Barriers to Work:

A survey of Deaf and Disabled people's experiences of the Access to Work programme in 2015/2016

StopChanges2AtW is led by Deaf professionals, Deaf and Disabled campaigners and BSL interpreters, set up in 2014, to give a voice to Deaf and Disabled people adversely affected by changes to Access to Work.

Report by Catherine Hale and commissioned by Inclusion London.

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Executive summary

Introduction

Over the last twenty years, Access to Work has been by far the most successful of the UK's policies aimed at supporting Deaf¹ and Disabled people to get into, stay in, and progress in work.

When it works, AtW is the model of what good disability employment support should look like. By meeting the extra costs of working with a disability, the scheme levels the playing field for Deaf and Disabled people and liberates us to compete and perform to our best abilities in the workplace. It also enables employers to open up job opportunities, creating a more diverse workforce and a stronger economy.

Best of all, AtW is cost effective. Research from 2004 suggested that there is a net return to the Treasury of £1.48 for every £1.00 spent on the programme.²

Access to Work should be the cornerstone of the government's current efforts to help more Deaf and Disabled people to participate in the labour market. Halving the disability employment gap³ was a welcome manifesto promise by the Conservative Party in 2015. Instead, a survey of customers found that the scheme has been beset with so much bureaucratic incompetence and obstructionism in recent years that, in many respects, Access to Work is no longer fit for purpose.

Top down reorganisation has resulted in unacceptably poor customer service. Shocking levels of delay, error, and the deskilling of staff are putting Deaf and Disabled people's jobs at risk. In addition, a short-sighted drive to reduce

¹ Throughout this report the term "Deaf and Disabled" includes people for whom British Sign Language (BSL) is their first language, people who are deaf, deafened and hard of hearing, people with sensory or physical impairment, people with learning difficulties, people with mental health support needs, people who are neuro-diverse and people living with long-term health conditions.

² The Disability Employment Coalition, 2004, *Access to Work for disabled people*, The Disability Employment Coalition. http://www.disabilityalliance.org/access.pdf

³ The disability employment gap is the difference between the rates of employed non-disabled people and employed disabled people. The gap is 32 percentage points in 2016 so the target is to hit 16 percentage points in 2020. This requires moving 1,074,000 (a third more) disabled people into employment and raising their employment rate from 48% to 64%.

individual awards has jeopardised the scheme's original purpose. As a result, many Deaf and Disabled people are no longer having their access needs met in work. They are losing out on job opportunities and are fearful for the future of their livelihoods. Thousands of other Deaf and Disabled people whose lives could be transformed by inclusion in the labour market are also missing out.

The Department for Work and Pensions' (DWP) current consultation on Work and Health presents a great opportunity to restore and refit the AtW scheme to meet the exciting challenge of increasing the numbers of Deaf and Disabled people in work. Last year's Autumn Spending announcement of an extra £25 million for the AtW scheme is a welcome start.

This report provides an opportunity for government to listen to the experiences and concerns of AtW customers 2015/2016. Deaf and Disabled people hope to work in partnership with government to implement the recommendations it contains to build on areas of the programme that continue to be successful and to fix those that are currently failing. To build a country that works for everyone, we must put Deaf and Disabled people back in control of our working lives.

Background to this report

This report is based on a survey of 320 AtW customers during 2016 by the campaign group StopChanges2AtW.

StopChanges2AtW was formed in 2014 in response to the operational changes to AtW introduced by the DWP at that time. The campaign prompted a Work and Pensions Select Committee inquiry which secured some notable improvements to fairness and transparency in the AtW system. However, the StopChanges group remains concerned that many adverse impacts of the changes are still unresolved and that there are fresh causes for concern, such as the cap on maximum awards and levels of administrative incompetence in day-to-day operations including lost paperwork and payment delays and errors.

Key Findings

- 1. Access to Work customers are an integral part of the UK workforce, often with highly developed careers. The majority of survey respondents worked full time. A broad range of employment sectors was represented, with non-profit being the most common at 28% followed by government and self-employment at 12% each. A third had been receiving AtW support for 10 years or more.
- 2. Almost a half of respondents had experienced changes to their AtW package. For the majority of respondents, the reasons for the changes to their support package were not known. However, respondents frequently linked the changes to their support with the call centre reorganisation which began in 2014.

