Quick wins... and missed opportunities

How local authorities can work with blind and partially sighted people to build a better future

Case studies

RNIB supporting blind and partially sighted people
Acknowledgements

We would like to thank everyone who shared the personal stories that make up these case studies. Their views do not necessarily reflect the views of RNIB or OPM but they are strongly held and can only hint at the everyday difficulties blind and partially sighted people experience in their lives.

We would also like to thank the local organisations supporting blind and partially sighted people who played an invaluable role in helping to organise and host focus groups for this research.
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Local authority good practice case studies

As part of this research we disseminated a call for good practice amongst people working in the sight loss sector to find out about how local authorities and partners are making a real difference to the lives of blind and partially sighted people.

We selected three local authorities and their partners across England and carried out several interviews to identify and understand how they are working most effectively to develop and deliver innovative solutions to meet the needs of blind and partially sighted people in their area.

The case studies are designed to gather insights from local authorities where a person-centred approach is being taken and the findings aim to raise awareness and inspire other local authorities to promote good practice.

The three local authorities and partners presented as case studies are:

- **Plymouth City Council and partners** – demonstrate the benefits of joint commissioning, early intervention and preventative services which enable blind and partially sighted people to thrive in their own homes and communities.

- **Leicester City Council and partners** – demonstrate how a commitment to the inclusion and involvement of blind and partially sighted people and disabled people more widely throughout the planning and design process helps ensure the city’s public realm is fit for purpose and accessible.

- **South Tyneside Metropolitan Borough Council and partners** – describe how effective partnership working, collaboration and service redesign have supported the development and delivery of innovative solutions that meet the needs of blind and partially sighted people and do so in the context of reduced budgets and streamlined services.

The case studies do not claim that the local authorities and partners are getting everything right all of the time for blind and partially sighted people. Rather they seek to shine a light on innovative practice that has been developed in local areas to share ideas and good practice so local areas can better empower and support their blind and partially sighted residents.

The case studies have been drawn on to inform the broader research findings and provide examples of how local authorities and partners are doing something that is making a positive difference to the lives of blind and partially sighted people.
Plymouth City Council

Introduction
Plymouth City Council is a unitary authority in the south west of England. The Council commissions and provides services for the 256,700 residents across the city.

Following a report in 2007 by the Commission for Social Care Inspection (now the Care Quality Commission) Plymouth City Council made a decision to focus more on sensory provision within the city. Joint commissioning between health and social care operates widely and there is a strong emphasis on early intervention and prevention. Plymouth Guild, a local charity providing health and social care to the people of Plymouth has been actively involved in shaping and developing new services for blind and partially sighted people. Plymouth Guild provides most of the sensory support for blind and partially sighted people in Plymouth in combination with specialist input by two full-time statutory Rehabilitation Officers for Adults with Visual Impairments (ROVIs).

Commissioning arrangements are designed to provide person-centred and holistic support enabling blind and partially sighted people to thrive in their own homes and communities. Strong governance arrangements support these outcomes with a Low Vision Practitioners Group meeting regularly to plan and review services for visually impaired people in Plymouth.

Joined up commissioning and planning
A number of services for blind and partially sighted people are jointly commissioned by Adult Social Care and NHS Plymouth.

As well as the joint procurement and monitoring of services, commissioners, service providers, practitioners and service users meet on a regular basis. The group is called the Low Vision Group and includes: managers from Plymouth Guild, ROVIs, health practitioners, clinicians and nurses from the Royal Infirmary Hospital, members from Action for Blind People, individuals working with learning disabled people, and a children’s mobility worker (to support transitions). The group meets on a quarterly basis to map out pathways, look at where there are gaps, share best practice and resolve issues. Members update each other on service developments and share strategies for service improvement and this information informs future commissioning decisions. The group set their terms of reference and objectives and there are also plans to involve service users in the group in the future.

The Low Vision Group is a sub-group of the multi-agency Physical and Sensory Disability Board which is a strategic board made up of commissioners and providers. The Low Vision Group has deliberately been kept separate to ensure that visual impairment issues do not get lost in wider disability-related issues. Maggie Paine, Assistant Chief Executive of Plymouth Guild explains why this is important:

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“I think it’s good that it is kept separate because there are some very specific issues. If you can’t see you have very different issues to someone who is physically disabled. It’s about mobility and how you continue to read and write and maintain your independence… As human beings we spend a lot of our lives communicating with each other so the needs of someone with a sensory impairment will be different to people with other disabilities.” (Maggie Paine, Assistant Chief Executive, Plymouth Guild)

**Timely registration and needs-led reablement**

The registration of blind and partially sighted people is the responsibility of the local authority, which holds the register. Staff at the Royal Eye Infirmary send over the paperwork to the local authority and advise the individual that someone will be in touch shortly. The local authority then makes contact and asks if the person would like to be registered (which is voluntary). If the individual decides to be registered they are phoned to have a ‘detailed conversation’ with a social worker or occupational therapist. During the conversation the individual is invited to establish some desired outcomes which are important to them and their life. This triggers an internal referral to the ROVIs, based within the home care reablement team. This is a very quick process with no waiting list, as Kelly Hollingworth, ROVI in Plymouth explains:

“The certificate comes in, they have the conversation and the referral is made and we make contact with the person that day. There is no waiting list, we do ‘today’s work today’. I will go and visit the person and look at what support they need to meet their outcomes.” (Kelly Hollingworth, ROVI)

Starting from identifying outcomes means that support can be tailored and person-centred, driven by the priorities that are important to the individual. Reablement is a short term intervention based on what the person needs and can include mobility training, putting in equipment and ‘house enablers’ to help develop new skills for independent living such as cooking and bathing. The support is not time limited so can be extended to meet the particular needs and circumstances of the individual. Kelly describes why this principle is important:

“Reablement is not time limited which is important because everyone is different. Life is not like that so if you put a time limit on it you’re saying you have to do it in a certain time. These are people that have lost their sight and you can’t say ‘It’s going to take x amount of weeks’. Often it’s a confidence thing – our job is to help them regain their independence and their confidence and you can’t put a time on that.” (Kelly Hollingworth, ROVI)

Rather than spreading out support to once a week over a longer period of time, support can now be offered in more frequent, intensive ways such as every morning for a week.
There are also strong pathways out of the reablement support. For example, after the initial intervention has been completed the case goes back to the social worker who does a further assessment. The ROVI may also refer someone to Plymouth Guild for further support such as equipment and courses.

**Early intervention and smoothing care pathways**

Plymouth has developed a new approach to support early intervention and smooth low vision care pathways. The low vision community liaison post arose from patients saying they had come out of the Eye Infirmary not knowing where to go or what support was available. There was a sense that people were slipping through the net between health and social care and not accessing the support they might need to help them adjust to their sight loss. A Commissioning Officer at Plymouth Council explains some of the reasons behind developing the new service:

> “There is no reason why people should live without support. We wanted to strengthen links between health and social care so that people weren’t going home and not accessing support. This way we could pick people up earlier and identify the appropriate support.” (Sophie Slater, Commissioning Officer, Adult Social Care, Plymouth Council)

Commissioners at the local authority met with the Plymouth Guild to share their ideas and jointly developed the specification. Half of the funding for the post was agreed by Plymouth Council and the other half of the funding for the post was secured by match-funding from the James Tudor Trust, a grant-giving charity. An additional benefit of the charitable funding is that the low vision worker is not constrained by geographical boundaries and can therefore see people from Devon and Cornwall as well as the city of Plymouth.

The low vision post aims to build links between people seen at the Eye Infirmary and support available from adult social care and Plymouth Guild. As Maggie Paine from Plymouth Guild highlights:

> “The aim of the low vision worker was to smooth how you got from the Eye Infirmary to the ROVI and the resource centre [at Plymouth Guild]. At an early stage it gave someone the possibility to talk about the impact of losing their sight – emotional and practical support. The low vision worker attends the relevant clinics at the Eye Infirmary and provides support to people there. He also works out in the community with GPs and opticians.” (Maggie Paine, Assistant Chief Executive, Plymouth Guild)

The post has a strong preventative and early intervention approach as the low vision worker is able to identify and support people pre-registration (for example, individuals who are visually impaired and having treatment but are not yet registered as blind or partially sighted). A ROVI describes the benefits of this approach:
“In terms of having a preventative and early intervention approach this is really helpful. The low vision worker picks up people and puts them through to us or the Guild if it’s a lower level need. So we are seeing people much earlier and we are able to have input before crisis point.” (Kelly Hollingworth, ROVI)

The low vision worker acts as a single point of contact and takes a holistic approach to providing support and information working across many different areas of support. This is done through providing information at the eye clinic and during home visits as well as signposting people to different agencies for support with finances, equipment and mobility etc.

Working closely with the Eye Infirmary is seen as crucial because it helps people, often elderly patients, make an initial link with community support and build trust in the service. The Nurse Manager at the Royal Eye Infirmary said:

“It means that even before our patients have seen the doctor and got shocking news they know there is going to be someone there looking out for them. They have already put a face to a person. When you’ve been given bad news you don’t want to then have to get to know someone – but if you have already met them you know what to expect. Now there is a seamless service.” (Vicky Brotherton, Nurse Manager, Royal Eye Infirmary)

The post is relatively new and has been funded initially for two years. Case studies are currently being collected to capture the full impact of the post.

Person-centred support for independent living

The floating support service (sometimes called an outreach service) was established in 2009 and is run by Plymouth Guild. It was established as an outreach function of the resource centre, set up by the Guild and aims to provide support to help keep people at home and living independently. The service was originally funded through Supporting People and is now funded through a service contract with adult social care. In 2010-11, 88 people received one-to-one support through the service.

The floating support service works with people who have a sensory or hearing impairment or dual sensory loss on a time-limited basis of up to three months although support can be extended if there are still support needs after this time. Staff at the service receive a referral and then create a support plan with the individual. The staff work with service users to support them to achieve their outcomes. Outcomes vary and can relate to social or financial inclusion, accessing leisure opportunities, housing support and purchasing equipment etc. As such, the support is holistic and person-centred: the principles of choice and control guide how the support plan is developed and then delivered.
The service is specifically designed for sensory impaired people and as such, staff are trained to work with visually impaired people. The floating support is designed to enrich, not replace, support provided by the local authority ROVIs as a member of Plymouth Guild explains:

“We are not duplicating the work that the ROVI does as this is very specialist – but we can build on what they have done or offer more practical things. We’re clear that we are not mobility officers, nor are we ROVIs, this is still provided by the local authority. What we offer compliments what is already provided and fills the gaps which is what the Guild is all about.” (Maggie Paine, Assistant Chief Executive, Plymouth Guild)

Practical and emotional support on diagnosis
As part of a wider contract, Plymouth City Council commissions Plymouth Guild to run a six week course for visually impaired people to adjust to living with sight loss. The Insight Course runs four times a year and was developed to provide timely support following a diagnosis of sight loss. Commissioners in adult social care and health reported that one of the gaps in provision was the initial support that could be given following diagnosis to try and help individuals understand quickly about what it might mean to be visually impaired. The six week intensive course was established to provide practical and emotional support at this critical juncture.

