# A Wales without barriers for people with sight loss



Golwg gwahanol See differently

### RNIB Cymru manifesto for the 2021 Senedd Cymru | Welsh Parliament elections



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#### Summary of our manifesto asks

- 1. End avoidable sight loss
- 2. Break down the environmental barriers faced by blind and partially sighted people
- 3. Tackle the postcode lottery of vision rehabilitation services
- 4. Embed accessible information practices into the NHS and wider public services
- 5. Lead the way in UK equality policy by reforming the way the public sector engages people with sight loss, and other disabled people

The issues discussed in this manifesto affect real people and our calls will make a real difference to their lives.



#### About RNIB Cymru

RNIB Cymru is Wales' largest sight loss charity. We provide support, advice and information to the 121,000 people living with sight loss across Wales, as well as their families, friends and carers. We campaign for improvements to services and raise awareness of the issues facing blind and partially sighted people. We support and empower people affected by sight loss to improve their lives and challenge inequalities.

#### What we do

- Support blind and partially sighted children and adults throughout Wales to live fully and independently. We help create more opportunities for them to live the life they want to lead.
- Support people newly diagnosed with sight loss to find their lives again.
- Provide advice on welfare benefits and on gaining and retaining employment, the right training and equipment.
- Transcribe books and other materials into audio, braille and large print.
- Work to prevent avoidable sight loss.

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### Introduction

The sixth term of the Welsh Parliament | Senedd Cymru will convene against the backdrop of the global coronavirus pandemic. The task ahead of this Senedd will be to build Wales back from the unprecedented events that preceded it. As we look to the future, the key question for the next Welsh Government will be:

How can we create a new normal that works for everybody?

COVID-19 has exacerbated the problems blind and partially sighted people face, but it has also brought to the fore some of the best aspects of our society. That generosity of spirit can spur the creation of a more equal and inclusive society for people with sight loss and other disabled people.

The true extent of the consequences of the pandemic have yet to fully become clear. What is clear, is that this once in a generation event will have a significant impact on public expenditure. It is therefore essential that we use our resources as efficiently and cost-effectively as possible.

Around 121,000 people live with sight loss in Wales today and every day 13 more people begin to lose their sight. [1] Annual costs to the Welsh economy associated with sight loss, both direct and indirect, amount to  $\pm$ 151 million and  $\pm$ 263 million respectively. [2] This includes costs due to lower employment rates and unpaid care provision. It is estimated that the associated reduction in wellbeing and health due to living with sight loss totals  $\pm$ 1 billion every year in Wales. [3]

This manifesto sets out the key steps needed to make Wales a more inclusive society: a society without barriers which empowers people with sight loss to live independently; where health services prevent sight loss that's avoidable and timely social care support is provided when it isn't; where blind and partially sighted people's needs are accounted for and their voice is valued in decision making processes.

The steps are straightforward and practical, the costs relatively modest, but the gains for society would be far-reaching and profound. With an ageing population and the number of people with sight loss in Wales expected to increase by more than 20 per cent in the next 10 years, the cost of inaction, both human and economic, will be severe.

### **Our policy calls**

To help us achieve a Wales where there are no barriers for people with sight loss, RNIB Cymru is calling for the next Welsh Government to:

### 1. End avoidable sight loss

Accelerate the transformation of eye care services, taking the lead on developing a national workforce plan and ensuring health boards have a clear improvement plan to achieve targets set out in the Eye Care Measures.

In eye clinics across Wales, far too many "at risk" patients are waiting too long for their appointments. Essential appointments are being delayed or cancelled, causing some patients to suffer irreversible sight loss which could have been avoided with timely treatment.

"I was definitely on the verge of a breakdown. It's just quite a traumatic experience to be mid-treatment and then have something postponed, by not even a week or so, but it could be a couple of months. And when your eyesight hangs in the balance you think that 'is that going to be the appointment that made me keep my sight or made me lose it?"

