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The cost of sight loss

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The cost of sight loss.

The Equality and Human Rights Commission report, *Is Wales Fairer?* (1), notes that the disparity between disabled people and non-disabled people is increasing in many areas of life in Wales. Poorer educational attainment and low levels of employment are reported and this is a trend that goes through life because the inability to find and retain work creates a greater dependency on the lifeline of disability benefits to meet the basic needs of daily existence. The tax and welfare reforms imposed by central Government have 'lowered many disabled people's living standards even further, and they are more likely to be living in poverty.' The report also suggests that 'disabled people are being denied their right to independent living and in many cases are not experiencing the progress seen for other groups.'

Are disabled people's finances really being hit so hard? Evidently. A growing body of research is supporting the view that disabled people are more likely to experience lower standards of living than non-disabled people due to the impact of the additional costs of support to meet their needs. Scope has published *The Disability Price Tag 2019* (2) stating that 'on average, a disabled person's extra costs are equivalent to almost half of their income (excluding that spent on housing).' This is echoed in the Thomas Pocklington Trust's research findings on the additional costs of sight loss (3): 'the budget for a severely sight impaired person of pension age, living alone, is 73% more than for a single pension age person without a visual impairment: £135.61 a week extra on top of a minimum income standard of £185.15 a week (not including housing costs).'

The Scope report suggests that the drivers of these extra costs are threefold: the need for expensive **specialist goods and services** that non-disabled people do not require; the **greater**

use of mainstream goods and services such as fuel; and the **higher cost** of mainstream services such as insurance. The TPT research findings state that half of the extra cost is for regular support in the home such as help with cleaning and dealing with paperwork, and most of the remainder is to pay for transport, social and leisure costs. 'In order to participate socially, severely sight impaired people of pension age can incur a higher cost for some specialized activities, and feel it is important to recognise the extra help of a companion by paying for meals, drinks and for part of their holiday costs'. Social participation is crucial to avoid social isolation and loneliness for all of us. It also offers up opportunities to volunteer and find work. While most of us take social engagement for granted, for disabled people it has an extra cost.

Barriers to digital inclusion.

Digital media and services are something which most people enjoy. We expect to find up-to-the-minute information on transport, news, opening times, and so on available through our phones and tablets. Many disabled people, however, experience barriers to participating freely because devices and software may not be accessible to someone who, for example, relies on synthetic speech to navigate applications. For many people with sight loss, there are additional costs of purchasing equipment and software that aid access. Swansea University looked at the usage of digital media by people with sensory impairment (6) and found there were financial barriers to digital inclusion. The researchers found costs of £500 upwards for products to support them - over and above the cost of the computer and software package. These additional costs may be applied to different devices as well. However, these adaptations are necessary to gain equal access to the social media, news, retail and employment opportunities that non-disabled people take for granted.

So, where is the money coming from?

TPT looked at matching income with needs (4) and found that the barriers to employment – employment that would help to meet material, social and disability-related needs - result in a greater dependency on state benefits. These benefits are vital 'but they can be difficult to access, stressful to claim and fall short of meeting the cost of a minimum living standard.' Importantly, the report concludes that 'the risk of and burden of vision loss are experienced disproportionately by those who are already socially disadvantaged'. Also, when examining the relationship between wealth, social status and developing visual impairment (5) the risk of at least moderate sight loss was higher for those in the two poorest wealth categories and for those in the two lowest social status categories. In other words, we must consider the negative impact arising from social and economic deprivation on the prevalence of sight loss and its impact on an individual. For example, in looking at the issue of the change of vision over time, the report found that 'those from poorer backgrounds, and those who perceived themselves as of lower social status were more likely to be in the deteriorating trajectories and less likely to be in the stable, excellent or good categories.'

PIP and problems with assessment.

Personal Independence Payment is being rolled out across the UK. It essentially replaces the Disability Living Allowance and those on DLA can expect to be transferred to PIP via a process that includes an assessment. The assessments in Wales are carried out currently under the control of Capita, a private company commissioned by the Department of Work and Pensions. There is anecdotal evidence that these assessments are conducted in a way to trick people into giving information that would reduce the level of financial support offered. For example, the claimants' answers to questions such as 'how are you today?' - said in the manner of a general

greeting - are used as part of the assessment data set. A response of 'I'm good, thanks' would be taken as an indication of their wellbeing and potentially used to reduce the level of support.