The Council have found that providing information and peer support at this time means that visually impaired people are more able to access the services they need and build up their own support networks. By doing that this individuals are more able to maintain their independence. The course helps individuals obtain a lot of information very quickly because the course draws in speakers from reablement, the Eye Infirmary and low vision specialists, amongst others. The course aims to give people back some confidence through providing information and promoting an environment of mutual support. A ROVI outlines the importance of the course:

“I think the Insight Course is great. It’s really good for people to meet other people in a similar position. There are such knock on social implications to going blind. I often find that although people have got a wife, husband or parent and as hard as that person tries it’s not the same as talking to someone else that’s going through the same thing.” (Kelly Hollingworth, ROVI)

Staff have found that peer support is an excellent way for group members to build confidence. People come up with their own ideas about how to adapt to sight loss and support each other with things like using a white cane for the first time which sometimes has a stigma attached to it for some people.

The Guild hopes that past participants of the Insight course will be involved in co-designing future services in the Plymouth area.
Fostering good practice
This case study highlights a number of local features that have enabled commissioners, providers and blind and partially sighted people to work together to foster good practice and trial innovative solutions.

• **Collaboration between commissioners and providers**: Local authority commissioners meet regularly with services and service users to monitor and get feedback on services. These relationships help to develop relationships built on trust:

  “Both the commissioners are very engaged and know what we’re doing and are therefore able to plan their own services more effectively. It is a well established relationship; there is trust and respect on both sides.”
  (Maggie Paine, Assistant CEO, Plymouth Guild)

• **Joint commissioning between health and social care**: Strong relationships between health and social care commissioners exist and are supported by structures such as the Physical and Sensory Disability Board and the Low Vision Group. In the future there is an opportunity to further strengthen this as health and local authority commissioners will be co-located.

• **Engage blind and partially sighted people to build responsive services**: Plymouth Guild demonstrates their commitment to engage with their service users to develop responsive services and innovate to meet their clients’ needs. A number of services have developed from needs identified by visually impaired people themselves.

• **Engage with charitable trusts to help innovate**: Over the years Plymouth Guild has actively engaged with charitable trusts to help fund new projects and ideas. This has involved securing seed funding for new projects and match funding.

• **Seamless services**: Having a clear map of what support exists and well developed referral pathways between services in health, social care and the voluntary sector means that local services can provide more joined-up and tailored support without duplication.

• **Person centred support**: By structuring support around an individual’s outcomes the assessment and support planning process is person-centred and tailored to support the outcomes which are important to the individual in their life.

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Leicester City Council

Introduction
As part of their research for the RNIB, OPM spoke to a number of local authorities and their partners across England to identify and understand how they are working most effectively to develop and deliver innovative solutions to meet the needs of blind and partially sighted people in their area.

The activity across Leicester City was identified as offering some useful learning for the research due to its person-centred approach to the design of its built environment. Leicester shows demonstrable commitment to the inclusion and involvement of blind and partially sighted people and disabled people more widely throughout the planning and design process to ensure the city’s public realm is fit for purpose and accessible.

Case study participants included Leicester City Council’s Disabled People’s Access Officer; the local councillor currently chairing the Inclusive Design Advisory Panel (IDAP); a representative from Leicester’s Centre for Integrated Living (LCIL) who is an external advisor on the IDAP, and a representative on the Leicester Disabled People’s Access Group (LDPAG); and a representative from Vista, an organisation supporting blind and partially sighted people across Leicester, Leicestershire and Rutland. Vista is represented on the Access Group and also provides input into the council’s Access Awareness Events.

Background to the activity
The decision making processes for schemes involving the built environment and public realms are complex both at a political, strategic and operational level, however Leicester’s experience demonstrates that it is vital to get the process right to prevent problems arising in the future. The activity outlined in this case study was largely prompted by the regeneration of Leicester’s city centre in 2005/6. The process of re-development created issues for disabled people for two main reasons. Firstly, as a result of a significant amount of work being done in the city at the same time there was an increased amount of obstacles in the public realm; and secondly because the council employed various external consultants, such as landscape architects, along with their own design and planning officers, who had limited knowledge of (or commitment to) inclusive design. This made achieving inclusive design very difficult, for example, at the time of the regeneration the fashion was very much for the public realm schemes to be all grey to allow things to blend in; however grey is a very challenging colour for visually impaired people. Other impacts on disabled people included increased walking distances (due to pedestrianisation, moving bus stops, and blue badge parking further out), and a decision to allow cycling within the pedestrian areas. These resulted in negative feedback from disabled people and the threat of legal challenge. In addition, at around this time the Audit Commission criticised the council for accepting minimum
inclusive design standards in new build development, rather than using its planning powers to achieve best practice.

**Leicester City’s response**
This situation prompted the formation of a task group of the Overview and Scrutiny Committee to review the way access and inclusion is considered in planning, transport and regeneration schemes. This involved key disability organisations, and led to the Council’s Cabinet agreeing a firm commitment to inclusive design and approving an **Inclusive Design Action Programme** to take this forward. This in turn was reflected in the Council’s Core Strategy (its key land-use planning document) which states that development should “meet the highest standards of access and inclusion, based on inclusive design principles, and the need to create lifetime neighbourhoods”.

An important aspect of the Inclusive Design Action Programme is the need to develop effective working relationships between the Council and local disability organisations. Joint working with VISTA, the LCIL, and the LDPAG have been particularly important to ensure the views of disabled people influence the City’s built environment and public realm. Leicester City Council’s Disabled Persons Access Officer leads this work; he is based in the planning service but gets involved in projects and issues across various departments to ensure a more integrated and strategic approach.

The Access Officer’s role is to improve inclusive access to Leicester’s buildings, streets, and spaces across Leicester. He attends and supports the Leicester Disabled Persons Access Group which is a key forum for disabled people and disability organisations to comment on development projects and access issues. He also services (and is a specialist advisor on) the Council’s Inclusive Design Advisory Panel which advises a wide range of Council officers, and other developers on inclusive design aspects of projects they are involved with.

Another important aspect of his job is to raise awareness and understanding of inclusive design and access issues. This includes working with these organisations on a rolling programme of Access Awareness Events, primarily for Council staff and Members.

**The Inclusive Design Advisory Panel (IDAP)**
IDAP provides advice to Council officers and others involved in the development on Inclusive Design aspects of their projects, with an emphasis on developing best practice. IDAP is chaired by a leading councillor in the Council’s overview and scrutiny work. It is made up of council officers representing key disciplines (access, design, planning and highways/ transportation), and an external advisor from LCIL.

As far as possible the Panel seeks to get involved in projects from the earliest stages. In the past issues tended to be picked up too late, and at times when projects were completed. Problems were then costly to rectify, and the resultant feedback did not reflect well on the council. IDAP’s role is about helping people to “get it right first time”. 
IDAP’s role complements that of the Leicester Disabled People’s Access Group (LDPAG), which is an independent organisation representing disabled people, rather than a specialist advisory panel. The Panel and the Group work closely together, for example joint consultation meetings are organised for some key projects, and the Access Group is able to refer key issues for IDAP to consider in more detail (the design and management of pavement cafes being a recent example).

The Access Awareness Raising Events

The Awareness Raising Event programme was started primarily to inform the Scrutiny Task Group review. It was instigated by the LDPAG, working closely with the Access Officer, and supported by Vista. It was attended by key Councillors and officers involved in the Task Group review, and by Sir Peter Soulsby, who at the time was MP for Leicester South, and who in 2011 became Leicester’s first elected mayor.

Following the event Sir Peter said:

“It was an incredibly worthwhile experience from my point of view and I now have a much better understanding of a whole range of issues facing those with visual impairments and those responsible for persuading public bodies to take their needs seriously. I was also very impressed by the way the event was organised and hope that it has achieved some good publicity and helped to raise awareness.”

Continuing these events on a regular basis was a key feature of the Action Programme which has taken forward the Task Group’s recommendations. They are open to all city council staff, Members and key partner organisations involved in the planning design and/or management of the city’s buildings streets or spaces. Participants can range from Strategic Directors and Cabinet Members, to service/project managers, technicians and operational staff. The events have a number of key aims: to raise awareness of the barriers many people face in getting to and around Leicester’s buildings, streets and spaces; to develop solutions and skills which participants can then apply in their day to day work; and to promote inclusive design – which is about making places which everyone can use easily, safely and with dignity.

The emphasis is on giving participants practical insights and helping to develop skills they can apply in their day to day work. Each event is for a small group of participants (usually around seven), usually outdoors, and is informal and participative. After an introductory chat, participants are given simulated visual impairments (using “simulation specs”) and shown how to find their way around with the help of a mobility cane. They are then taken on a guided walk (approximately 1–1½ hours) around the City Centre. This is under the expert tuition of staff from Vista, with support from the Council’s Access Officer.
Local authority good practice case studies

“During one demonstration we had a person from the highways department say ‘who put that stupid pole there’ our answer was ‘you!’ It was quite an eye-opener for him.” (Eric Day, LCIL)

Participants are invited to take a turn (with support, and without being visually impaired) getting about in a wheelchair; they also learn about some of the barriers experienced by a wider range of disabled people (eg those who can’t walk far, have balance problems, are deaf or hard of hearing, have learning disabilities); they are also encouraged to discuss their experiences during the walk, and at the end of the session. Although the focus of the events is usually the external environment, some aspects of building design are also discussed, and internal spaces may be visited.

The events tend to have a focus on visual impairment, and the Access Officer makes it clear to participants why this is the case, as opposed to focusing on deafness or learning disability. For example, within the public realm there are some very special issues of significance that effect blind and partially sighted people that do not impact as much on others, such as street obstructions. There are also some very specific tensions between aesthetics and the practical needs of blind and partially sighted people, in other words what might look nice to some people may in fact pose a barrier for visually impaired people. Visual impairment is also quite easy to simulate to give participants an idea of how challenging it can be. Organisers ensure that they emphasise to participants that they are having an immediate experience for a couple of hours but that it takes blind or partially sighted people years to learn how to manage the public realm.