In 2018, the Welsh Government introduced Eye Care Measures for NHS Outpatients in Ophthalmology which prioritises all new and follow up patients based on their clinical need i.e. priority and urgency of care required by each patient. Priority is the risk of harm associated with the patient's eye condition if the target review date is missed. Urgency is how soon that patient should be seen given the current state and/or risk of progression of the condition. Patients are given an individualised target date for when they should be seen.

The Welsh Government has published monthly Health Board data on ophthalmology outpatients assessed as being at risk of irreversible harm or significant adverse outcome should their target date be missed (Health Risk Factor R1) since June 2019. The data records patients that were seen within their target date, or within the time period 25 per cent beyond their target date.

The publication of this data has been a major step forward in making health boards more accountable for the delivery of eye care services. However, the outbreak of the coronavirus pandemic has meant that publication of this data has been suspended from February until December 2020. The publication of data on Health Risk Factors R2 (risk of reversible harm or adverse outcome if target date is missed) and R3 (no risk of significant harm or adverse outcome) is also necessary to get a true picture.

### Our key concerns:

- In July 2019, the Senedd's Public Accounts Committee outlined serious concerns about health boards' lack of progress at reducing waiting times for outpatient follow up appointments and provided a series of recommendations to address the backlog. [4]
- Yet evidence shows that progress has been slow. As at May 2020, more than 40 per cent of R1 patients (those at the highest risk of irreversible harm) are waiting beyond their clinically safe target date. [5]
- As at December 2019, 74 per cent of patients on the waiting list had been allocated an R1 HRF. It is unclear how patient care will be prioritised when almost three-quarters of outpatients are in the same, highest, category. This raises questions about priorities within the R1 category, as well as among R2 and R3 level patients.
- The overall size of the waiting list for eye care continues to be substantial

   and represents 5 per cent of the entire Welsh population.
- Of course, the coronavirus crisis will have affected eye care services in a similar way to other clinical areas, but, as publication of the Eye Care Measure data has been suspended since February 2020, the full extent of the impact on waiting lists is unclear and so is the irreversible sight loss experienced by people in Wales which could have been avoided with timely treatment.

The introduction of the Eye Care Measures has increased awareness of poor waiting list management and associated risks. It has also highlighted the magnitude of the shortfall in capacity, something that the next Welsh Government cannot ignore.

### Solutions and priority actions

The national strategy for health and social care: A Healthier Wales [6], provides the strongest message to date for the need to improve integration and partnership in order to use resources efficiently as possible. It focuses on the philosophies of prudent healthcare, prevention and early intervention as means by which to make the best use of finite resources to reduce the impact of poor health.

Our calls align with both A Healthier Wales and the recommendations of the Public Accounts Committee's inquiry. They set out the key steps needed to transform eye care services and to put an end to avoidable sight loss.

A key factor in delivering the Government's vision for eye care in Wales is the need to develop a pan-Wales eye care workforce plan that is clearly linked to capacity and demand data. Some individual health boards are demonstrating good examples of workforce planning on a local scale and regionally. But the pace of change must increase if we are to achieve service redesign and deliver additional capacity to meet current and future demand within the eye care system right across Wales. This work must be overseen by government at a national level. Detailed improvement plans need to be put in place by each health board to redesign services so people receive the right support, in the right place at the right time. Business as usual is no longer an option and pockets of good practice won't address the all-Wales waiting list problem – health boards and Welsh Government must make transforming eye care services with ambition and pace a priority.

Another critical factor in the successful implementation of the Eye Care Measures is the rapid development and implementation of a pan-Wales Electronic Patient Record (EPR). Last year, research showed how poor administrative and patient management systems are negatively impacting capacity. Funding has finally been announced for a digital solution but timescales and consistent implementation of this is essential for delivery.

There needs to be better integration of community optometry and hospital eye services. The move to primary care is slow and inconsistent. There are great examples of best practise, but this needs speed and consistency across Wales. For example, more treatment is now being delivered through **Ophthalmic Diagnostic Treatment** Centres (ODTCs) in the community, but there is still limited understanding and data on the impact ODTCs are having on sustainability. Capital funding also needs to be in place to resource ODTCs. To date there has been a reluctance amongst some consultants to embrace service redesign and new models in

primary and secondary care e.g. skilling up other professionals to undertake some elements of clinical care.