Wales Council of the Blind fed into a BBC report on the incorrect use of Snellen and LogMAR charts in PIP assessments (10). For people with sight loss (who constitute 0.8% of all PIP clients), PIP assessors have been known to use the Snellen or Logmar Charts - the eye charts for assessing sharpness of vision - to conduct a sight test. There are problems with this. First of all, visual function involves more than just visual acuity - it has to consider field of vision, colour perception, involuntary eye movement and so on. To use the chart as a perfunctory measure of a person's visual function is lazy and insufficient. The TPT findings in *Changes in vision in older people: causes and impact* observes that 'it is possible that objective measures of visual acuity may not reflect the reality of visual function', and even that is when the test is carried out under ideal conditions - not, as has been reported, in the home with inconsistent lighting and shorter distances than should be adopted. Secondly, the distance at which the chart is used and the lighting conditions are scientifically defined. The assessors are known to be using it incorrectly, creating false results that give the impression that the person's vision is better than it really is, leading to reduced levels of payment or none at all. It is clear that qualified optometrists ought to be engaged in the process of assessing vision where this needs to take place. However, it is questionable as to whether it needs to be assessed at all, since it is likely that the person would have evidence in the form of a Certificate of Visual Impairment from an eye clinic or registration with their Local Authority sensory support team. The latter, combined with a letter from a qualified Rehabilitation Officer for VI, should be sufficient evidence of the impact of sight loss on an individual's daily activities.

Citizens Advice has collated evidence provided by their advisors and clients on their experience of PIP and ESA assessments (7). The findings are that 'assessment reports are often contentious. 92% and 81% of advisors report seeing inaccuracies in PIP assessments and Work Capability Assessments (WCAs) respectively. Many advisors cite inaccurate assessment report conclusions ranging from unjustified extrapolations from assessors' observations to wholly contested versions of events. Clients often tell our advisors that these inaccuracies tend to overstate their capabilities.'

The appeals process, called Mandatory Reconsideration (MR), is relied upon by a large number of claimants as a way of getting what they feel to be the correct level of support. 'For all but a minority of applications, Mandatory Reconsideration (MR) confirms the initial decision. Official statistics show 65% of PIP appeals result in a changed award. '...high appeal success rates support claims from our advisers that reports and decisions are regularly inaccurate. The design and administration of the assessments, evidence collection and decision making process are not consistently effective.' Indeed, the more cynical view might be that PIP assessments are being geared towards downgrading the level of support in the hope that the decision would not be challenged, and that fewer challenges would result in better money-saving targets.

So, it appears that the processes of assessment are geared towards a lowering of levels of support. The reduction of these crucial allowances has a serious impact on the ability to meet basic daily needs.

Employment.

The TPT findings identify factors that can help to find or sustain employment. Help from VI organisations, volunteering, Permitted Work and, importantly, a supportive employer as

well as support from Access to Work. Volunteering is a stepping stone to paid employment for some people but, unfortunately, the support for employees from Access to Work does not extend to volunteering, so the additional costs of support for disabled people in these essential developmental opportunities have to be met by the hosting organisation, the individual, or simply not met at all, making the experience less representative of ideal working conditions.

Access to Work provides crucial support to disabled people to ensure they retain employment. However, in 2016 Wales Council of the Blind and RNIB Cymru with partner organisations conducted a survey into employees' experiences and impressions of the Access to Work scheme in Wales, particularly in the light of changes to the way it is structured and run. The survey revealed deficiencies throughout five key aspects of the service and these prompted a set of recommendations. The five areas were: contact with clients; provision of information; advisor skills and knowledge; assessments; and payments, reviews and personalised budgets.

Three years on ...

WCB recently repeated the survey to see if the problems persist or have been ameliorated or solved, and has published a report on its findings (8). The review covers the same areas as the original report and essentially considers people's responses in comparison to three years ago.