Accessibility problems with AtW

- 3. Only 15% of respondents said they found AtW easy to apply for, or use. More than half found it difficult to use, with one in four reporting severe difficulty. A great number of respondents said they effectively lost support because the processes for claiming AtW have become so complex and protracted that the scheme was no longer a viable form of employment support. Respondents often referred to AtW processes as "jumping through hoops".
- 4. The most frequently mentioned administrative problems with AtW were:
 - Not being told when their award was ending, leaving them indebted to support workers and unable to perform their job.
 - A large increase in time spent disputing their needs with AtW staff, resulting in lost productivity in work.
 - Lengthy delays in assessments for support meaning they were unable to take up a new job or offer of work.
 - Lengthy delays and frequently lost paperwork in processing payments, leaving them in personal debt.
 - Very poor levels of Deaf and disability awareness among AtW staff affecting accessibility of the scheme for some customer groups.
 - The loss of personalised support relationship with an AtW adviser, meaning all aspects of communication are slower and less efficient than before.

Reductions in individual awards

- 5. "Cuts" or "cost cutting" was the most frequently given reason for changes to AtW support. Respondents were usually given no explanation other than the need to ensure value for money to the taxpayer. Many respondents noted that they were now made to feel "like scroungers".
- 6. There was evidence of rationing strategies being deployed at various levels including:
 - More frequent re-assessment, often leading to a reduced award.
 - Tighter eligibility criteria for support.
 - A higher burden of proof of need for support.
 - Increased complexity and unnecessary repetition in AtW forms.
 - A perception by respondents that they were under surveillance and suspicion.
 - Increased restrictions on the use and portability of support, especially for the self-employed.
 - Rules restricting the duration of support for those doing Permitted Work in receipt of Employment and Support Allowance (ESA) which do not align with ESA regulations.

Who was most affected by changes to AtW?

- 7. Disproportionate impact on Deaf customers. They experienced the double impact of structural reorganisation (with call centres ill-equipped to deal with non-hearing customers) as well as measures to drive down the cost of BSL support essential to do their jobs. It is, therefore, very concerning that, going forward, 90% of those affected by the new capping policy for maximum awards will be Deaf people.
- **8.** Most respondents who were adversely affected by changes to AtW had low or average value awards. The majority of respondents experiencing reduced support received under 5 hours of support per week.
- **9.** Many were self-employed, affected by the changes to guidance on self-employed earnings, as well as restrictions on the portability of support between contracts.

Impact of changes to AtW

- 10. Nearly all of those experiencing changes said they had impacted negatively on their work, reducing their standard of work or their productivity. Nine people had lost their job, turned down work or reduced their income as a result of the changes. Many expressed anxiety about losing their job.
- **11.** The changes also resulted in the loss of their ability to progress in work. For example, the loss of communication support for Deaf people resulted in them having to turn down meetings or training events.
- **12.** Many respondents reported a personal, as well as professional, impact from the changes: through stress, poorer health, and loss of self-esteem or confidence due to feeling "like a burden".
- **13.** Many respondents expressed frustration and anxiety at the risk of unemployment and benefit dependency, which would come at a much higher cost to the State than the support package they needed to remain in work.

Summary of recommendations

- 1. Commit to an Access to Work programme that embodies core principles and values. The aim of AtW must be to level the playing field for Deaf and Disabled people. It must acknowledge that we are the experts in our access needs. Support through AtW should focus on our abilities and enable us to fulfil our potential. It should not disadvantage or place Deaf and Disabled people at risk.
- 2. Place AtW at the heart of the government's strategy to increase the numbers of disabled people in work.
- 3. Equip AtW to enable Deaf and Disabled jobseekers to move into work.
- 4. Improve job security and stability for Deaf and Disabled people in work through.
- 5. Introduce digital systems to improve delays, reduce inefficiencies and tackle fraud.
- 6. Improve communication with new and existing customers and employers.
- 7. Improve decision making in AtW.
- 8. Remove the cap which discriminates against Deaf and Disabled people with high support needs and in senior job roles.
- 9. Review the current guidance on self-employment 'business viability'.
- 10. Put Deaf and Disabled people back at the centre of the AtW process. Consult with StopChanges2AtW, and other user-led organisations of Deaf and Disabled people on any further revisions to AtW policies or operational changes to AtW processes.
- 11. Address the disproportionate impact of changes to AtW on Deaf/deaf, deafened and hard of hearing customers.