#### Key calls:

We want the next Welsh Government to prioritise ending needless sight loss in Wales by:

- Developing and overseeing a national workforce plan that is clearly linked to capacity and demand data.
- Prioritising the transformation of eye care services by ensuring all health boards have a clear and expediated improvement plan to achieve the targets set in the Eye Care Measures.
- Driving forward the development and implementation of the EPR and ensuring that it is routinely and consistently used across Wales.
- Accelerating the move to community-based provision in the eye care pathways to release consultant capacity.
- Publishing the data on patients allocated R2 and R3 for greater transparency.

## 2. Break down the environmental barriers faced by blind and partially sighted people

Everyone should be able to live, travel and enjoy the same opportunities.

The ability to make independent journeys safely and confidently is a vital part of living an active, healthy and fulfilling life expected by fully sighted people. Blind and partially sighted people rely on walking and public transport to maintain their independence and to access key services like healthcare, to travel to work and to socialise. Despite this, blind and partially sighted people tell us that barriers to journey-making, including inaccessible streets and transport, are one of the biggest challenges they face. [7] Four in 10 people are unable to make all the journeys they want or need to. [8]

These barriers are longstanding and deep-rooted, but the coronavirus pandemic has exacerbated many preexisting issues and made independent mobility even more difficult. At the height of the pandemic the Welsh Government allocated funding to make significant changes to street layouts and public spaces in towns and cities across Wales as part of the longterm recovery strategy. This event has afforded the opportunity to build on the reduction in the use of motorised traffic and encourage a lasting shift towards more sustainable travel.

We fully support the Welsh Government's aim to encourage this shift, but street layouts can cause difficulties at the best of times for blind and partially sighted people who often use learned routes using familiar landmarks and layouts to orientate themselves. When environments are altered and new schemes introduced without consideration of the potential negative impacts these might have on disabled people, this can mean that local spaces become inaccessible, effectively excluding them from society.

"Things are changing from day to day so you're not quite sure if you go to a different area of town what will be there the next day... Usually I'm quite confident but I've lost all that confidence."

From the perspective of people with sight loss, accessible street design means detectable kerbs and walkway edges, physical separation between footways and cycle lanes, signal controlled pedestrian crossings, tactile paving, detectable colour contrasted barriers and dedicated footways free from obstructions.

"I use a long cane to help find my way around obstacles and have had my cane hit by cyclists riding on footpaths and in pedestrian zones."

It is crucial that public spaces are designed with disabled people in mind. The impact new designs might have on the disabled members of our society must be properly explored and understood before they are implemented. Failing to do so will further exacerbate existing feelings of loneliness, isolation and exclusion experienced by disabled people.

### Our key concerns

RNIB conducted a Travel Survey in May 2020 to find out more about the experiences of blind and partially sighted people when making journeys. This research found:

- 80 per cent of respondents said that bicycles affected their ability to make walking journeys.
- 97 per cent of respondents said that signal-controlled pedestrian crossings were important or very important.
- 86 per cent of respondents said that it is important or very important to them to be able to make walking journeys independently, without a sighted guide.
- 90 per cent of people agreed or strongly agreed that it was important to them to have the option to travel by bus.

RNIB research into the impact of coronavirus from April and May 2020 found that two thirds (66 per cent) of blind and partially sighted people feel less independent, compared to before lockdown. [9] We are being consistently told by blind and partially sighted people that the changes to public spaces make them feel that they are not able to leave their homes. Reported loss of confidence, independence and feelings of isolation are worryingly high.