“Getting involved in awareness days, looking at things like where glass is and using the cane; that for me has been fantastic. It’s only when you do that that you really appreciate what the issues are.” (Cllr Newcombe, Leicester City Council)

Organisers find that participants come to the events with numerous assumptions, for example, they commonly assume that if you are blind you cannot see, and if you are a person with a guide dog you don’t have any sight; in reality however most people do have some peripheral vision. Participants also assume that all blind or partially sighted people have a dog or use a cane, again in reality this is not the case, many choose not to use a dog or cane to avoid the stigma associated with their use, and their increased vulnerability to being mugged.

The representative from the LCIL raised concerns about the attitude of people following their attendance at an event. A concern he had was that following attendance participants would then think they know what it is like to be a disabled person. Despite this however, he also recognises that the benefits of the events outweigh the negatives.
“I don’t really like the attitude that “we know what it’s like now”. They’ve only experienced it for a few minutes. I was a bit worried about this at first, but the way Paul’s been running them they have been good […] it’s still better to have that short experience than not at all.“ (Eric Day, LCIL)

To date the event participant feedback has been very positive and there is now a regular programme of events which is in its fourth financial year of delivery.

The impact and benefits
Feedback from participants on the Access Awareness events and from those involved in IDAP has been a valuable basis for developing the format and effectiveness of the programme and the Panel. Their positive impact and influence on the design of the city can also be demonstrated. For example, more recent city centre schemes are more useable by disabled people as a result of their needs being better understood, and considered earlier in the process. The experiences of Councillors, designers and planners trying to navigate the city from the perspective of a visually impaired person has been a huge help.

“It’s wicked! By getting the councillors out there doing it, by putting them in the situation where they have to get across the inner-city ring road in 5 seconds, it makes them think, and as a result we are able to influence planning and highways; we have been able to impact on the traffic lights that now enable disabled people to cross safely.” (Stephen Payne, Vista)

There are a number of additional outputs and outcomes that demonstrate the council’s activity is having an impact:

• **Producing best practice guidance:** this is mainly in the form of brief information sheets on different aspects of inclusive design, for example in the use of visual contrast, design of street furniture, ramps etc. The emphasis of these is to fill gaps in existing guidance and encourage best practice. For example, experience has shown that the use of darker colours for poles and other street furniture (with lighter contrasting banding where necessary), generally makes them more visible. Features such as lines of paving to provide informal guidance for visually impaired people are also now regularly incorporated into schemes. The Council has also instituted a new policy to control the placement and design of advertising boards.

• **Breaking down the communication barrier:** participation in the access events has helped to increase people’s empathy for those with a visual impairment and as a result it has been easier for access representatives to explain the barriers that visually impaired people face in terms of the design of the built environment. Getting disability on people’s radar has made getting changes made to schemes that much easier.
• **Early intervention/ involvement:** Having the IDAP that advises the council planners on the implications of their plans on disabled people encourages a preventative approach to planning and ensures any issues are dealt with before they become bigger, more costly problems in the future. This approach also supports sustainability and suitability, with the council getting it right first time rather than having to change it later. In the context of the social care and benefits agenda, the right to control and the expectation that disabled people should be able to live independently, it makes inclusive design of the built environment, technology and systems much more important.

• **Supporting the wider system:** The appropriate design of the built environment also has a positive knock-on effect on other services. For example, by having an accessible built environment VISTA’s reablement team are better able to deliver effective and efficient reablement services to blind and partially sighted people:

  “If the built environment is different and appropriate the reablement team are able to reable someone quicker, into an environment that’s accessible.”
  (Stephen Payne, Vista)

**Learning from the challenges**

• **Attendance:** on occasion it has been challenging to get people to attend the events. Councillor invitations tended to be distributed with other training information. A more direct approach is now being developed to target those that hold key positions and influence planning and design within the council.

• **Commitment from the top:** in 2011 Leicester city council had a radical change in administration, with the election of Sir Peter Soulsby as City Mayor, which was followed by major restructuring. The City Mayor and his Executive have a strong commitment to equalities, and a priority for the Access Officer is to bring them up to date with progress on the Inclusive Design Action Programme. Top level commitment has always been the programme’s strength, and will be important in taking it forward.

• **Getting in early enough:** it is important to have mechanisms in place that allow the input of disabled people from the planning and design project start up stage and then throughout the life of the project. Events such as the awareness raising events should not be done in isolation to other activity; they are not in themselves a quick fix and should go hand in hand with access advice at the early stages of any scheme. There is an important relationship between raising awareness, involving disabled people and access advisors, getting strong commitment, and achieving really good outcomes.

• **Partnership and influence:** Interviewees highlighted the importance of commitment and perseverance at all levels for the partnership to be effective, but particularly from the leadership. The access officer comes from a design background, so he is able to
“speak the language”, and relies on contacts and support across all relevant departments in the council. This has helped encourage a wide variety of people from across the various council departments to participate in the awareness events, and become more aware of the work of IDAP and the Access Group. The councillors also play an important role however by not just attending the events but taking their learning into their wider role. “There is always more that can be done […]... you can never really do enough and you can’t be complacent about it either.” (Cllr Newcombe, Leicester City Council)

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**South Tyneside Metropolitan Borough Council**

**Introduction**
In South Tyneside, effective partnership working and collaboration has supported the development and delivery of innovative solutions that meet the needs of blind and partially sighted people and do so in the context of reduced budgets and streamlined services.

It summarises work that has taken place in South Tyneside. We spoke to South Tyneside Metropolitan Borough Council (one officer and one councillor), to local provider and charity **Sight Service** and to a service user who has direct and recent experience of journeying through the system in South Tyneside in order to access the equipment he needs to continue to live independently.

It provides a whole system perspective and shows that with an emphasis on collaboration and commitment amongst key individuals, it is possible to develop and deliver innovative solutions that meet the needs of blind and partially sighted people. It also demonstrates how person-centred approaches to support can result in more effective and more efficient services.

**South Tyneside’s approach to meeting the needs of blind and partially sighted people**
The teams at South Tyneside Council and Sight Service are committed to the personalisation agenda and to using this approach to provide a service for people with visual impairment that is cost efficient and focused on outcomes. In order to fulfil these intentions the Council, Sight Service (a local visual impairment charity commissioned as a voluntary sector provider) and service users, have been working closely together to design, refine and refresh such services.

Sight Service has been operating for over a decade, Chief Executive Sue Taylor says:

“Sight Service has a contract to work with South Tyneside council; the only council officer for blind people works in our office and is managed by my staff. We work together to deliver assessments, rehabilitation, mobility services and benefits advice.”

Alongside services funded by South Tyneside council, Sight Services also provide emotional and peer support when people have lost their sight, IT training, social groups and activities, counselling (from a qualified councillor) and advocacy if necessary. Peer mentors work with clients, meaning people with visual impairment are at the heart of local delivery and there is a well established user group feeding into the improvement and development of local services.
Within the Adult Social Care team at the council departments have been restructured, there is now one team operating in the East and one in the West and integrated care for those who have physical or sensory needs is available from the age of 18 to end of life from both these teams. This move reflected feedback the council had from service users and the community who said they wanted to be able to contact just one team and have their needs met.

In the past, social care services have operated via systems and processes imposed from the top down and the journey for service users has been at times overly rigid. South Tyneside have drawn on national policy and evidence from across the UK to drive forward a fresh person-centred approach to which they are all committed.

**Peter’s case**

In 2010 Peter Bennetts was invited to become involved with South Tyneside’s personalisation pilot scheme. Peter is registered blind having been diagnosed with a sight condition when he was 14. Peter is now in his 50s and maintains an active life (he goes dancing and attends the gym) but he requires some support from his local services. Peter moved to South Tyneside in 2010 and began the process of registering with the local authority. At this time the local authority were conducting a consultation process (the Big Care Debate) with people in receipt of social care services and Peter was invited to participate. The consultation was to shape the authorities’ response to both budget cuts and the implementation of personalisation and increase understanding of how these changes would impact upon local residents.

At this event Peter met with a senior officer who invited him (as part of his registration and assessment) to take part in the pilot of personalised services for people with sensory disabilities – he agreed, as a former local government officer he has the motivation and confidence to work with local services on improvement and development.

Peter is very positive about his experience in South Tyneside and everyone involved agrees that a positive outcome was reached for all concerned. Although there were hiccups along the way, what makes this example stand out is how these hiccups were dealt with.

Issues were discussed openly and honestly and information from Peter outlining his journey as a service user through local care systems has given the authority invaluable insight on which they have drawn to refine and improve services.

Peter fed back on a number of key points, the first related to the care assessment process; Peter was assessed under Fair Access to Care Services as having critical and substantial needs but he felt the number of hours of assessment he underwent to reach this conclusion and the number of staff he engaged with meant the process overly complex. Following assessment the local authority initially offered Peter five hours per
week from a support worker, but Peter was aware of a piece of equipment that would support him more effectively and be more cost efficient and so he asked the local authority to consider this as an alternative solution. An agreement was reached and Peter was given a direct payment to purchase the piece of equipment he needs to live independently. This piece of equipment is also more cost efficient than the provision of a support worker.

**Working together to improve local processes**

Peter’s case was less straightforward than some and it took time to reach the right solution. What makes the case special is the way the authority and Peter worked together (alongside representatives from other local organisations including Sight Service and the RNIB), to discuss these experiences and use them to improve local services for residents. Peter wanted to be constructive and to feedback information that would help local partners improve outcomes for himself and others.

As a result of feedback, the assessment process has now been amended and refined. There is now an initial contact team which provides basic advice and puts people through to the right service, referrals are screened and these feed into the self assessment questionnaire (SAQ), certain questions on the SAQ have been changed so equipment and telecare needs are discussed upfront and if a piece of equipment can meet needs and maintain independence, the council will provide it. The emphasis is on asking the individual what they want and need before beginning the formal assessment process – a clear example of personalisation.

Peter reports having very favourable meetings with the council and feels that all the staff he dealt with approached his case in a positive and open manner. Peter highlights the value of the attitude, openness and personalised approach shown by South Tyneside:

“At the end of the day it is about a willingness to work in a cooperative manner, to listen, to review, to improve, to change and I think South Tyneside council have demonstrated that which has resulted in a positive outcome… I’m very grateful.”

Peter is also grateful for the willingness of South Tyneside officers and councillors to try new approaches and to be open to radical changes in the way sensory (social care) services are delivered within an environment of significant budgetary and organisational constraints:

“I know the last two years in local government have been particularly challenging and to be faced with the implementation of a new process like this alongside the challenge of budget reduction…They have tried their best to turn those negatives into a constructive and positive win-win situation.”
This spirit of cooperation and collaboration is reflective of the wider approach in South Tyneside. Councillor Emma Lewell-Buck summarised how budget cuts, painful as they may be, have prompted a new level of creativity and collaboration:

“It’s been difficult… In the past two years at adult and social care services we have been through a lot of change. We have had to be a lot more creative. We are looking more towards the wider community and things that are already there, which we never utilised before! You could see that as one of the positive sides to the cuts really.”