Case studies

Case study 1

"Sayeeda"

Sayeeda has a learning disability. She works part time as a Finance and Admin officer in the not-for-profit sector. She says: "Access to Work is good because I would not be able to have a paid job without the scheme. If it was not for [the organisation] I would be doing unpaid work.

Sayeeda receives the help of a support worker but her hours have been reduced to 20%, even though her needs have not changed. "I have got Access to Work support for over ten years, I don't understand what has changed."

Sayeeda sums up her experiences with AtW:

"Before my Access to Work ran out I notified them but they didn't get back to me for 6 weeks, which meant we could not claim Access to Work. They also called me at home, which we have told them not to do because at home we do not have our support."

"The way Access to Work treated me was horrible. I was talked to in a way where the advisor thought that they knew better than me about the support that I need to do my job. It was always a very aggressive tone."

"Their letters were not accessible, they never called back, They have only renewed my support for 1 year. We have been told that now when there is an application for renewal, this will have to be taken forward by making a completely new application."

Case study 2

Angela

Angela is an independent support officer, working with disabled children and young people and their families. She has cerebral palsy. Her AtW package includes equipment, a note taker and a support worker.

"It took 7 months to secure the funding for support workers. I had to rely on my manager to make endless calls to the new ATW call centres. I found it tiring having to repeat the same information to half a dozen operators! I would not have been able to apply if my line manager had not assisted me."

During this period, I frequently went without anything to eat and drink all day because I did not have a support worker to assist me with feeding.

It took 5 months to get the correct in-work electric wheelchair and almost 3 months to get my travel to work organised and authorised. During this period my NHS electric wheelchair broke down 3 times on London Underground due to over-use. The impact has been struggling with the rush hour commuters, ie passengers walking into me, accidentally hitting me in the face with their rucksacks and briefcases, being trapped on the bus when the ramp is not working, being trapped on the underground when the lifts have been out of service and not being able to get to where I need to be when there have been suspensions on the Jubilee line.

Because ATW will not pay support workers an economically viable rate I have to go without support for half a day.

Had I been working in the private sector I would have lost my job."

Case study 3

Caroline

Caroline is a freelance TV Producer/Director and is Deaf

Has your AtW package changed? Yes. I fought very hard for a freelance agreement, I had to get my local MP involved. I finally negotiated a one year self-employed freelance package which runs till this November. I am currently trying to renew this package and they are being extremely difficult, refusing to renew it as a self-employed package and insisting it can only run for the duration of my current contract and that I must reapply each time I get a new job, which doesn't work in my area of the industry (media).

Have these changes affected your ability to do your job? Yes. As a freelancer I need to be available to start work on short-notice. If I need to apply for support each and every time I start a new job (which could be on numerous occasions throughout the year) then this will render me unemployable.

How have you found applying for or using AtW? I was assured that if I needed to increase the hours then it would be a straightforward process. I applied for an increase in hours earlier this year and I had to get my case escalated to a manager, but in the end we agreed an increase in hours. I'm currently in the process of applying for a second year of freelance support and I have had to escalate this to senior management level once again as the advisor is adamant that I can only have a package for my current contract, which ends February, and will not renew my freelance contract on a yearly basis.

Please tell us something about the scheme you feel could be improved. The application and renewal process needs to be drastically revamped. At the moment it's a horrible, horrible process and my heart sinks every time I receive an email from them. I'm made to feel like a drain on the system and some sort of fraud for applying. All I want is to do my job at the end of the day. They increase my workload so much, it really isn't necessary.

Case study 4

Sue

Freelance Independent Social Worker. Sue has difficulty hearing and applied for new hearing aids due to deterioration in her hearing.