### The most commonly cited barriers include:

- Increased street clutter and physical obstacles like signs, advertising boards, outdoor seating areas, and inappropriate barriers.
- Shared use areas which force blind and partially sighted pedestrians to interact with approaching bikes, e-scooters and other vehicles that they will often be unable to hear or see, increasing the risk of collision.
- Inaccessible public transport infrastructure, such as bus stop bypasses which force pedestrians to cross cycleways in order to access bus stops. Lack of audio announcements on vehicles and at stations.
- Visual cues used to mark out new layouts and enforce social distancing like painted lines and floor markers which are not accessible for blind and partially sighted people and make independent navigation extremely challenging.
- Difficulties accessing accessible information about changes to local public spaces and for planning journeys.
- Lack of meaningful consultation with local disabled people, often leading to the introduction of changes which make public spaces inaccessible.
- Where public consultations do take place, blind and partially sighted people are often excluded due to a lack of accessible information, communication and engagement.

### Solutions and priority actions

All public authorities have a duty under the Equality Act 2010 and the Public Sector Equality Duty to ensure they meet the needs of disabled people, and actively involve disabled people in the design and delivery of their services such as the provision or improvement of pedestrian routes and cycle routes.

A public realm that is inclusive by design and removes the barriers faced by disabled people facilitates the creation of a more equal Wales, one of the seven wellbeing goals set out in the Well-being of Future Generations (Wales) Act 2015.

Similarly, the Active Travel (Wales) Act 2013 requires Welsh Ministers and local authorities, in the performance of functions under the Highways Act 1980, to take reasonable steps to enhance the provision made for walkers and cyclists. The Act explicitly includes disabled people who use aids to mobility – such as guide dogs and canes – under the definition of "walkers and cyclists". The active travel design guidance document reiterates the need for routes to be inclusive by design.



### Key calls:

To truly build back better and create an environment that is inclusive and accessible for everyone, the next Welsh Government must:

- Protect our pavements by immediately putting an end to any new shared use paths, so that people with sight loss can make journeys safely and independently.
- Where shared use paths and areas are already installed, these should be reassessed, and dedicated footway space reinstated to re-enable a safe, inclusive and positive walking experience for blind and partially sighted people.
- Ensure that transport operators, cycle and e-scooter rental schemes take appropriate steps to ensure pedestrians are kept safe.
- Ensure that any new cycling infrastructure is physically separated from pavements and walkways. Where a cycle lane must be crossed (i.e. to cross a road or reach a bus stop) pedestrian-controlled crossings must be installed.

- Ensure all applications and online travel information, booking and payment processes are fully accessible. This includes compatibility with screen reader and magnification technology and other accessibility requirements.
- Hold local authorities to account for undertaking robust Equality Impact Assessments when making any changes to the built environment. This includes proactively and meaningfully engaging with people who share protected characteristics before changes are implemented and making alterations to plans in order to mitigate against any potential adverse equality impacts.
- Create a system of monitoring of local authorities around Wales to ensure guidance is being properly adhered to and clarify the consequences for non-compliance.
- Take action to ensure local authorities which have not properly adhered to guidance correct this as soon as possible.
- Require planners, engineers and architects to put accessibility for disabled people and the thorough understanding of inclusive design at the heart of their own personal development programme and a central pillar of their future built environment work.







### **3. Tackle the postcode lottery of vision rehabilitation services**

Every person diagnosed with sight loss, wherever they live, should be able to access the support needed to empower them to live safely and to take an active part in society.

Sight loss can be devastating and overwhelming. But, people can, and do, adjust to loss of sight and continue leading independent and fulfilling lives. The key to such adjustment is timely, effective rehabilitation.

In recent years, there has been a steady decline in vision rehabilitation services in Wales. As a result, many blind and partially sighted people are failing to receive the vision rehabilitation support that they need when they need it.

Vision rehabilitation is structured support, delivered by a Rehabilitation Officer for the Vision Impaired (ROVI), to help people adapt to sight loss and enable people to live safely, independently and contribute to society as active citizens.

It is one-to-one training in mobility (getting out and about safely and independently), daily living (the essential skills of managing medication, food and drink preparation, dealing with laundry, organising household tasks), and communication, (managing mail, using a phone, and sign posting into access technology). ROVIs also use their expertise to assess a home environment to identify potential hazards, and they enable access to adaptations, equipment and aids that someone with recent sight loss would otherwise have no knowledge of.