New approaches and ways of working prompted by the reductions in available resource, good local relationships and a willingness to try new ways of delivering services have had positive outcomes already in South Tyneside. Sue Taylor spoke about the integration of systems and processes locally to create a more joined up process for local residents with sensory impairment:

“Things have changed over time…we have always had a very good working relationship with council officers and councillors…but we have developed suggestions and proposals for working more closely and have seen the benefit…if you look across the UK having council staff seconded and working to our team is very rare, but it works very well…we have also got RNID [now Action on Hearing Loss] working out of our offices, so all sensory services are under one roof…We eliminated a waiting list of over 100 people in four months…previously some people were waiting more than two years for assessment and now no one waits more than two weeks…funding has been cut by 20 per cent, but delivery is more focused and we have a better service overall.”

The future in South Tyneside

Partners in South Tyneside are very clear that personalisation is the way forward for sensory and adult social care services. Sight Service are encouraging those who meet the criteria to take up a personal budget and through their work with partners in the council, are encouraging other services to consider the needs of people who are blind or partially sighted and to co-design services that are flexible enough to meet needs and often for less resource. Locally elected members are heavily engaged in this effort and believe in the value of personalisation to the local population, local councillor Emma Lewell-Buck says:

“One of our greatest strengths is that we really have a handle on personal budgets. It can look good on paper but it is about showing its value, and selling it to service users, that is the real challenge…sometimes people perceive them as the local authority absolving their responsibility, but actually it is more about…giving people more control over their lives.”
Sight Service are expanding their remit and have set up a social enterprise called Angel Eyes. Angel Eyes is for visually impaired people of working age who want to find and (crucially) create employment and volunteering opportunities. Angel Eyes will also deliver training to schools and businesses – the local authority are very supportive of this venture.

Across South Tyneside third sector organisations are building networks for the benefit of the local population and local services and are coming together to look for opportunities to improve outcomes in intermediate care and reablement. They are also using the good work being done in South Tyneside to generate greater understanding of sight loss and its impact on peoples’ lives.

The local authority remain committed to learning from best practice locally and nationally; they have established regional personalisation groups and are heavily focused on this agenda as it develops. Sue Taylor stressed the importance of this clarity and dedication at the organisational and whole system level:

“We are all being really positive about it and know this is the way we want to go and that is becoming the culture throughout all our services. We have buy in from elected members and any new changes in adult social care policy are discussed at highest level…we have a very clear communications channel…what it means is reinforced wherever necessary…key for us is to work in partnership with those with visual impairment to understand their views and keep communications channels open.”

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Individual case studies

Purpose and method of the interviews
As part of this research we undertook five in-depth interviews to explore in more detail a number of themes and findings arising from the focus groups with blind and partially sighted people. The interviews explored participants’ everyday lives, what helps them lead a fulfilling life and what restricts them, what changes they would like to see locally and what their hopes are for the future.

The interviews were designed to be fairly unstructured and conversational in style in order to explore areas which are important to the individuals in a relaxed manner. The interviewer spent approximately half a day with the interviewee in their home or other setting.

These interviews have been drawn on to support and illustrate the broader findings from the research.
Alex Wheen’s story

Background
Alex is 26 years old and has been partially sighted since he was eight. He is now registered blind.

Alex is currently unemployed and has been living with his parents for a number of years. He lived independently in a flat before but was forced to move out because he got a guide dog and the landlord would not allow animals on the premises.

Since then, Alex has been living at home with his parents, but is looking for places to move to where a guide dog would be accepted.

Alex supports and has marched with the Hardest Hit campaign, which lobbies the government to stop cuts to services for disabled people.

At the moment, all of Alex’s friends are blind and partially sighted. He explains:

“Now I have a fairly decent circle of friends who are all blind or partially sighted. My previous friends who are fully sighted and non-disabled I see very little these days. Just because we live very different lives. They’ve got jobs, are putting down a mortgage on a house, they’ve got long term relationships.”

A typical week for Alex
Most days, Alex will be in his room on his computer searching for jobs. He also plans for his blind tennis support group and every so often he will do some volunteer work for RNIB or tin-shaking. Alex finds doing sports and socialising particularly fulfilling.

Alex sees isolation as a big problem, both from the point of view of being a partially sighted person and also living in such a rural part of Hertfordshire. There are no pavements so it is impossible to walk anywhere even if it is just 15 minutes away. This means that transport, either through the use of a car, taxi or public transport, is essential.

“If you can’t afford a taxi to the local store and it’s two miles away, it doesn’t really matter if you’re blind or partially sighted, it’s going to be dangerous for you to walk down the road that far if there aren’t any pavements.”

At the moment, Alex depends on his mother to care for him, such as giving him lifts to wherever he wants to go. Often Alex feels guilty about doing this and would prefer to be independent so that he can go by himself to do things like see his friends. At the moment, he receives £15 a week from his DLA but he feels this is simply not sufficient for what he needs to do to live a normal life. Alex’s view is that:
“Blind people haven’t really ‘come through’ in Hertfordshire, which is something that I really wish to change. By ‘coming through’ I mean making decision makers aware of blind and partially sighted people. It can be difficult when the numbers are low and you’re all spread out.”

**Employment**

Alex is currently unemployed and is looking to get a job in the blind and partially sighted sector. So far he has come up against a lot of barriers from employers’ unwillingness to make reasonable adjustments for him and misunderstanding his condition.

One example is a previous job at a pizza restaurant. Often the mistakes Alex made as a result of his partial sight were misinterpreted as stupidity and sometimes he was bullied because of this. The employer did not consider making things more accessible for Alex such as having large print receipts so that he could read them properly and place orders correctly.

For many years, Alex also tried to hide his visual impairment from employers because he thought he would do better that way, but he is much more open about it now.

“A lot of the times I would hide [the fact that I was partially sighted], to try and disregard it as much as possible, hide it under the carpet. I really didn’t want to discuss it. And [my employers] really resented that. I was completely unaware of [schemes like] Access to Work and I think a lot of employers are as well actually.”

Now when Alex is looking for jobs, he searches online and receives some support from Action for Blind People. Initially, he did not know that he was entitled to this support because he was told by the job centre that Action for Blind People did not provide services in his area. Eventually, through some of the work that he does with RNIB, Alex was referred to Action for Blind People by his job centre.

The support Action for Blind People provides to Alex includes recommending jobs to him, going through forms with him to ensure he understands and has filled them out properly as well as giving general advice about applications and interviews. Action for Blind People also provides IT support through advisors and raises awareness about the software packages blind and partially sighted people can use to access the internet and write job applications.

**Charity work**

Alex does tin-shaking (charity box collection) for Metro Blind Sports, a charity that supports sports for blind and partially sighted people. Often he will attend charity box collections along with a group of other blind and partially sighted people and they will stand together in a busy location such as St Pancras Rail Station to attract donations.
Alex does voluntary work to keep himself busy, however it is not ideal. He said:

“I would prefer to fill out a grant application form because you can get more money that way – say £1,000. You wouldn’t be able to get that in one day of tin-shaking.”

Alex finds charity collections quite tiring as he has to stand around for long periods of time. He sees fundraising in general as requiring a lot of skills, for instance good social skills so that you can feel comfortable with strangers and having the ability to interact with different sorts of people.

Alex comes across a range of different attitudes from people whilst he is doing collections. Some might go up to him to ask about directions, others might be aggressive whilst some are friendly and strike up a conversation with him. Alex has come across prejudice much during this activity; rather it is ignorance from people who simply do not care about blind and partially sighted people.

Support in Alex’s area
Until January 2012, Alex reports there were no services for blind or partially sighted people in his area apart from a local society which has four outreach workers. The local society only caters for those who became blind and partially sighted in later life, which means people like Alex are excluded from their services.

Alex and a number of others from his area who are also blind and partially sighted were sick of the lack of services and desperately wanted to be more active and engaged in society. As a result of this frustration, they decided to set up two support groups; one is a support group called Four Swans Vision, and the other, which Alex set up, is called Hertfordshire Visually Impaired Tennis Club. In January 2012, the two groups managed to receive some funding from their locality budget.

“We want to be doing sports, socialising, being more engaged in society really.”

The groups found out about the locality budget through a leaflet sent around by a local councillor saying they were looking for good groups and local causes to give money to. Alex got in touch with the councillor and was referred on to his local authority’s community development officer. As a result, Alex’s tennis club was given £480 from the locality budget to help with one year’s running costs.

The biggest issue for Alex is living in a rural area, coupled with the lack of transport and the lack of mobility this results in. Something that he thinks would help which he has seen work quite well in London is a taxi card scheme. Alex feels that this would be a great form of targeted support for blind and partially sighted people in Hertfordshire:
“It’s frustrating because if you were to compare Hertfordshire to London for example, something like a taxi card scheme would just be of amazing value to blind and partially sighted people. There’s one bus a day that goes past my house so if I wanted to get to a job interview the following day at 9am I would have to catch a bus at 1pm the previous day!”

Alex thinks that locality budgets might be a good means of funding more targeted support. He believes this would be more effective because it would cut out the middle person and enable the funding to go directly to blind and partially sighted people where it is really needed.

In terms of personal budgets and direct payments, Alex says that there is a perception in his area that you have to be on “death row” in order to receive this kind of support, because it is so difficult to get. The main types of financial support that Alex receives are ESA, DLA, the funding for his tennis club, RNIB and meetings with the Four Swans Vision.

In addition to better, audio described transport, Alex thinks there needs to be an unemployed support group for blind and partially sighted people in Hertfordshire.

The cuts
So far the cuts have had a limited impact on Alex in terms of the area in which he is living because there were so few services there to begin with. In fact, since he helped start up the two support groups in January 2012 and received funding for that from the local authority’s locality budget, Alex has been part of creating an improvement in services for blind and partially sighted people in his area:

“In terms of cuts, in Hertfordshire, there really have not been any cuts, but that’s only because we’ve started with nothing! So we’ve gone up slightly but there’s still a long way to go.”

Alex goes to London regularly and finds out about what is happening there through his contact with London-based blind and partially sighted people. He knows for example that Lambeth has cut its support for blind and partially sighted people.

Alex is concerned about a couple of very vulnerable people he knows who depend on these services in London. In one instance, there used to be a cooking group in Lambeth which for many visually impaired people, would be there only chance during the week to get out of the house. Alex thinks that isolation, depression and possibly suicide are some potential ramifications of these services being removed.

“The people in London who had their funding cut…I don’t like to think about it to be honest with you.”