Has your AtW package changed? Yes. Although I only receive one-off help with equipment, the number of hoops now to be jumped through before help is given, is ridiculous, and the time taken to jump through them has resulted in significant loss of work.

Have these changes impacted on your ability to do your job? Yes. Whilst spending ridiculous amounts of time trying to jump over all the hurdles put my way by AtW, I have had to turn down a large amount of freelance work. This could mean loss of future work also as commissioners will have taken their work elsewhere whilst I have been unable to accept it due to not being able to hear well enough without the aids.

How have you found applying for or using AtW? The way I have been treated by AtW and the amount of obstacles repeatedly put in my way, have very seriously affected both my ability to continue working, and my mental health, to the point that my GP has had to intervene.

Tell us something about the scheme you think could be improved. Link up AtW with the Government's agenda for disability employment, and ensure that AtW decisions don't contravene this agenda. I have been told that all the obstacles put in my way with my current claim for help, are "because the money comes from the public purse". No-one seems able to understand that delaying or denying me the assistance with the equipment essential to enable me to continue working, has resulted in immediate loss of work, and hence the public purse has lost considerable amounts of money from the absence of the income tax and national insurance payment which I would have had to pay, had I been able to work.

Introduction to Access to Work policy and reforms

1. Access to Work, disability rights and employment support

What is Access to Work?

Access to Work (AtW) supports Deaf and Disabled people to take up and retain paid employment by helping with payments for aids, adaptations and support so they can work effectively. It is provided where the employee requires support or adaptations beyond those "reasonable adjustments" which an employer is legally obliged to provide under the Equality Act 2010. Access to Work also provides advice to employers on reasonable adjustments. It was launched in June 1994 and is delivered by Jobcentre Plus.

AtW can be used to fund single or multiple adaptations or pieces of equipment, or ongoing support, for example work-related travel costs, communication support for Deaf people, Support Workers for people with learning difficultiess or autism, or help to overcome difficulties at work presented by mental health issues.

AtW is available to people in full-time work (16 or more hours a week), people undertaking permitted work (low hours work while still claiming out-of-work benefits), and to people undertaking apprenticeships or Work Trials arranged through Jobcentre Plus.

When it works well, AtW is a personalized, flexible support scheme which increases choice and control for Deaf and Disabled people over their working lives and their participation in society.

The government spent £108million on AtW in 2013/14. In the financial year 2015/16 36,470 individuals were helped through AtW, which represents a small drop in the previous year⁴. The average AtW award is around £3,000 per annum.

⁴ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/538443/access-to-work-statistics-march-2016.pdf

Access to Work and equal rights for Deaf and Disabled people

The AtW programme was designed to level the playing field so that Deaf and Disabled employees enjoy the same opportunities to compete for jobs and have same chance of success in work as their non-Deaf and Disabled counterparts. The right to inclusion in the economy is a key component of the United Nations Convention on the Rights of People with Disabilities⁵.

The establishment of AtW in 1994 is a cornerstone of the movement for equality and civil rights for Deaf and Disabled people in the UK. It operates in partnership with the Disability Discrimination Act (DDA) of 1995 (now enshrined in the Equality Act 2010). Central to the DDA is the concept of "reasonable adjustment". This places a duty on employers and other service providers to adjustments to remove barriers in the workplace that would otherwise disadvantage Deaf and Disabled people.⁶

The AtW programme is a vital commitment by the UK government to undertake the cost of making adjustments and adaptations that bear down disproportionately on employers

Access to Work and disability employment support

AtW sits within a broader programme of measures implemented by the Department for Work and Pensions (DWP) aimed at increasing the numbers of Deaf and Disabled people in employment. Official data show a substantial gap between the employment rate of working age Disabled people (51%) and that of the general working age population (73%).⁷

The Conservative party manifesto in 2015 included a welcome commitment to halving this gap. The Work and Health Green Paper published in November 2016 expands on the strategies proposed to achieve the aim of increasing the numbers of disabled people in work. However, AtW is only briefly mentioned in the document.