It is critically important that this specialist support reaches people quickly, as it focuses on achieving independence and promoting wellbeing, and links those new to sight loss into local support agencies and national support organisations that can offer many other resources to support them.

Research by Cardiff University shows a significantly greater improvement in visual function for participants that had received visual rehabilitation, compared to those on waiting lists. Qualitative feedback from participants of the same study shows 89% found the intervention helpful or extremely helpful. [10]

"Having no sight at all, it was about changing my mindset from "can't do" to finding a different way to do things. My ROVI has taught me new skills that enable me to feel safe in my own home, as well as remain independent."

Timely provision of vision rehabilitation services also has significant economic benefits. Early preventative strategies help to ensure the costs of associated issues do not rise. For example, in Wales, it is estimated that 15,300 people with sight loss aged over 65 experience a fall per year. Of these falls, 7,210 are directly attributable to sight loss. [11] In 2011, falls in Wales were estimated to directly cost the NHS £67 million per year [12] and 2013 research put the cost of falls in Wales related to vision alone at an estimated £25 million annually. [13] With the number of people with sight loss on the rise, this figure will have increased dramatically over the last 7 years.

Independent research by the Office for Public Management showed that vision rehabilitation services not only contribute to meeting a set of needs experienced by people with vision impairment, but the financial value resulting from these services - in the form of costs avoided, reduced or deferred – significantly outweigh the financial costs of delivering them for the health and social care sector. The report states that this equates to an average saving of £4,487 per referral, more than three times the cost of the service. [14]

#### Our key concerns

This support has never been more necessary, given the unprecedented levels of change we are experiencing as a society. The ever-changing landscape of towns and cities in response to coronavirus means access to timely rehabilitation services is vital to enable people with sight loss to live safely and contribute to their communities as active citizens.

However, evidence from 2018 shows that there is a postcode lottery of rehabilitation services across Wales, negatively affecting blind and partially sighted people. [15] The situation has not improved in recent years.

- Only eight local authorities in Wales meet the Association of Directors of Social Services (ADSS Cymru) and Social Services Improvement Agency's set minimum standards of 1 ROVI for 70,000 of the population.
- Where best practice is applied, people are experiencing an efficient service, but in some areas of Wales people are waiting upwards of 12 months to see a ROVI. This postcode lottery of provision is not acceptable.
- Where the minimum standard of 1 ROVI per 70,000 is met, people are seen sooner.
- There are currently 31.7 full time equivalent (FTE) ROVIs and 7.7 ROVI assistants practicing in Wales. Good practice guidelines suggest that there should be 44.9 FTE ROVIs. We expect six ROVIs to retire over the next five years.

There is already a substantial existing backlog of people in Wales waiting for vision rehabilitation assessment and services. The reasons for this are complex, but include:

- Vision rehabilitation not being seen as a high priority by local authorities.
- A shortage of specialist ROVIs and this number is in steady decline.
- Local authorities being increasingly unwilling to commit funding for training for the two year foundation degree course required to become a qualified ROVI.

- There are no available courses in Welsh Universities – the Universities and Colleges Admissions Service (UCAS) currently lists such a course at only one UK institution for the academic year 2020/21.
- The process of issuing Certificates of Visual Impairment (CVI) can be slow, impacting on the offer of rehabilitation support and registration.
- Individuals being largely unaware of their rights, and the nature of support that should be available.
- Some local authorities suspending rehabilitation services in response to COVID-19, and ROVIs being redeployed away from rehabilitation duties in response to frontline pressures, which will have undoubtedly increased waiting times. Where assessments do take place, they are being carried out over the telephone and needs are often identified that are unable to be met until face-to-face service is resumed.

With the number of blind and partially sighted people expected to increase by 20 per cent by 2030, this situation will worsen dramatically if no action is taken. It is essential that local authorities and Welsh Government invest in this workforce now.