The Access to Work Scheme is an essential ingredient in the support available to disabled people in employment. It helps to create an even playing field in the workplace by financing support to meet the access needs of disabled people. This, ideally, takes away the disincentive to employ a disabled person by making cost-neutral changes to the job in the form of access technologies, transport costs and PA fees. With the

support in place the employer ought not to perceive the access problems as a burden on the role in terms of cost and time, thus placing the disabled person on an equal footing in terms of employability. That's the ideal. But it requires a service that is responsive to the demands of the workplace being placed on the employee. The survey found this responsiveness to be lacking for many people, leaving them reliant on the goodwill and patience of the employer at best or, at worst, finding them unable to fulfil the role.

Another survey (9) conducted in England into the Access to Work scheme there yielded a phrase that highlights a key problem with the scheme as a whole. One respondent described it as 'a shop with blacked out windows', a powerful metaphor for the manner in which AtW keeps its cards close to its chest, creating a mystique around the scope and depth of the support it can offer. WCB's survey reveals that there are still strong perceptions that the support on offer is somewhat hidden from the client and, importantly, *potential* clients. This, coupled with barriers to accessing the service due to badly designed forms and taxing methods of claiming payments, leads to a service that looks as if it doesn't want to maximise the support it gives to clients. It appears, rather, to be discouraging claimants in order to save money – hardly surprising in these times of austerity in public finances.

However, there are changes that can be made that need not impose a financial burden the service directly, yet would make a considerable improvement in the delivery to the client. The quality of communication between client and advisor is crucial for maintain a strong relationship built on an understanding of the client's particular circumstances. This builds up trust and enables the client to feel confident that they can request changes to support when the job demands it. This communication also extends to the assessor, who is engaged by Access to Work to listen to the client and advise them of possible solutions to access problems. These assessments

are now largely undertaken over the phone and this is clearly a problem insofar as there is not the detailed understanding of the particular workplace requirements.

All this points towards a change in culture that seems to have stemmed from the service-wide reforms that occurred in 2011. No longer does the client have a single advisor with whom a relationship can be built, and no longer is detailed work being carried out by the assessor in the client's place of work to identify the best and - in the long term - most cost-effective solutions.

It must be remembered that the scheme is considered by most to be extremely good when it is working to the client's needs. Comments were made that reiterated the scheme's enduring importance and value, making it all the more frustrating when it is not delivering the goods. Inflexibility with the distribution of payments, such as not responding quickly enough to the variable requirements for travel within work, puts pressure on the employee to find money to pay for support out of their own pocket until the amount is agreed with - and processed by - AtW. Also, delays in agreeing and delivering the required support have placed clients under the goodwill of the employer in continuing to pay the worker until the support is in place. This can be for as long as four months. That kind of pressure and uncertainty undermines an employer's faith in the usefulness of the scheme and risks their developing an attitude of negativity towards employing disabled people in the future. That is not a desirable outcome of the service.

Trust emerged as an issue for some people. There was a sense that AtW would err on the side of caution and insist on demonstrations of proof. For instance, one respondent was asked to provide a bus pass as evidence that they couldn't drive. Another said she was effectively being asked to prove she was still disabled – her condition was not going to get better.

Poor communication has resulted in people missing the renewal cycle, causing an unwelcome delay to the processing of further claims. One client was even asked to reapply from scratch because of a missed renewal date.

So, the Access to Work Scheme - an essential component in the accessibility programme - requires some systemic changes to make it work fully for disabled people and change the imbalance reported in 'Is Wales Fairer' that only 34% of disabled people are in employment compared with 73% of non-disabled.

This was a brief overview of some of the areas that impact financially on disabled people generally and people with sight loss specifically. It is evident that disabled people experience considerable additional costs to daily living but are less likely to be in employment to cover those costs. Furthermore, changes to the system of benefits and allowances make it harder to meet those additional costs. Another important consideration is that people who are socially disadvantaged are more likely to be experiencing deterioration in sight disproportionately to those who are better off.

- (1) *Is Wales Fairer? Summary Report 2018*, Equality and Human Rights Commission, 2018.
- (2) *The Disability Price Tag 2019*, John, Thomas and Touchet, Scope 2019.
- (3) *Sight Loss and Minimum Income Standards: the additional costs of severity and age*, Research Findings No. 55, Thomas Pocklington Trust, Jan 2017.
- (4) *Experiences of Living with Visual Impairment: Matching Income with Needs*, Research Findings No. 58, Thomas Pocklington Trust, June 2018.

