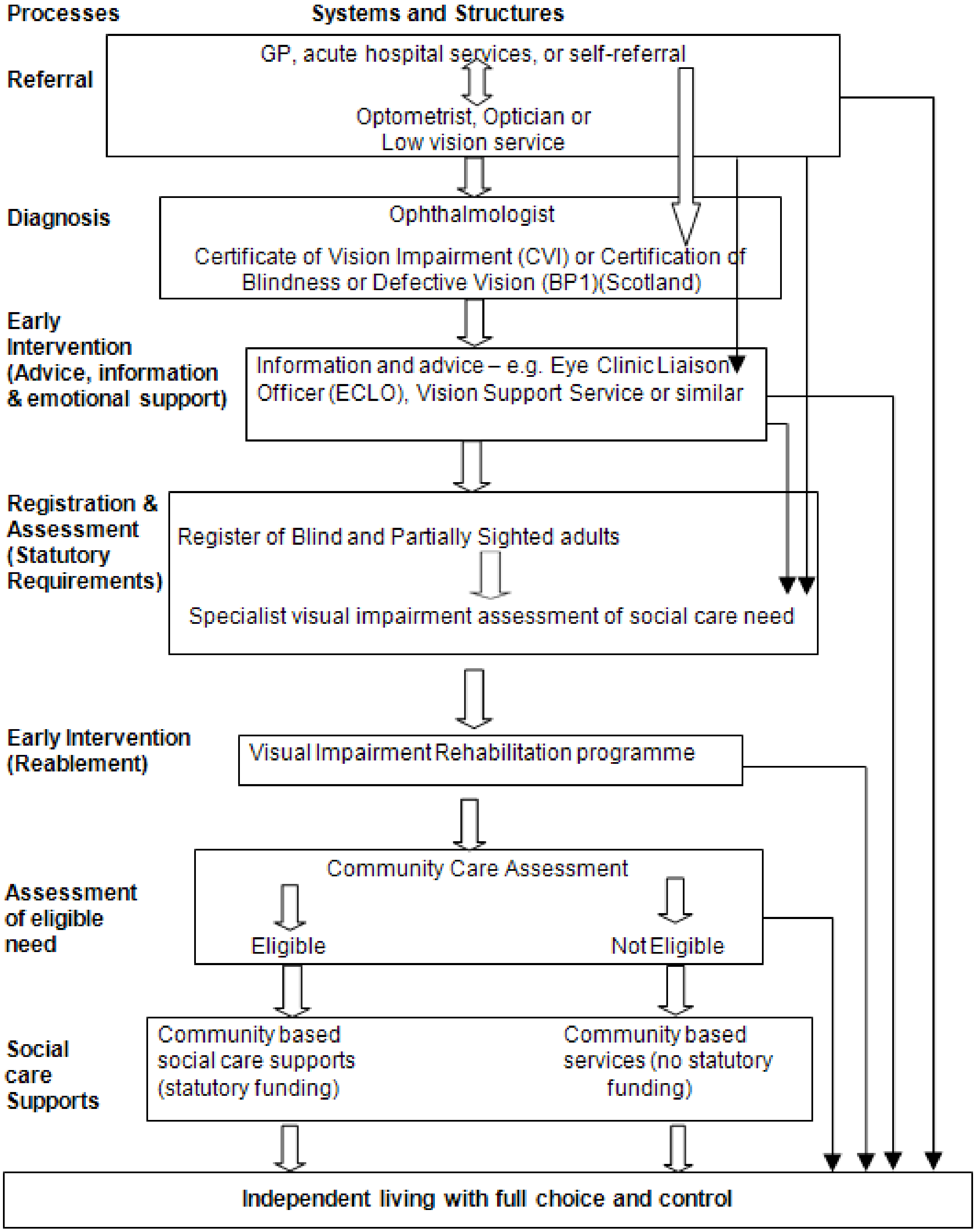
A **symbol cane** is the shortest type of cane. It is intended only to inform other people that your sight is impaired. It is not intended to be used as a mobility aid and, unlike a walking stick, it is not strong enough to support your weight.

A **guide cane** is designed to be a mobility aid to help you locate obstacles in your path or warn you about pavement edges, and kerbs. They are also not designed to be used to support your weight.

A **long cane** is also a mobility aid but it is much longer than a guide cane. It is used to scan the ground in front of you as you walk. The scanning takes the form of sweeping the cane in an arc from one side to the other just beyond the width of the body to locate obstacles and changes in surface level such as kerbs and steps. Before you can use a long cane, you will need to be trained by a Mobility Officer (ROVI*). A long cane is not designed to support your weight.
Source: Kent Association for the Blind

APPENDIX 4

The Adult UK sight loss pathway



CONTACT INFORMATION

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