Quick wins… and missed opportunities
The future
Alex looks forward to seeing RNIB’s new strategy for service provision and hopes to get a job in the sight loss sector. He will be getting involved in more consultations for blind and partially sighted people to watch where the cuts and the implications for blind and partially sighted people. With regard to cuts to services, Alex fears for those who are most vulnerable and will find it difficult to get by. He believes it could result in instances of people “dropping the ball” more often, such as in the highly publicised case of David Rathband, the blinded police officer who committed suicide after suffering from depression for a number of years. Alex’s biggest fear is that discrimination against blind and partially sighted people keeps increasing.

“My personal feeling is that now we are in an economic recession, funds are being cut and not only that, donations are reducing as well. People are holding onto the funds that they have because they have to make sure they have food for themselves and their children.”

To help combat some of these negative impacts, Alex thinks that local authorities should help blind and partially sighted people forge better connections amongst themselves and other organisations so that they can support each other because there is power in numbers. He hopes that Hertfordshire makes sure its budget is used really appropriately and effectively for blind and partially sighted people.

“I think having a strong connection with blind and partially sighted people really does make a significant change. With local authorities and locally in general.”
Anne Rigby’s story

Background
Anne has been registered blind since birth and has no residual vision. She has some light perception but no useful vision, only being able to tell whether it is light or dark and make out the occasional shape.

Anne was born and raised in Germany and moved to the UK in 1991 when she was in her early 20s. She came here to build on her existing English language skills and is now fluent, using English as her main language. Anne spent five years in London and now lives in Chester.

Anne has always been very ambitious and a high achiever, she has a degree and postgraduate qualification and is multilingual, but is unable to get work and is concerned about the discrimination facing blind and partially sighted people in the labour market.

Anne moved to Chester to be with her partner (now husband) in 1996. They live just outside the town centre with their guide dog. Her husband is also registered blind.

Anne’s home life
Anne no longer works but she does volunteer work for RNIB and the Chester and District Federation of the Blind. Her husband works in IT and has been with the same company since 1985 – he works largely from home. They have a well organised home – a cleaner and a gardener visit once a week, a friend helps with paperwork and household bills, they use the internet for online shopping and sources of entertainment such as talking books, CDs and talking Twitter updates. They also use a local taxi firm.

Anne does not have a typical routine and her weeks vary but she spends a large amount of time reading, using the computer, doing household chores and voluntary work. The family have a range of aids in the home to support them to live independently and are able to help each other with day-to-day tasks such as making lunch, answering the door and caring for their guide dog.

Anne enjoys living in Chester. They have no family in the area and do not have children or attend any local activities so feel a little removed from the wider community, but she has formed friendships with sighted, partially sighted and blind people. She tries to get out and about – there is a row of local shops a ten minute walk away. Anne finds the community in Chester to be friendly and polite, but perhaps less outwardly welcoming than she has encountered in other areas of the UK.
Anne goes into the centre of Chester occasionally but feels limited by her lack of familiarity with the high street and tends not to venture beyond the two or three shops she knows well. Sometimes she is able to go with a friend she met through her RNIB campaigning work to one of the large local supermarkets or to buy larger items like furniture.

**Education**

Anne was educated in Germany, attending mainstream schools with integrated support for blind and partially sighted children. She went to university in Hamburg where she began a teaching degree with English as her core subject – she had wanted to study languages but did not feel comfortable moving to southern Germany to attend the language school. Anne found university an isolating experience:

“In Germany you organise your schedule by yourself and don’t have an [established] peer group…who follow you to your second year and beyond. I found it very, very difficult and quite isolating… [Also] at the time, there were no computers or clever equipment and it was difficult getting teaching materials together.”

Anne lost confidence in her ability to teach during the course, concerned that her lack of sight would impact on the quality of her teaching materials. She also believed course examiners were determined not to allow her to pass, no matter the quality of her work:

“I knew from other people how hard it was and I know that it would have always been harder for me as a blind teacher to be imaginative enough and to get enough materials together and be as good a teacher as I maybe could have been if I was sighted…There were also examiners there that pretty much said ‘you can go through with it, but be damn sure I’m not going to let you pass’, they did not think it appropriate for a blind person to be teaching.”

Because Anne could not read the printed course materials, she felt her English was not sufficient to pass her exams so looked to spend some time in an English-speaking country. With some funding from a local charity she was able to take part in a student exchange programme with a college in Glasgow. Anne recalls this experience with enthusiasm, describing how welcome she was made to feel and open Glaswegians were towards her:

“I had a great time there – apart from the weather! The people were so much friendlier than they were back home and I loved it.”

After moving to the UK permanently, Anne continued to gain qualifications, undertaking a management trainee scheme in London and then attending weekly classes in Chester to obtain an International Communications Diploma.
**Employment**

Anne was unable to find work during her first 18 months in London, but then in 1993 managed to obtain a position when she volunteered to do work experience for a new company working in corporate events and then became a full time employee. After a year the small company ceased to trade.

Anne was unemployed for a few months before obtaining a place on a management apprenticeship scheme (run by the charity Scope). This gave Anne the opportunity to study and earn money at the same time and she successfully completed this course. She went straight from this to a position with RNIB as an executive assistant to the then Director General. Anne thinks having a management qualification helped her obtain the position and to excel in the role:

“It was a really good learning job and I stayed in that job for 15 months, I could have stayed longer but during that time I met my now husband and he lived in Chester and we decided it was better to live in the same town. Leaving was quite a wrench as I really loved that job.”

When she moved to Chester Anne found a job with Chester City Council; the council purposefully recruited a disabled candidate to promote the employment of disabled people. Although Anne is pleased she had this opportunity, she did not find the job met her expectations or reflected her experience and did not feel challenged:

“It wasn’t as good as my job in London, it was ok, but compared to my previous role it didn’t stretch me – there were no promotion prospects and I was earning a lot less money but this was the least of my worries, it was just a bit of a disappointing job.”

Anne spent three years with the council before going back to work for RNIB in 1999 as a Link Officer working with local societies for blind and partially sighted people. However, short-term funding meant this role came to an end in 2003. Anne was offered another role at RNIB as a Campaigns Officer but was unable to move to London for the work because of her commitment to her family. She regrets not being able to take up this offer and thinks she would have performed very strongly in this position. Anne has since found it difficult to find a role of this kind – one that stretches her and allows her to make the most of her many skills.

Anne then obtained another role with RNIB supported by National Lottery funding. Anne worked as part of a group of five, delivering workshops to public and private sector organisations in England and Wales. The group devised the training materials and delivered the workshops and Anne found this very enjoyable:
Individual case studies

“It was about blind and partially sighted people’s rights and how to provide accessible information – encouraging providers so they see it is a good thing to do… I had fun doing it and got some good feedback from the workshops I delivered – it’s good to get some positive feedback now and then.”

Anne finally decided to try and set up her own business to enable her to use her language and translation skills. Unfortunately this did not work out and she gave up after three years:

“I did some translation work but could not get enough work to make it pay and some of the work wasn’t accessible to me eg scanned images and PDF files… I couldn’t get enough hours support from the Access to Work scheme to make it work, so it couldn’t be justified and also I wasn’t very good at marketing myself – it’s hard to market yourself!”

Unemployment and volunteering

Anne is currently unemployed and does not hold much hope of finding work. Anne now undertakes voluntary work and is currently an RNIB campaigns volunteer and a regional RNIB member representative. She is also a Trustee of the Chester and District Federation of the Blind; through this charity she is involved in the delivery of visual impairment awareness sessions to children in local schools and colleges. Anne is harnessing all her skills and experience in helping with the design and delivery of sessions suitable for children and young people aged 4-20:

“We raise awareness of visual impairment and what it means, we do practical exercises to show them what the issues are for blind and partially sighted people and how difficult it is without sight. The reaction from them has been great… especially the younger ones.”

Although Anne is currently happy volunteering, she has found her blindness a significant barrier in the labour market and has had to undertake a number of unsatisfactory positions. Anne thinks it is much harder to find work as a blind person because of the assumptions others make about the capabilities of those who are blind or partially sighted:

“I think it is hard even to get work experience as a blind person, perhaps more so than with other disabilities. I think there are very serious prejudices against blind people, from both employers and people in general. They think that we can’t get upstairs, read or write, do this or that… I’ve never got into a job then changed people’s minds because of how good I am, because I’ve not really been let in anywhere where people were sceptical about me.”
Anne has actively looked for work many times but feels that when an employer discovers a candidate is blind or partially sighted, barriers go up:

“They fear they’ll have to adapt their workplace, that we won’t be as quick or productive, or that other people will have to do part of our job... People also fear blindness... they think ‘if I couldn’t see I couldn’t do anything’ and they transfer that onto the blind person... I have been denied interviews before because I would have to go upstairs to get to the interview! So, I do that every day!”

**The local area and local services**

Anne has minimal contact with local services; she takes part in some local council consultations and is confident contacting them when she needs to, she also uses mainstream local authority services such as waste collection.

Anne thinks certain provisions such as leisure services (public and private) are not very encouraging of, or accessible for, blind people; she wonders whether the affluence of Chester is a causal factor:

“I know in some areas fitness facilities are very good... I think because Chester [city] is very affluent they don’t try as hard to be accessible. If I went to Ellesmere Port, even though it is in the same local authority area, they would have more interest in being accessible or making an effort... I think in more deprived areas they sometimes make more of an effort to open themselves out... for example to ethnic minorities, people on low incomes... but they are not really prominent [groups] in this area... In other areas the whole infrastructure is more geared towards people who [may be] disadvantaged in society, there is more of an attitude in those areas to opening places out... they make themselves more attractive to other groups... this is just a theory that I have!”

She finds the lack of public transport in Chester difficult but lives close enough to town that it is a manageable £4 taxi ride away. Anne recalls living in London and believes that despite it being bigger and busier it was easier to live independently as a blind person because of the wealth of public transport and support available, for example the RNIB resource centre.

**Funding cuts**

Anne has not yet felt direct impact from cuts to public sector spending, but is due to attend her Incapacity Benefit reassessment (in line with national reassessments). Her immediate concern is that she will be put onto Employment Support Allowance and her benefits will reduce by around £5,000 per year. She thinks this will severely limit her independence. She expresses her annoyance and disappointment that someone registered blind since birth, with an unchanging condition, need go through this process.
Given her previous experiences, Anne also thinks it unlikely that she will find paid work again – especially work that matches her skills set. She has only ever been employed by visual impairment related organisations or local authorities (both of which are losing staff in the cuts) and is worried about the impact on blind and partially sighted people as the job market becomes more challenging.