⁵ http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilitie s.aspx

⁶ House of Lords Select Committee on the Equality Act 2010 and Disability *The Equality Act 2010: the impact on disabled people* Report of Session 2015-16 - published 24 March 2016 - HL Paper 117

⁷ Office for National Statistic, Labour Market Statistics, November 2014, Statistical Bulletin; table A08 [employment rate for disabled people includes people with a disability as defined by the Equality Act 2010 and/or work-limiting disabilities]

The main vehicle for supporting Disabled people into work since 2010 has been the mainstream welfare to work scheme called the Work Programme. 139,000 people with long term health conditions and impairments started on the Work Programme since 2011⁸. Just 7% of them achieved a job outcome (a period of 13 weeks in employment) by December 2015. A separate specialist employment scheme for Disabled people called Work Choice had a far higher success rate of 44%.⁹ However, there is evidence that the majority of Work Choice clients have less severe or complex support needs than those on the Work Programme because the majority do not have work-limiting disability as defined by the Work Capability Assessment.

AtW sits quite apart from these welfare-to-work programmes because it is not a disability benefit. Initially it was aimed at Deaf and Disabled people already in employment, not those seeking work. In recent years the scheme has expanded to include some Deaf and Disabled people on specific preemployment schemes such as traineeships and internships arranged by Jobcentre Plus (JCP).

However, AtW is very far from being fully integrated with the employment support received via the Employment and Support Allowance (ESA) pathway. Moreover, Deaf and Disabled people who have the opportunity of taking on short term or one-off contracts are excluded from AtW. This denies them the opportunity of progressing from benefits into employment. Often taking on work on an ad hoc basis initially will lead to employment opportunities at a later date. There is currently no support under the AtW scheme for people who fall into this category.

2. Background to changes to Access to Work

Expanding Access to Work – the Sayce Review

The Coalition Government commissioned an independent review of the whole range of employment support given to Deaf and Disabled people from Liz Sayce, Chief Executive of RADAR, in December 2010. The resulting report, published in 2011, found overwhelming support for AtW among customers as

⁸ These figures exclude ESA awards of 3 or 6 months which indicate a short term period of ill health and would not therefore meet the definition of disability in the Equality Act 2010.

⁹ Work Choice; official statistics. February 2016

well as employers, as well as evidence that the scheme provides excellent value for money. 10

The Sayce Review found evidence that AtW only supported a minority of Deaf and Disabled people who might benefit from the programme. It recommended doubling the number of people helped by the scheme and increasing the numbers of people with mental health conditions and learning disabilities who are significantly under-represented among AtW customers.

A main recommendation of the Sayce Review was releasing funding from other, less successful disability employment schemes to bolster the budget for AtW. The DWP should also make a strong case, it said, for extra investment by the Treasury in AtW, recognising the benefit savings it generates. Research cited in the report suggests that there is a net return to the Treasury of £1.48 for every £1.00 spent on the programme¹¹. The DWP backed up this research by showing there is an even higher social return on investment for every £1.00 invested in the programme, if potential healthcare savings are included in the calculation alongside increased tax revenues and reduced spending on benefits on Deaf and Disabled people in work. ¹²

Extending AtW support within a finite budget

In 2012 the government accepted the Sayce Review's recommendation to expand AtW, and allocated at extra £15 million to the scheme. A Workplace Mental Health Support Service was launched in late in 2011, contracted to Remploy.

However, apart from the one off injection of £15 million, the planned expansion of AtW to more customers has not been underpinned by a greater share of the disability employment support budget. Instead, DWP has sought to expand its customer base by creating efficiencies and cost savings in AtW.

Attempts to streamline AtW and reduce costs were not formally announced to customers by DWP. Two changes in particular had hugely negative consequences for some AtW customers, and led to the formation of the Stopchanges2AtW campaign. These were:

¹⁰ Sayce, L. (2011) Getting in, staying in and getting on: disability employment support fit for the future.

¹¹ The Disability Employment Coalition, 2004, *Access to Work for disabled people*, The Disability Employment Coalition. http://www.disabilityalliance.org/access.pdf

¹² The Department's social return on investment analysis.