- (5) *Changes in vision in older people: causes and impact*, Research Findings No. 49, Thomas Pocklington Trust, September 2015.
- (6) *Digital Media Usage of Sensory Impaired Users in Wales 2018*, Wu, Lindsay et al, Swansea University, 2018.
- (7) *PIP and ESA Assessment Inquiry: Evidence from Citizens Advice*, Citizens Advice 2017(?).
- (8) *How accessible is Access to Work for people with sight loss in Wales? - 3 years on*, O. Williams, R. Bowers, June 2019.
- (9) *Working Age Group Project online consultation report*, Retina UK, 2019.
- (10) Wales Council of the Blind: 'Meaningless' sight test hits claims, BBC Wales report, <https://www.bbc.co.uk/news/uk-wales-48682106>, 2019. Video at: <https://www.bbc.co.uk/programmes/p07dsqt2>

Macular Society and CIB information and Training Day

On Monday, 24th June, the Macular Society and CIB held an information and training day at Cardiff Institute for the Blind. The event was led by Adele Francis, Regional Support and Development Manager for the Macular Society.

George Jones, Policy Lead on the Older People's Commissioner's 3-year plan, 'Ageing Well'.

George began by sharing the Commissioner's vision, which is to make Wales the best place in the world to grow older.

There are 877,000 people over the age of 60 in Wales and this is set to increase to over a million by 2030 and the number of people over the age of 85 will double by 2040. The Commissioner wants to celebrate our ageing society and to do this she has set out three key priorities: Ending ageism and age discrimination; stopping the abuse of older people; and enabling everyone to age well. Over the next three years there will be public campaigns to help highlight and challenge the issues faced by older people.

The plan includes putting measures in place to empower older people to effect change such as ensuring older people understand their legal rights and how to exercise them, working with transport providers and health services to encourage better communication and making communication in Wales more age friendly.

The Commissioner is also conducting research with Aberystwyth University into crimes against older people. They are hoping to identify what causes people to become abusive

towards older people. In addition, a mapping of support services for victims of abuse will be carried out.

Ophthalmologist, Rhianon Reynolds, gave an overview of Age Related Macular Degeneration and the current treatments available. At present, wet AMD patients in Wales receive Lucentis and Eylea injections and treatment times are the same from health board to health board. The 'Treat and Extend' method is used which involves patients receiving injections every 4 weeks until there is no more disease. Once a patient has had three 12-week periods of no treatment, the injections could be stopped. It is believed that 50% of people with wet AMD in one eye will get it in the other.

The drug, Avastin, which is currently used to treat colon and other cancers has shown to be effective and a cheaper alternative for treating wet AMD. However, it has not been licensed for use in the eye.

Geraldine Hoad is the **Research Programme Manager** for the Macular Society.

Geraldine reported that there are approximately 1.5 million people with Macular Degeneration in the UK. There are several studies and research projects being carried out to find the cause and to improve treatments.

A study was carried out in the USA as to whether a certain formula of supplements can help slow down the progression of AMD. However, the conclusion was controversial and has resulted in mixed views. There is no proven clinical evidence to show that they work. Therefore, NICE has recommended further research be carried out. The Macular Society hopes to begin clinical trials within the next year or so.

The Macular Society is currently undertaking several research projects which include exploring treatments being administered

via eye drops to replace the current injections, gene therapy for dry AMD and treatment for Charles Bonnet Syndrome.

Trials are also being conducted in the USA for stem cell treatment for dry AMD.

In terms of laser surgery, the current procedure can cause some damage and reduce vision. Therefore, a micro-pulse laser treatment is being developed to deliver short bursts to the affected area, resulting in a reduced risk of damage. Clinical trials are currently being conducted.

Michelle Jones, Centre Manager for Cardiff Institute for the Blind, highlighted some of the services hosted and provided by CIB. These included social and support groups like the Macular group, who meet on the last Monday of the month from 10.30am to 12.30pm, computer training, information and advice and much more. CIB also has a wide selection of low vision aids in its resource centre and can offer advice and support in buying the most suitable product to help with daily tasks.