### Solutions and priority actions:

The Social Services and Well-being (Wales) Act 2014, along with the fundamental principles and code of practice that underpin it, places a clear emphasis on prevention and early intervention to minimise the escalation of critical need, including through vision rehabilitation support for blind and partially sighted people.[16]

A Healthier Wales set out Welsh Government's vision for a future in which everyone in Wales is able to remain active and independent, in their own homes, for as long as possible. [17]

To make this vision a reality, long term workforce planning for the specialist ROVI workforce must be a priority. Expanding the Degree Apprenticeship scheme, from 2021, to include the training of ROVIs would be a crucial step to address the backlog and ensure future needs are met.



Local authorities must take three clear steps to ensure that they are meeting the needs of blind and partially sighted people – see, plan and provide. This process outlines the necessary steps to ensure timely access to rehabilitation. [18]

- See: everyone with a vision impairment must receive a specialist face to face assessment with a ROVI.
- 2. Plan: everyone must have a plan in place, identifying the outcome of the assessment. We recommend that local authorities adopt the 10 nationally agreed Principles of Good Practice in Vision Rehabilitation<sup>18</sup> which notes that all blind and partially sighted people should be seen and receive a specialist assessment from someone with appropriate skills, knowledge, training and qualifications, within 28 days of initial contact with the local authority.
- **3.** Provide: any agreed vision rehabilitation support must start within 12 weeks of the person's initial contact with the local authority.



#### Key calls:

### The next Welsh Government must:

- Hold local authorities accountable for the delivery of specialist vision rehabilitation services.
- Take an all-Wales approach to planning and investment for the future of this specialist workforce.
- Add vision rehabilitation to the list of qualifications eligible for the apprenticeship levy.
- Ensure local authorities develop and implement a referral pathway between low vision service Wales and adult social care. This will aid in early identification of people with sight loss and improve vision rehabilitation interventions, reducing the need for further long term care and support as vision and mental health deteriorates.
- Oversee an all-Wales campaign to raise awareness of the role of a ROVI amongst health and social care professionals and to raise public awareness of the role as a prospective career path.
- Make clear that preventative services, including vision rehabilitation, must be prioritised in parallel with needs assessed services, rather than consecutively, once coronavirus restrictions end.

## 4. Embed accessible information practices into the NHS and wider public services

People with sight loss should receive information in a format that works for them, by right and without fight.

People with sight loss in Wales are routinely not provided with information in appropriate formats or communicated with in a way that is appropriate to their needs. This means they cannot access information in the same way as fully sighted people and are unable to make informed decisions about their own healthcare.

The All Wales Standards for Accessible Communication and Information for People with Sensory Loss<sup>19</sup> were introduced by the Welsh Government in 2013. They set out the level of service delivery that people with sensory loss [19] should expect to be met with when they need healthcare.

Since November 2017, GP surgeries in Wales have had the functionality to identify and record the information and communication needs of their patients with sensory loss. Further functionality is being developed to enable referrals but to date very little progress has been made and the Standards have not led to demonstrable change for blind and partially sighted people in Wales.

"I am continually asked, despite being a patient of at least 12 years, to read and sign things I can't see." "Despite requesting audio they still communicate appointments by letter and so I have to ask someone to read it to me."

### Our key concerns

Ineffective communication with patients with sensory loss is a patient safety issue. Patients are at risk of not receiving the right support to enable them to engage in and fully understand consultations with healthcare professionals.

Health providers and other public services must meet their legal obligations under the Equality Act 2010, to make reasonable adjustments for those with a disability, so that they are not placed at unnecessary risk and experience the same levels of independence and privacy expected by everyone else. The communication needs of individuals must be considered and information provided in their preferred accessible format by right and without fight.

The COVID-19 pandemic has highlighted the importance of making accessible information standard practice. One in five people aged 75 and over have sight loss and many blind and partially sighted people have comorbidities, making them a high-risk group.

It is essential therefore that information about changes in policy, procedures or advice is produced in a range of accessible formats, giving it the best chance of reaching those at high risk from the virus. Now, more than ever, blind and partially sighted people must be able to access vital information in a format that they are able to read so they can keep themselves safe.

For example, the shielding letters, which were sent to the 130,000 people in Wales at highest risk of severe illness from COVID-19, were not sent out in accessible formats for people with sight loss, despite containing potentially lifesaving information.