- The "30 hour rule" to reduce the value of awards to people using full time support workers. This was an attempt to control the costs of BSL support, which make up a significant proportion of total AtW expenditure. Some 3,430 people received AtW funded BSL interpretation in 2013/14 (around 9% of the total caseload), at a total cost of around £25 million (24% of total AtW expenditure)¹³
- Organisational restructure from 78 regional contact centres embedded in JCP to just three call centres known as "centres of excellence". From May 2014 all telephone calls to AtW from both new applicants and existing customers were routed through one of these central call centres. Details of their case or query are passed to a trained AtW Adviser, who calls them back; customers are not able to contact an Adviser directly. The purpose of this new call centre was to have administrative structures in place which were sufficiently robust to cope with an increasing caseload.¹⁴

Work and Pensions Select Committee inquiry into changes to AtW

Concerns from Deaf and Disabled customers of AtW prompted the Work and Pensions Select Committee (WPSC) to hold an inquiry into the changes to AtW. This inquiry reported in December 2014.

The WPSC concluded that changes to AtW aimed at expanding the programmes without a corresponding increase in funding were having a significant adverse impact on certain groups of AtW customers. The main issues covered by the inquiry were:

- **Guidance on support workers and BSL pay issues**. The WPSC concluded that the "30 hour rule" demonstrated a lack of understanding of how BSL interpretation is used and recommended an urgent review of this issue which adversely affected Deaf people.
- Clarity and transparency of decision making. The WPSC concluded that guidance available on DWP must be much clearer and more transparent about the basis on which it makes AtW award decisions and the processes by which applicants and customers can challenge decisions and make complaints.

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¹³ Work and Pensions Select Committee (2014) *Improving Access to Work for disabled people.*

¹⁴ WPSC (2014) ibid.

- Support for the self-employed and business owners. The inquiry recommended substantial
 - clarification and amendment in the guidance to fully reflect the circumstances of self-employed people's businesses, and the financial realities of working on a freelance basis.
- Administrative problems. The WPSC recommended making the call centre system more flexible and customer-friendly, including by improving the flow of information from the call centre to trained Advisers, and improving communication to customers. The inquiry also recommended replacing outdated paper -based processes by an online service.

About this survey

Background to StopChanges2AtW

StopChanges2AtW is a campaign led by Deaf and Disabled people and BSL interpreters set up in 2014 to raise awareness of, and challenge, the detrimental impact of changes to the government's Access to Work on the employment prospects of Deaf and Disabled people.

During November 2014, StopChanges2AtW who appointed the law firm Leigh Day, sought to take a judicial review into the AtW scheme. The letter before claim covered issues such as the '30 hour rule' (now defunct), as well as the inconsistent, unlawful and opaque application of AtW. The outcome of threatened legal action was the publication of the guidance issued to AtW advisors for deciding awards. This now enables customers to see how staff at AtW make decisions.

This guidance can be found at: https://www.gov.uk/government/publications/access-to-work-staff-guide

The campaign was successful in securing the reversal of changes introduced such as the "thirty hour rule" and in highlighting the many operational difficulties arising from restructure of call centres. The report and recommendations from the Work and Pensions Select Committee inquiry into Access to Work reflected many of the campaign's key concerns.

However, although improvements have been made since the initial restructure, we are still hearing anecdotally about ongoing problems that continue to put Deaf and Disabled people's jobs at risk.

Methodology

In November 2015 StopChanges2ATW launched a survey (see Appendix 1) with the aim of capturing current issues with Access to Work, both positive and negative with a view to making further recommendations for improvement of the programme to better meet the employment needs of Deaf and Disabled people. The survey was put together using SurveyMonkey. Easy read hard copies were also available for people to whom the online survey was not

accessible. The data from returned hard copy surveys was then electronically inputted. There were 320 responses.