VI Volunteer Mentoring Scheme

Vision Support's Active Inclusion "VI Volunteer Mentoring Scheme" aims to support vision impaired individuals over the age of 25 who live in Flintshire or Wrexham and are long-term unemployed or economically active. The "VI Volunteer Mentoring Scheme" will provide training and support to individuals over a period of ten weeks in order to increase confidence, skills and independence to enable service users to progress into volunteering, further learning or employment opportunities.

During this time, service users will receive training including (but not limited to):

- One-to-one sessions to identify barriers to participation and possible solutions
- VI awareness training
- Workshops for interview skills and disclosure of vision impairment
- Digital Inclusion training
- Workshop on how to access further training and job search
- Mentored volunteer taster sessions

The aim by the end of the ten-week period is for the supported person to have gained the tools necessary to take on volunteering and/or learning opportunities. Individuals will grow in confidence and independence through connection with the local community, as well as increasing their potential for future employment.

If you know of or come across anyone whom you feel may benefit from this service, please refer them to Vision Support. The project will run until December 2019, and is being

delivered in partnership with Wales Council for Voluntary Action. It is being funded by the Welsh European Funding Office.

Please do not hesitate to contact Vision Support with any further enquiries, or call our Prestatyn Sight Loss Centre on 01745 472558.

Royal Blind Children's Society Family Support

We work in partnership with a range of organisations to be on hand from the moment parents hear the news about their child or young person's sight loss, and offer support to the child, young person or the family as a whole.

Are you, or your child struggling to accept their sight loss, we are here to help whether you need us now or in the future, if you feel you would benefit from our support read on!
We are a charity of 180 years' experience, who offer support to families, children and young people with sight loss.

How we can help:

- We enable children and young people to create a better life for themselves, by helping every young person we work with to find and fulfil their own unique potential.
- We are there for you from the moment we are contacted, guiding you and your families on your journey.
- We provide you with a combination of support and opportunities to help develop the resilience and skills you will need to navigate your futures.

You can contact us on 02031980225 or via the website www.rsbc.org.uk

JobSense

What is JobSense?

The Centre of Sign Sight Sound (COS) have recently been funded by the European Social Fund through the Welsh Government a 3 year employability project called JobSense, delivered in partnership with Action on Hearing Loss Cymru and Elite Supported Employment Agency.

What is COS' role?

COS will be working specifically with people who are blind or who have sight loss. To be eligible to participate you must be over 25 living in Wrexham, Flintshire or North Powys and are economically inactive or long term unemployed.

JobSense uses Specialist Employment Advisors, to assist people with sensory loss (hearing loss and visual loss), who feel excluded from the job market, to secure and sustain employment. This bespoke person centred approach will help them moving closer to employment.

With a range of interventions tailored to the needs and circumstances of people that will help with confidence building, vocational skills, practical help such as transport and benefits, as a well as specific outcomes for those exiting the programme which could be:

- Supporting them into employment
- Completing work experience placement or volunteering opportunity
- Gaining a qualification or work relevant certification
- Or engaging in job search.

For further information or to make referral please contact us:

Email: - jobsense@signsightsound.org.uk

Karen Phelps – Team Lead - 07435967326

Project Admin - 01492 530013 (Mon-Wed)

Web: <https://www.centreofsignsightsound.org.uk/jobsense>

... and the JobSense Project is in South Wales also ...

ELITE Supported Employment are pleased to launch a new and exciting 3-year project funded by WEFO (Welsh Education Funding Office) for people with sight loss or a visual impairment. The Project provides support to improve confidence and gain skills that will enhance the employability of all participants. The project will be delivered in Cardiff, Newport, the Vale of Glamorgan, South Powys and Monmouth.

The JobSense team at ELITE will support participants by providing specialist guidance to help build their confidence and increase their vocational skills. They will offer a wide range of bespoke and person-centred services to help participants overcome their barriers to work. ELITE's Specialist Employment Advisors will provide intense one-to-one practical support to enable participants to travel independently, through training and route familiarisation. They will enable participants to identify realistic and appropriate options for work, access training programmes to learn additional skills and achieve accredited training qualifications relevant to their journey into paid employment. They will also provide support to access further and higher education programs, promote awareness around assistive technology that is available to support individuals with sensory loss in the workplace, as well as providing access to work experience, work placements, volunteering opportunities and job tasters through a wide range of employers.