Digital communications from official sources were – and in some cases still are – not fully accessible, particularly for screen reader users.

While most organisations responded promptly, the fact that third sector organisations had to be reactive and bring this to their attention, highlights the reality that accessible information is not standard practice for many public sector organisations.

"I am a very independent person but feel disempowered by the lack of accessible information that has been sent out regarding Covid-19. It feels like people with sight loss are being left out. I feel like we've been treated as if we don't exist."

The Senedd's Equality, Local Government and Communities Committee's inquiry into COVID-19 found deficiencies in the provision of information and guidance in accessible formats during the pandemic. It called for the appointment of an accessibility lead within the Welsh Government to oversee the production of all key public health and other information in accessible formats. [20] RNIB research conducted in April and May 2020 supports the Committee's findings. It shows that one in four (26 per cent of) respondents had struggled to get written information in a format that they could read and 17 per cent said that they had struggled to access online information.[21]

### Solutions and priority actions

The NHS and other public services should ensure that people with sight loss are routinely asked about their communication needs. These should be systematically recorded, and all information provided in their preferred accessible format.

This should include receiving letters, test results and appointment reminders in an accessible format by right and without fight, enabling the same levels of independence and privacy expected by everyone else.

Key staff within health boards and other public organisations should receive training to better understand the communication needs of blind and partially sighted people and how to meet their communication preferences.

Systems should be in place in primary and secondary care to record patients' communication preferences and to support staff to proactively deliver on patients' stated preferences. The Welsh Government should appoint a national accessibility lead to embed accessible information practice into all public services in Wales.

#### Key calls:

The next Welsh Government must:

- Embed accessible information practices into the NHS and wider public services so that people with sight loss receive information in a format that works for them.
- Require health boards to report on progress in implementing the Standards and reports must be made available for public scrutiny.
- Clarify the consequences for health boards who fail to comply to the standards.
- Add audio and alt. text to all videos from public sector organisations to ensure that they are accessible to screen reader users.
- Adopt a zero-tolerance approach to inaccessible social media posts from any public sector organisation, deleting and reposting any that are subsequently found to be inaccessible.
- Coordinate a national campaign to ensure blind and partially sighted people are more aware of their rights.

- Create a documented step in the development of all public sector communications, signed off by a named individual, that Equality Act sensory impairment accessibility needs have been met.
- Appoint a national lead for accessible information, responsible for ensuring that accessibility is embedded into public sector communications and ensuring compliance.
- Coordinate national level training for all relevant staff.



### 5. Lead the way in UK equality policy by reforming the way the public sector engages people with sight loss and other disabled people

Disabled people must be given a stronger voice in decision making.

All too often, blind and partially sighted people encounter barriers to inclusion because the world around them was not designed with them in mind. Social, environmental and attitudinal barriers mean that disabled people are often unable to participate equally and have fewer opportunities than non-disabled people.

The Social Model of Disability explains that most of the problems faced by disabled people are caused by the way society is organised. For example, there is no reason why a person with sight loss would not be able to make journeys independently if public transport and the built environment was designed in a completely inclusive way. Similarly, if all information was made available in a range of accessible formats, like audio and braille, then there would be no reason why a person with sight loss would be unable to access this information.

The Social Model is an alternate way of understanding access issues and social exclusion and sees the problem as a society that disables people and does not treat all of its members as equals.

Governments at all levels in Wales have committed to the advancement of the Social Model of Disability and, whilst progress has been made, we continue to see examples of disabling and exclusionary barriers. If disabled people are to be able to participate equally in mainstream society, then the way society is organised must be changed and disabled people must be given a stronger voice in decision making.

#### Our key concerns

All public authorities have a duty under the Equality Act 2010 and the Public Sector Equality Duty (PSED) to ensure they meet the needs of disabled people, and actively involve disabled people in the design and delivery of their services.

When implementing the PSED, public authorities should undertake a thorough and robust equality impact assessment which uncovers the potential negative impact of proposed policies in time to make changes to them.