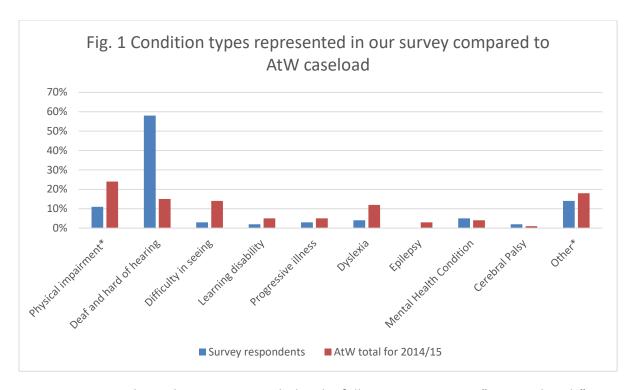
The survey aimed to strike a balance between a multiple choice "tick box" response and a free text response format. We wanted to obtain evidence of the numbers affected by changes to AtW, but not to predetermine what those changes consisted or, or what their impact might be. As a result, most of the data on changes to AtW and their impact is qualitative rather than quantitative. The text-based responses were analysed using content analysis by the report author. This was done by reading all the responses through once before reading them through again in order to highlight the main themes. The themes were then entered into a spreadsheet and the responses were read through again in order to code them according to the themes.

Who did we hear from?

We heard from AtW customers from all walks of life: from psychiatric nurses and occupational therapists to post office workers; from university lecturers to theatre performers; and from IT consultants to teachers of BSL. Many were in senior roles within local government, business or the charity sector.

Fifty-eight percent of our respondents listed their primary medical condition as Deaf or difficulty hearing.

Fig x shows the spread of health conditions and impairments represented in our survey and how these compare with the total AtW caseload for 2014/15. Our survey used the same classification of primary medical condition used by DWP for AtW statistics.



Notes on Fig. 1: Physical impairment includes the following categories: "arms or hands", "legs or feet" and "back or neck"

"Other" includes additional categories recorded by DWP with less than 1% of the caseload, such as diabetes and spina bifida, as well as other conditions not recorded by DWP such as Autistic Spectrum Disorder/Asperger's Syndrome.

Fig. 1 shows that Deaf AtW customers responded to our survey in much greater proportion than customers with physical impairments or health conditions or visual impairment.

Fig. 2 shows that respondents worked in a broad range of sectors including public, private and not-for-profit. Nearly one third worked in the not-for-profit sector.

Fig. 3 shows that the vast majority of our respondents were working full time.

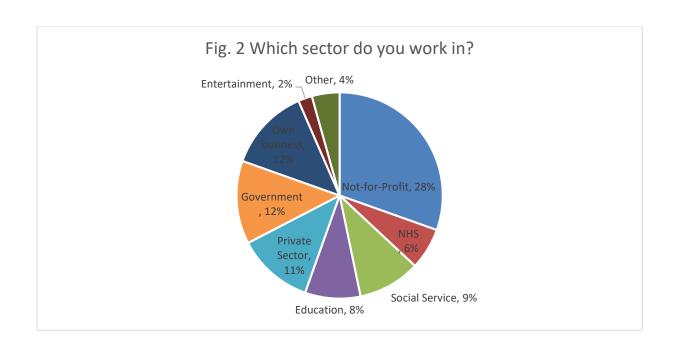
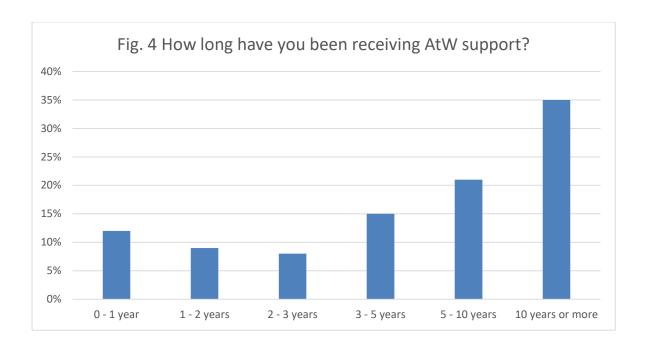




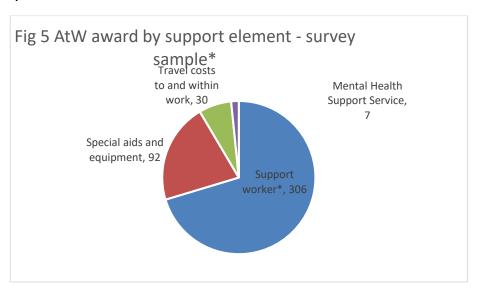
Fig. 4 shows that the largest proportion of our respondents had been receiving an AtW package for 10 years or more.