Lisa Harding, Specialist Employment Advisor for South Powys, has already supported participants to enrol on college courses and is setting up a social group in Brecon to address social isolation.... "The nature of the project enables us to provide participants the support they feel they need. We understand

some people may not feel ready for work, in which case we can explore so many other options that are suitable, such as volunteering opportunities and work trials. Many people I've spoken to, particularly younger people with sight loss, feel isolated and unaware of other people in the area that they can connect with. I am also looking to set up groups that address this gap and take on board feedback from what people want, whether it be a meet up at a local café or perhaps an active activity, such as a walking group.”

The JobSense team have been busy since the launch in April, attending meetings with various organisations, including Wales Council of the Blind to ensure there is an awareness in the community of the support available. Amey Chappell, Specialist Employment Advisor for Newport and Monmouth, has a background in education and has worked with students who have a sight loss, “The latest figures of unemployment for people with visual impairments are disturbing; there is no reason why any person who wants to work shouldn't have the right opportunity. With the support we provide, to both the participants and employers, our intention is to ensure everyone who comes onto the project grows in confidence and gains the skills and experience to either move into employment or move closer to the labour market”. Amey is currently developing a social media profile for JobSense and engaging with people and organisations through Twitter to promote the project. “I'm really hoping that people who feel this multi-faceted support will be beneficial to them will contact us, as we've got so many resources at our fingertips.”

The team at ELITE JobSense have a wide range of experience working with participants with a range of disabilities. Maxine Levett is the Specialist Employment Advisor for Cardiff and the Vale of Glamorgan.... “I have worked with ELITE since June 2018. I have 25 year's experience working with participants who have various disabilities and always wanted to work in employment to provide people with the opportunity to have fair

access to work, meet their potential and have fulfilling and rewarding work experiences and/or career opportunities. I currently host job clubs across various locations to develop relationships with all participants and provide guidance on suitable roles with the intention of securing sustainable employment. Working alongside participants providing intense, structured support has been a positive and rewarding experience”

So, what are the next steps for JobSense? Team Leader Paula Bowen is working hard with the Specialist Employment Advisors, Support Services and employers and feels, “Everyone at ELITE Supported Employment are excited about the JobSense Project and the support we can provide to participants. We’re still in the early stages of the project and our objective at present is to engage with participants who may feel our intense support will be of benefit to them, so if anyone wants to work alongside us, please get in touch!”

For further information regarding the JobSense Project please contact:

Amey Chappell

Tel: 07494209521

Email: achappell@elitesea.co.uk

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Sometimes power cuts can happen for reasons beyond our control. During a power cut we are able to help.

We know it can be particularly worrying if you rely on electricity for medical equipment or if you are elderly, very ill or disabled. If you depend on electricity for a reason such as using a nebuliser, a kidney dialysis machine, an oxygen machine, a ventilator – or any other reason – you should register with us.

WPD provides a FREE Priority Service Register, which helps us to identify customers who may need a little extra help during a power cut.

If you join our FREE Priority Service Register we can:

- Give you a direct number to call in the event of a power cut so you can get straight through to us.
- Agree a password with you before we visit you, so you feel safe.
- Provide special help, if needed, through the RVS (Royal Voluntary Service) or British Red Cross.
- Ring and tell you about planned interruptions to your electricity supply.
- Keep you as informed as possible in the event of an unplanned power cut.

To join, call **0800 096 3080**, or visit our website
www.westernpower.co.uk

Smell gas?

Staying safe in six easy steps

If you smell gas in your home or business, we're here to help. Here's what to do.

- 1 Call us immediately on Freephone 0800 111 999. We're available 24 hours a day, 365 days a year and will send out an engineer to make your property safe.
- 2 Turn off all your gas appliances and, if possible, switch off the gas at the meter (unless the meter is in the cellar or basement, in which case don't go in).
- 3 Open windows and doors.
- 4 Don't use any electrical appliances or switch lights on or off.
- 5 Don't smoke or use naked flames.
- 6 If there's a smell of gas in the cellar or basement, please wait outside or with a neighbour.



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AND PIPELINE SERVICE



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UTILITIES