Anne is worried that national benefit reassessments will leave blind and partially sighted people in difficulty as state support is reduced without opportunities in the job market being made available:

“I met three other people who had significantly better vision than me and they couldn’t even get work experience places…I couldn’t understand it, I was baffled!…You just are not given the benefit of the doubt…do training schemes, get us interview ready, work experience and so on but that is not doing anything about prejudice of employers…who is going to give us jobs! It doesn’t work out, there is a gap somewhere in the system…it’s not about capability at all.”

**Hopes for the future**

Anne’s hope for the future is that people who are blind and partially sighted are given control over the resources allocated to them through for example personal budgets, so they can buy the support they need, rather than have services dictated to them or have their lives scrutinised, for example, during community care assessments:

“I was asked by a re-adaptation officer…three or four years ago…what kind of service I would like and I said ‘someone who can take me for a walk or take me shopping every now and again’ but was told that they didn’t approve of that. I could have someone every week to do some reading for me, but I didn’t need that! It’s down to the criteria and whether it fits. They all have a policy and [idea] of what constitutes a valid service.”

Anne thinks it will be a long time before things become easier for blind and partially sighted people. She supports single issue campaigns and has been to see her local MP about benefit changes; she found him to be friendly but felt the meeting to be ineffectual as issues were passed to the Minister, who gave her the stock response. She is sick of getting the same kind of letters from central government.

Anne’s ultimate hope for the future is that employers and people in general start to change the way they view people who are blind or partially sighted:

“I would like it if people in general and employers in particular, saw us for what we are, saw our skills and could see past the blindness…if I didn’t feel I was sidelined and disadvantaged all the time…talk to us more, tap into our skills, its not just non-functioning eyes, there is a whole person behind there.”
John Wilson’s story

Background
John was registered blind in 2005. He has macular degeneration and following a haemorrhage at the back of one eye, now has only minor peripheral vision. John lives in South East London with Win, his wife of over sixty years. They are both in their eighties. John and Win are fiercely independent and their energy and vibrancy defies their years. Their house and garden are immaculate and they maintain it entirely on their own, receiving no home help. In our time together John refers extensively to “learning to cope”.

John does not have a guide dog and does not use a long cane; he prefers to use a shorter white stick. This way people see the stick as a symbol of visual impairment but it also provides him with some physical support and stability when he is walking.

John is keen to point out that despite suffering sight loss he manages to live “a normal life”, and “just get on with it”, but both he and Win are very clear that their partnership makes this possible and that John would not be able to live alone or manage without the considerable assistance and support provided by Win.

Daily life and community
John is 87 and was born in Islington, North London. He lived in Dagenham for 20 years before moving to the estate where they currently live. He was in the Navy from 1943-46 and married Win in 1950. In 1951 he went to work for the Post Office and retired in 1984.

John and Win have a weekly routine and manage to get out and about shopping together. On Tuesdays Win has a “me day” where she goes dancing and out with friends for lunch then to a group called Lively Minds. On Fridays and Saturdays they often go to the East Dulwich Constitutional Club, where they have been members for 37 years.

They have extended family within a commutable distance and visit their children, grandchildren and great grandchildren when they can, using the rail network to get around. In recent years they have altered the routes they take to use stations they can get around without having to contend with lots of steps which are difficult for them to manage, especially with luggage.

John and Win say they are “very lucky” to live in their community; they have always had a good circle of friends and Win went to school with their next door neighbour and several other people on the estate. This community and social network is an additional source of support and help for John and Win:

“There is still a nucleus of people around here we have known for donkey’s years and if you should want anything and you ask them it would be no problem. Same if they want anything, they come and ask us.”
Individual case studies

John used to love playing bowls and travelling with his team but has stopped doing this since he lost his sight. His friends have encouraged him to try but he is reticent to do so. He now spends much of his time listening to talking books.

Losing his sight
John first started to lose his sight in one eye in 2000. While on holiday he looked out to sea and noticed his left eye was distorting the horizon:

“I was on the beach one morning with friends and as I looked out to sea I could see a big kink in the horizon. And as I looked at it, it moved. I went back to my book and all the text was up in air. Obviously this wasn’t right, so I went to see the optician and she sent me to hospital. It started there and got worse, until the sight in that eye had gone completely.”

On his return John was diagnosed with macular degeneration. He saw a consultant at King’s Hospital for regular checks over the next five years and his sight continued to degenerate.

John tried to carry on as normal and continued to drive and play bowls, until 2005 when during a game of bowls he suffered a haemorrhage in his other eye:

“Everything went red, I tried to play the rest of the game but couldn’t and I couldn’t drive the car home, I went to see the doctor and he said I’d had a massive haemorrhage in my eye, it all went downhill from there and in 2005 he registered me as blind, from then on we have had to cope as best we can.”

By 2005 John could no longer see and the consultant registered him as blind; he wrote a referral providing John with one copy, sending one copy to his GP and sending a third copy to the local council. The consultant gave him basic information about the services and benefits he should expect and then handed his case over to the council.

In the last couple of years John has had cataracts removed from both eyes. The first one mildly improved his recognition of colour but he says if anything, in his second eye his vision was worse after this surgery.

Support and services
Once John had been registered blind, he was put in touch with the Sensory Services Team which provides services and equipment (subject to eligibility criteria) to residents with visual impairment in the London Borough of Lambeth.

The council took over from health services, sending John his registration, helping him to understand his new rights and providing him with information about the services available to him. John was told that he was allowed a greater personal allowance before income tax and an attendance allowance and he made aware of the equipment and resources available from RNIB.
The council registered John as a member of Dial-a-Ride (a free transport service for those with disabilities), a member of the Taxi card scheme (subsidised transport in taxis and private hire vehicles for people who have serious mobility or visual impairment) and got him a Blue Badge parking permit, for use when he is out with his family.

John received a follow up phone call sometime later with the offer of further help, but he and Win did not feel it necessary. John says he has had “no problems whatsoever” with the council since he was registered blind and speaks very highly of his experience:

“If you ever need anything, any time at all, I phone up the Sensory team and they will sort it out. They deal with people with the loss of various senses and I have never had a problem [with them].”

Whilst they received sufficient support with practical measures neither John nor Win were offered any rehabilitation or emotional and psychological support; they do wish more of this had been available at the time. Win says:

“At first I thought the world had come to an end…when John said he had gone blind, that was really a shock.”

John says:

“I didn’t worry about it so much when the first eye went, but when it happened to the other one…well, I must confess, I did feel more than a little bit down and worried about what would happen next…but all you can do is accept it.”

The Council’s talking book service is very important to John. Before losing his sight he was an avid reader; he does not read braille so talking books have made a positive impact on his life since he lost his sight. John stresses its value in our conversation:

“As long as I’ve got my talking books I’m alright, and the Lewisham talking newspaper which comes every week…well, there’s nothing else to do is there!”

Win adds:

“John was a great reader until this happened, and if it wasn’t for these talking books he would be absolutely lost.”

John and Win have no access to a car and use the local buses and trains but are finding this “more and more arduous”. John emphasises what a blessing the Freedom Pass is – a free travel pass for older and disabled Londoners, paid for by his local council and the Dial-a-Ride service, which they use when they need to do a big supermarket shop.

John does not feel he has suffered with the public sector spending cuts, but he is sad to have seen the mobile library service go in recent years as a result. The mobile library used to come to the estate every Tuesday but the service has now been cancelled. As it ended, the librarian gave John a telephone number to register for the outreach service.
Now once a month somebody comes with a selection of talking books and swaps them for John, even recording (via a simple sticky label) which ones he has had in the past to ensure he does not receive the same book twice.

The Peabody housing association, who run the estate the couple live on, are also aware that John is registered blind. Instead of writing to John, they have been to visit him to discuss issues on the estate and the couple feel they are a good housing association.

John and Win do not personally know other individuals or families living with visual impairment but they are connected to RNIB and to the Macular Disease Society. Both organisations send them audio copies of their newsletters and magazines. John and Win can also reach the RNIB’s resource centre on Judd Street via a direct bus. John has little need for equipment, accessing only basics such as a talking watch. They do not have access to a computer or the internet, although they would like to know how to use it.

The impact of sight loss on daily life
John is resolute that as a team he and Win can deal with his sight loss and places great emphasis on “learning to cope” following his sight loss and learning to adapt. They think of themselves as fortunate to be able to cope so well together and say they have always found people very helpful.

They still lead very active lives but John has had to curtail his activities and he really misses being able to play bowls. They both miss trips to the theatre which they now don’t see the point of; however they still go on holiday and receive help at the airport and when boarding the plane.

John and Win highlight the simple things that John is no longer able to do, they provide the example of John being asked for his signature and not being able to remember how to do it (as Win now manages all the paperwork and household bills). They talk about the assistance Win gives John for example in preparing food and in dressing appropriately (they recall getting as far as Sutton on the train one day, before realising John was wearing mismatched shoes!), putting toothpaste on his toothbrush, or opening a toilet roll. Some obstacles they simply now avoid, for example wine glasses or tumblers at the dinner table:

“I hate glass! If there are glasses on the table I’m scared. If it’s full of red wine I can see it! But otherwise its just not there, and it should be!”

Looking to the future
John and Win’s main hope for the future is to carry on as they are and to maintain their health – John says at the age of 87 he tries not to look too far ahead. Win is particularly concerned with maintaining her current state of health so she and John can both continue to live independently:
“I just hope my health especially continues as it is, which at the moment is fine. I had a quadruple bypass seven years ago but fortunately got over that ok and have been well ever since, and long may it continue. We keep our fingers crossed.”

Win thinks John’s sight is getting gradually worse and she is finding she has to help him more than she used to, she is noticing he is unable to perform tasks he once could such as seeing his medication. But they do not think they need more help, support or relief than they currently get: “if we can cope without all well and good”. They have never asked for extra help beyond what they get now and do not feel they have needed it:

“We don’t need extra support or social care services. If you’re on your own maybe you do need to, but when there are two of you and we’re together 24/7.”

John says, “clearly it would be a different story” if Win were not there to help him. They are obviously worried about how he would cope if this were the case. John is clear that in every case when someone has sight loss, only they will know (based on their circumstances) what help they need and what support is necessary and what isn’t:

“It affects different people in different ways and you can’t generalise.”

At the moment they feel adequately supported by each other and by local services. They do not come across major challenges in going about their daily lives and anything small they choose to overcome themselves in the best way they can:

“I suppose if we had to call on somebody we would probably get help, but we are not in that position…we do know that if anything arose and we needed assistance there is somebody somewhere we can phone up.”

But Win says:

“Whilst I can cope I am quite willing to do it.”
Harriet Keeling’s story

Background
Harriet is in her 40s and has been visually impaired all her life since she was born with cataracts. Her husband Michael is also visually impaired. Harriet and her husband both retired a number of years ago. Harriet has been retired for over 10 years and previously worked for a disabled children’s charity and the civil service. She was signed off for early retirement at her last job for medical reasons related to her visual impairment, she says:

“It used to be that if you were visually impaired, you either tuned pianos or did massage. You were put into a box.”