While legislation and guidance are clear, it is our experience that this often does not translate to a material change of practice on the ground. In some cases, impact assessments are not carried out at all, or are superficial. Sometimes impact assessments appear to have been written in order to justify a decision, rather than to truly analyse its impact.

It is our experience that Equality Impact Assessments (EIA) can fail to identify risk, and so do not include mitigating measures. Equally, where risk is correctly identified, the proposed mitigations are often ambiguous or insufficient. The outcome, in the delivery of the scheme or policy, such as a change to a familiar location can often make it unexpectedly dangerous for people with sight loss.

We hear time and time again from our members of instances where changes have been introduced which create unintentional barriers. Common examples include suddenly painting white lines on pavements to indicate a shared area for pedestrians and cyclists or tabling junctions and removing kerbs to slow traffic in the interests of safety. At first glance, such measures would seem to create a better environment for people with sight loss, but a thorough EIA, which engaged with them and took their views into account, would show that both situations have "inadvertently" put them at risk.

Where public consultations do take place, blind and partially sighted people often feel excluded due to a lack of accessible information and communication. Engagement and consultation with disabled people should not be considered a tick box exercise which fulfils an obligation. Rather, as a critical step which enables policy makers to truly understand their lived experiences and an opportunity to co-design workable and innovative solutions for the betterment of everyone in society.

The Well-being of Future Generations (Wales) Act 2015 puts in place a "sustainable development principle" which tells organisations how to go about working towards achieving the well-being goals and meeting their duties under the Act. "Involvement", defined as 'the importance of involving people with an interest in achieving the well-being goals, and ensuring that those people reflect the diversity of the area which the body serves', is identified as a key way of working for public bodies under the principle. [22]

The Future Generations Commissioner's most recent assessment of progress in achieving A More Equal Wales, states that while there are signs of increasing civic participation and many public bodies are discussing "involvement" and "equality", these don't necessarily go beyond broad statements.

The Commissioner calls for more targeted approaches to working with specific groups who face disadvantage to truly put in practice the 'involvement' way of working. [23]

### Solutions and priority actions

Effective policy making relies on enabling those affected by a policy to participate in its development in an authentic way. To do this, policy makers must proactively engage diverse citizens at the earliest stages of crafting new policies in order to fully understand and appreciate their lived experiences.

Consultations should be designed to be accessible and facilitating meaningful conversations with as many people with experience of the system as possible, particularly people with protected characteristics.

By enabling meaningful participation from people with a variety of experiences and levels of involvement with a policy – from experts and decision makers, through to service delivery professionals and the "enduser" and their families - it is far more likely that innovative and workable solutions will be identified. It also affords greater opportunities for testing and increases likelihood that any negative impacts will be resolved prior to implementation. Getting it right first time has positive cost implications and reduces waste and duplication.

The end result is policies that are more responsive to the needs and experiences of diverse groups and therefore far more likely to achieve the intended outcomes. This approach also demonstrates the public sector's responsiveness, transparency and inclusivity.

There is a growing community of practice in public sector organisations around the world that are utilising codesign or co-production methodologies to improve how public policy is developed and implemented. Working in collaboration with policy professionals, designers bring the human element into the policy process and to create stronger feedback loops between policy and its impact on the ground.

Governments should strive to coproduce all relevant policies and services with disabled people in a holistic, rather than tokenistic way. As "experts by experience," disabled people are in the best position to be able to inform and guide governments and local authorities in order to ensure policies and services are workable and accessible for them.

#### Key calls

To create a fairer, more equal society which truly advances the social model of disability the next Welsh Government should:

- Commit to reform the way the public sector engages with disabled people, proactively involving them in the design of public services from the earliest stages to identify and remove barriers.
- Review the practice and training for public sector staff in developing EIAs to take into consideration the impact of policy changes on disabled people.
- Ensure all future public consultations and engagement activity are fully accessible to blind and partially sighted people by producing information in a range of accessible formats.
- Foster a culture of innovation in the public sector, exploring possibilities to adopt the principles of co-design and coproduction with disabled people to improve local services.

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