They have two sons, David, 13 and Mikey, 17, as well as a daughter, Victoria, 19. David and Mikey are also visually impaired and have Marfan syndrome, a condition inherited from their father. Marfan syndrome is a genetic disorder of the connective tissue which can cause physical difficulties. Often Michael and David need to use wheelchairs in order to manage their symptoms.

Harriet and her family have moved around quite a lot in the past 10 years. Originally from Luton, they also lived in Spain for around eight years, but moved back to England two years ago because services for visually impaired children over there were too expensive and therefore limited. They first moved to Exeter for a year then moved to Paignton, to a house specially built with their input, so that it could meet their specific needs.

Moving to Spain and back again
In Spain, the charity ONCE or Organización Nacional de Ciegos Españoles (National Organization of Spanish blind people) is Spain’s equivalent of RNIB. Spanish citizens who live in Spain are entitled to free support and services from ONCE. If, however, you do not meet those criteria, you have to pay. In the time that Harriet and her family lived in Spain, they had to pay for the support they received, which was very expensive for them. Because they could not afford a lot of the support they needed to get through school, both David and Mikey struggled whilst living in Spain. This was the reason why the family moved back to England.

Following their decision to move back to England, Harriet approached the local authority in Exeter for support. They agreed to put Harriet and her family on a housing list. During this time, they moved to temporary accommodation in Exeter, which was also near West of England School, where Harriet planned to send David and Mikey. After a few months a house in Paignton came up for them. This was very lucky Harriet said, as it usually takes a few years for a family with their level of need to get a house. Harriet and her family were able to give input into how the house was adapted to fit their needs, including making it wheelchair accessible and making the windows touch sensitive.
**Everyday life**

A normal week for Harriet is very busy. Usually it will involve two or three visits to the hospital for appointments with family members. In addition, she does all the food shopping, cleaning and cooking. Sometimes the hospital appointments prove very costly because she and her family have to use public transport and taxis. If she has an appointment in London for instance, it can cost over £100 to go there and back. Harriet thinks that travel costs should be covered if she can’t get the health services she needs locally, as she doesn’t think it’s her fault that she has to travel.

Apart from her household duties, Harriet is an exuberant person who likes to go out. She takes the bus to Paignton town centre most days and will often take the bus to Exeter or Torquay. Every so often she also takes the train to London, as sometimes her children have appointments at Moorfields Eye Hospital.

There are clubs geared towards blind and partially sighted people in Harriet’s area, however she says that they mainly cater for older people. Harriet likes going to the gym and enjoys music but finds these things difficult to do by herself. She says that if she had support from an enabler, she would be able to do more of these things. She cannot afford to pay for an enabler however, and because she is not receiving income support she would not get that help for free.

Another thing that Harriet finds challenging is the fact that a lot of the activities in her area which support people with visual impairments, eg sailing, are only geared towards people with visual impairments. Harriet prefers not to mix with blind and partially sighted people all the time, as she said:

“If I want to get out and do something, I want to go out and do it as a normal person would do it.”

Harriet’s husband was offered some help with socialising when he first lost his sight, but this involved going to a social club where the youngest person was in their 70s, so it wasn’t really appropriate for him. As an alternative, Michael was offered a place at Manor House in Torbay, which was used to rehabilitate people who have just lost their sight. He went there for 12 weeks and had some really valuable experiences where he learnt how to deal with his mobility issues.

Apart from the above, there is nothing much for Harriet and Michael to do in their area which accommodates their needs. British Blind Sports and other blind sports charities run sporting events that Harriet and her son Mikey would like to go to. However those tend to be more geared towards elite disabled athletes and place restrictions and conditions on membership based on your level of visual impairment:

“You get judged in the mainstream and you get judged by VI people,” said Harriet.

“T would go to normal groups and clubs, but it’s difficult” said Mikey.
Individual case studies

If Harriet ever wants to find out about what support might be available to her or her family members, she looks on the internet or rings social services to speak to the sensory team there.

Education

When Harriet was growing up in Luton, she did not like the school for visually impaired children and wanted to go to mainstream school. She did not see her visual impairment as a disability and did not want to be labelled as such. In the end, her parents paid for her to go to private school. However, the school was not very accommodating to her needs, and she found she spent most of her time at a photocopier enlarging textbooks, articles and other students’ notes from previous classes. Harriet is now looking into adult learning because she would like to study more:

“I am very independent. If you acknowledge someone is visually impaired, you are putting yourself in a box.”

Harriet’s youngest son David goes to mainstream school where he receives one-to-one support from a teaching assistant. Her eldest son Mikey attends West of England School and College for young people with little or no sight. Mikey receives a great deal of support in terms of his mobility needs.

David chose to go to a mainstream school because he found the West of England School challenging in the sense that it lacked a social aspect. He was in a class with children who had a variety of complex needs in addition to visual impairments. This meant that they also had widely varying levels of educational and social ability. David was the only child in this class who was just visually impaired, so he found it difficult to socialise with children who had such complex needs. Overall, David now prefers not to be involved with visually impaired children and special schools.

Harriet believes that in the past few years, the composition of the students at West of England School has changed. Whereas in Mikey’s peer group, a majority of those accepted into the school were just visually impaired, now she believes that the school is taking on a far higher proportion of children who have more complex needs in addition to their visual impairments, such as physical and psychological needs. She thinks this may be the result of the cuts that her local authority are making to other services for children with special educational needs, resulting in the West of England School absorbing a lot more children with complex needs. Harriet has also noticed that her local authority has started to try and get more visually impaired children to go to mainstream schools, which she feels is in order to save the council money.
Mikey
Mikey likes to go out with his friends when he is feeling well. Sometimes they will come to his house or they will go to football matches together. Mikey does not see himself as being part of the “mainstream social environment” because of the fact that he goes to a school specifically for visually impaired children. He tends to be friends with the same ten people. One of the challenges is if one of them has an argument, it affects the whole friendship group.

Mikey finds it difficult to meet new people and when he does, sometimes he lies about the fact that he goes to a school for visually impaired children. He does this to avoid the stigma that he feels is attached to this and also because he was bullied previously about his eye condition.

Mikey currently attends West of England School and would really like to go to college next year. His ambition is to study law at university. Mikey is a very confident, articulate and aware young man and understands a lot about services in his area and what he is entitled to.

One of the issues Mikey is coming up against in terms of his education is that he will lose his financial support to meet his special needs if he goes to a college other than Exeter College next year. This has considerably limited Mikey’s options in terms of where he can apply and the subjects that he can study for his A-levels. It also puts a great deal of pressure on him to succeed in his current studies in order to ensure he gets a place at Exeter College.

At West of England College he receives a lot of support and equipment to help with his visual impairment, and this is all funded by his local authority. The school itself gets involved in a lot of fundraising activities to support their students. Due to the transport difficulties in his immediate area Mikey spends his week boarding at the school and goes home at weekends. Mikey thinks that mainstream schools do not give the same level of support as places like West of England College. One particular drawback of mainstream schools for Mikey is that they do not understand or acknowledge the rationale for time off for hospital appointments or mobility issues when going to and from lessons. He says that schools often misconstrue this time as truancy. In contrast, the West of England School trains its students to deal with mobility issues and is much more understanding when a student needs time off for health reasons.

Mikey has also observed how over time, the number of children with solely visual impairments admitted to West of England School have reduced, giving way to a greater number of students with multi-sensory impairments. This is reflected in the facilities at the school such as a multi-sensory studio and mobility departments. Mikey outlines one consequence of this change:
Individual case studies

“VI children are not wanting to go to VI school because of the complex needs of the children they are with. It’s all changed, levels simply don’t match – there are too many mixed levels in one class.”

One of the reasons why Mikey prefers to go to a school like West of England is that he experienced bullying at a mainstream school he attended previously. He believes that going to West of England school safeguards him from being bullied again.

Improving things

One example that Harriet thinks would help improve the situation for blind and partially sighted children in mainstream schools involved David’s mainstream school, where they brought in some facilitators to discuss blindness with the students. This involved raising their awareness about what it’s like to be blind and having an open forum for questions. Mikey points out that West of England School organises similar sessions but he believes they are not used enough to do these sorts of things:

“Mainstream and VI schools should be more integrated. VI schools go around and provide talks, but mainstream schools don’t go to VI schools.”

Harriet thinks that there is also a great need for staff and teacher training in mainstream schools so that they know what to expect if they are to include blind and partially sighted children. She has found that sometimes parents and visually impaired adults can help come up with simple and easy to do ideas for schools. In one instance, she suggested putting brightly coloured tape in the corridors of David’s school to help him navigate independently.

From Harriet’s point of view, there is a lack of awareness about the kinds of services that are available for both blind and partially sighted people at different stages in their life, and mainstream schools who might take on visually impaired children from a range of different local authorities:

“People don’t realise how much is involved and they’re put in the deep end. Small changes can make a huge difference.”

Harriet thinks that schools are often too scared to seek advice:

“Schools don’t go to the LA because they don’t want to upset the boat and appear like they are failing their children.”

Another thing that Harriet thinks would help visually impaired children in school is for them to have an individual manual which outlines their needs in a simple and straightforward manner. This is because she has found that her sons are often repeatedly asked to explain what their needs are, which they can find stressful.
**Transport issues**
Harriet and her family have had some issues with the location of their house, even though the house itself meets their needs very well. Paignton is a very hilly area which makes it difficult to use a wheelchair. Since Michael and David are visually impaired as well as non-electric wheelchair users, they often need to rely on Harriet, who is less visually impaired than them, to guide them and push them around. She cannot physically push them up the hill on their street to get to the bus stop, so they end up having to take taxis everywhere, which can be very expensive. To add to this, buses do not have wheelchair access and are not audio described in their area. Harriet laments the fact that they do not have a taxi card system in her area like the one implemented in London.

“I think it’s a bit unfair. But what with all the cuts, that’s just how it is.”

Harriet herself can only use the bus during the day because her visual impairment stops her from seeing where she is going when it is dark. Sometimes she asks bus drivers for help, but they often forget to tell her where to get off. Local buses only operate twice an hour between 9am and 11pm, and often Harriet will have hospital appointments that require her to travel before 9am, so she has to get a taxi instead. These issues with transportation have become quite costly for Harriet’s family and have resulted in them losing an element of their independence.

**The cuts**
Harriet has found the local authority to be unsympathetic to her family’s needs and she thinks this is because they have a nice house. The transport situation in Harriet’s area makes it challenging for her and her husband Michael to leave their house. Harriet also thinks that the local authority are more used to visiting older people who have her impairments, so do not have the facilities to cope with families like hers. Harriet has also witnessed some issues with staffing in her local authority. For instance in Torbay, Harriet thinks there is only one person in the local authority who is responsible for both disabled children and adults.

Harriet has also observed some of the differences between local authorities in terms of waiting times for various services. For example, in Exeter, you usually do not have to wait longer than 6-8 weeks, whereas in Torbay waiting times can go on as long as 6 months to many years. This lack of consistency troubles Harriet.

“It’s swings and roundabouts. By living in different places we’ve learnt quite a lot. If you’re going to make cuts it should be the same between local authorities. In Exeter, there’s a lot more support than in Torbay, where you have to pay for it.”
The future
In terms of her hopes, Harriet would like to do something for herself which doesn’t just involve looking after the rest of her family. She would particularly like to do a course and get involved in further learning. She also hopes that Mikey manages to secure his education at his preferred college next year:

“I want him to do his A-levels and just think about his A-levels, not worry about anything else.”

Harriet thinks that RNIB could do more to reach out to visually impaired people through local authorities. At the moment, she views RNIB as just a shop for equipment. One of the things that Harriet thinks RNIB could do as part of this reaching out is to make it clearer what they offer in terms of services.

Harriet’s final message to local politicians and other people in power is:

“Talk to VI people directly if you want to know something. Go directly to the source, the children and mothers and people who have the difficulties. There are so many people who talk for you who haven’t got a clue what life is like for us.”
Joan Barnett’s story

Background
Joan was registered blind in 2005, when she was 57. She lives with her husband of 43 years in a farm cottage on the outskirts of Guildford in Surrey. Her husband was born half a mile down the road and has lived in the village all his life. Joan moved to the village in her early twenties when she met him and has lived there ever since.

Joan and her husband are now both retired. Joan worked until her sight loss prevented her from continuing; she used to provide domestic support to older people in nearby sheltered housing and was a cake decorator. Her husband used to work on the farm they reside on and was a gardener.

Joan does not have a guide dog and prefers to use a cane. She has taught herself to read braille. She knows her way around her home and with some help, manages to undertake tasks such as cooking and for special occasions – for example her ruby wedding anniversary – returns to cake decorating.

Losing her sight
Joan has always been short sighted and suffered from cataracts; as a result her vision through her left eye is very poor and has worsened considerably over the last seven years. Although the condition has now stabilised Joan has only basic light and shape perception in her left eye and lives with the worry of losing this vision completely. Her right eye had reasonable functionality until an incident in the car in 2004 led to a detached retina:

“We drove past some road works and there was a trench they hadn’t filled in properly. We went over it with quite a wallop! Over the next few months every time I moved my eye there was a line running across my vision and then in March 2005 I woke up with no vision in my right eye at all, it was totally black.”

Joan spoke to her specialist and had surgery to try and correct the retinal damage but this was unsuccessful. Restricted by existing damage including her extreme short sightedness (which alters the shape of the eye), surgeons at the Royal Surrey Hospital were unable to save her sight:

“I went back and forth for check ups…but eventually they said there was nothing they could do and I needed to think about registering [as blind]… Of course this gives you a little bit of a turn! I did not expect to be registered blind, I thought it would just be partially sighted.”
Individual case studies

When registering, the doctor strongly recommended Joan let someone come to see her to help her cope with her sight loss. She agreed and she becomes emotional as she talks about the point at which SAVI (Surrey Association for Visual Impairment) came into her life: “It was the best piece of advice ever.”

SAVI have helped Joan physically and emotionally, she has received advice, information and support, undertaken mobility training, been offered counselling and been shown a range of aids for use around the home, all of which mean she can continue to live independently and remain active at home, despite her sight loss. She also receives an audio newsletter once a month called Lines of sight.

Coping with sight loss

Joan says she has had some positive experiences – she has begun to notice things she didn’t before such as the scent of fresh flowers in the church, she has met a new group of people through her work with SAVI and she is happy that she is able to help others through volunteering work.

But there are also real negatives: Joan no longer has enthusiasm for one of her favourite hobbies – gardening. Unable to see the garden she found she was digging up the wrong plants and became demoralised. She also really misses being able to go for a walk around the local neighbourhood without fear of falling and extreme trepidation.

Joan emphasises the impact of losing your sight when you weren’t expecting to be without it. She talks about the steep learning curve as she began to adjust in the early days.

“It is not the same as being born blind…This is not what I’ve always known. You try and carry on as much as you possibly can, doing what you’ve always done…except I can’t…I’ve found if I try to do things in a hurry without thinking about what I’m doing…you start knocking things over, you just have to do something slightly differently and you swing your hand around and over everything goes.”

Joan fell nine times in the first two years after her sight loss and now finds she is only comfortable walking on flat ground. She has had mobility training which she says is extremely helpful, but she is still anxious when she is out and about and finds it extremely tiring to be anywhere unfamiliar.

Joan continues to lead a busy life and volunteers for SAVI in a befriending role. She is also an active member of an email group set up by SAVI to provide blind and partially sighted people in the area with a network. Joan uses this network herself and describes the group as a safe channel through which she can “groan and moan or discuss the garden, or just find out who is out there.”
Joan has met or spoken to many people who have become blind or partially sighted; she finds it upsetting that some have not been able to accept their sight has gone or cope with their situation and as a result become resentful or anti-social; she does her best to reach out and befriend people she sees struggling where she can. She says:

“If you can get to grips with and accept what has happened, then your life goes along – not the same, but different…You find people say ‘you are so good’ and the inevitable ‘aren’t you brave’. They say this because when the onlooker looks, they think ‘I’d never be able to cope like that’, but you have two choices, either you accept it or you become [angry] and no one wants to know you and I’d far rather have people know me, otherwise life becomes very isolating and its isolating enough when you can’t see.”

Joan places a lot of emphasis on being able to cope and when she first lost her sight she concentrated on reaching a stage where she was coping and on finding the courage to start to use a cane.

“You’re announcing to the world that you’ve got something wrong, you’re not the same, you’re not what they term ‘normal’ anymore…now I walk around with my cane and carry it with pride, I won’t go out without it, but you have to get over that stage and I guess it’s the same for anybody with a difficulty.”

**Retirement and village life**

Joan was 57 when she lost her sight and believes things would have been much harder if she had been younger and needed to continue to work; she wonders what would have happened if she had been only 40 and needed to retrain. Joan points out that continuing with her career was not an option:

“I don’t think I could have carried on doing people’s housework. Asking them, can I come and knock all your stuff over please?!”

Joan has lived in the village since 1969 and meets people in the street who she knew before she lost her sight. She finds that living in a small area, people will ask her about her sight loss and she is able to have good conversations with them about her situation. In her experience most people when they see her white cane react with kindness and she has never experienced discrimination.

Still active in village life, Joan remains in contact with people she used to work for and visits some of them occasionally for a cup of tea. Joan and her husband also hold an open garden event once a year with some of their neighbours to raise money for charity. Since losing her sight Joan supports SAVI through these events.
Support and services
After she lost her sight Joan started to receive Incapacity Benefit and continued to receive this until 2007 when she reached 60 and went onto a pension. She also receives the higher rate Disability Living Allowance. She found the process quite straightforward but does recall being sent many letters indicating her case had been passed to different advisors and having to fill in multiple forms, which she requires someone to do for her. She would have liked to manage these formalities over the phone so she could do it herself and counts herself lucky to have people who can help her with this.

Joan does not tend to have problems accessing local services and has found most public and private sector organisations easy to deal with. She would like to be able to receive more information over the phone. She has also had to request written information be sent to her in large print multiple times, but does not see this as a reason to complain. She has not experienced any barriers when she has requested information in alternative formats from the local authority, doctors, pharmacy or banks and has had a positive experience at her local theatre.

Joan has written to the local authority about the poor quality of the pavements in Guildford but doesn’t remember their response. She also took part in a formal consultation where she fed back on this issue. She received a reply from the authority who said the matter “will be addressed in due course” – she does see improvements to the town centre happening slowly.

Joan thinks appropriate support for blind and partially sighted people comes from a two way exchange of information; she thinks the onus should be on the person with sight loss to state what they need, require or want and to ask for help. Joan thinks this is as good way of ensuring individual needs are understood and of minimising unnecessary effort or cost. Joan praises the staff at the SAVI resource centre because of the simplicity of their service (direct sales line and goods delivered directly to your home) and their expertise and integrity – “they won’t sell you anything unless you really need it”.

Funding cuts
Joan recalls her fear when public sector funding cuts were first announced, that SAVI and its resource centre would be forced to close as the local authority made cuts to local budgets. Indeed the charity has undergone a significant restructure, losing a number of staff and reducing the working hours of others.

The braille class has also lost its venue and some of its teachers and Joan fears the loss of the talking book service – she is aware of some local areas where the council have stopped paying for this and thinks this is unfair for those who cannot afford to purchase talking books for themselves.
“I don’t know what we would do if the council couldn’t afford to give [SAVI] anything...what would happen to people newly registered, I don’t know. I don’t see how the local council could provide a person, you’d have to have someone in every area...but if you closed down that facility altogether, would we be back to square one and there’d be nobody to help us? That doesn’t bear thinking about.”

Joan praises the services available in Surrey and has spoken to friends from other counties whose experience has been less positive. She has had moral support, practical support, support with benefits applications and mobility support, most of this through SAVI.

Joan understands that public services are struggling for money – she wonders about how public money is allocated and how authorities might design services and solutions that meet the needs of multiple groups, acknowledging that this must be a difficult task.

She has written to her local MP a number of times as cuts to services have been announced and she has supported RNIB campaigns. She has received a response from her local MP and feels her understanding of the issues facing blind and partially sighted people is good, but notes that she tends to get stock responses from central government departments.

Joan wonders if the national review of Disability Living Allowance will affect her, she thinks not as she is close to 65.

**Hopes for the future**

Joan feels she is lucky to have a supportive and helpful husband and wonders what life would be like if they could no longer cope alone and needed help at home. She hopes they will be able to continue to live independently for a long time.

Joan’s wish is for an aid that supports blind and partially sighted people to be more fully mobile; something that helps people get around without walking into obstacles or tripping. She highlights the number of younger people that would also benefit from this as for example, members of the armed forces injured in service, are required to learn to cope being blind or partially sighted. Joan feels most people who are blind or partially sighted just want life to be accessible to them so they are able to participate.

Finally, she also hopes that over time people will understand that people who are blind or partially sighted do not want sighted people to do things for them without asking, to override them, patronise them or prevent them from trying things for themselves. Remaining independent is extremely important to people with sight loss.