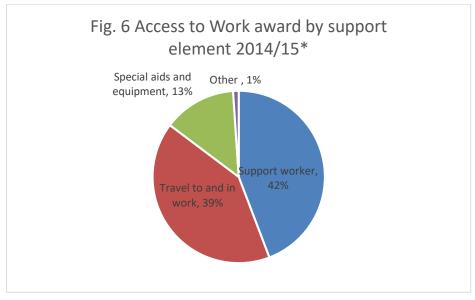


What type of support did respondents receive?

"I couldn't have continued at work without their intervention and support. Equipment that was necessary was so expensive my employers would not buy it and paying for my taxi when my back is at its worse is a lifeline and enables me to attend work even on a bad day."

Figs. 5 and 6 shows the main types of support awarded by Access to Work in 2014/15 comparing respondents to our survey with the national AtW caseload for 2014/15, according to the broad categories used by AtW information systems.





Notes on Figs. 5 and 6: The totals for support element received add up to more than 100% because more than one type of support can be awarded to each customer.

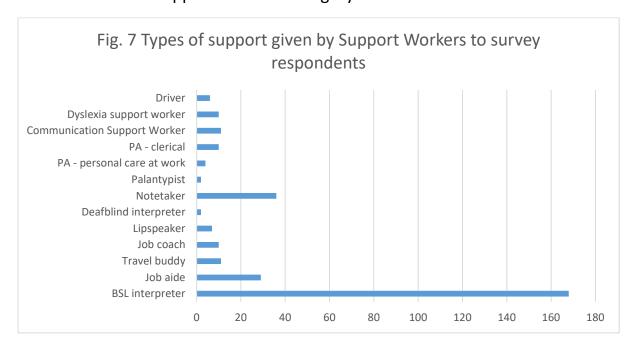
The awards for Mental Health Support Service are not recorded in DWP statistics for 2014/15.

"Other" support elements recorded by DWP include communication support for interview, adaptation to premises or vehicles, and "miscellaneous", each of which represent less than 1% of total awards.

The cost of AtW assessments is also recorded by DWP but not represented here.

Breakdown of Support Worker roles

Fig. 7 gives a breakdown of the variety of roles and tasks classed together under the broad "Support Worker" category.



The DWP statistics published for Access to Work awards do not specify the roles or tasks played by "Support Workers". However, types of Support Workers are listed in the Staff Guidance published by DWP. ¹⁵

The vast majority of support workers were BSL interpreters. This partly reflects the over-representation in our sample of Deaf or hard of hearing respondents.

Some respondents said that their support worker fulfilled more than one of these different roles or tasks. Some did not specify the roles or tasks performed by their support worker.

¹⁵ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/541858 /access-to-work-staff-guide.pdf

Why is the AtW scheme so important?

"I can hold down a job. It's changed my life. Simple as".

Despite difficult changes in recent years, respondents to our survey overwhelmingly supported the AtW scheme. A large majority credited Access to Work with keeping them in employment, enabling them to do their job to their best ability, empowering their employers to understand and adjust to their needs, and adding to their quality of life.

No less than 50 respondents stated that without AtW they would be unemployed and reliant on benefits. Comments like this were common: "If AtW didn't exist, I would be unable to sustain full time employment. I'm extremely glad to be able to continue working."

The support valued by our respondents from AtW extended to:

- BSL support for Deaf employees to facilitate communication in meetings, training and events: "AtW allows me to have the access I need in order to do my job within a hearing organisation." "Having a BSL interpreter enables me to do my job and provide a good service to my clients and lets me be a part of my team."
- Getting to and from, and within work: "I could not get to work or do my job without the equipment I use and my transport to and from work."
- Support with self-employment: "The scheme is incredible and has really helped me in my first couple of years in business, I couldn't have done it without the help I now have a very successful business."
- Support for people who are neurodiversity in a neurotypical workplace: "I couldn't work without it as I cannot cope with other people's ways of communicating & behaving."
- Support with physical impairment: "I had equipment and training provided which greatly improves my RSI." "Advice and equipment is important for individuals to feel able to work effectively. Without that, I wouldn't have been able to continue to do the job I was trained for."
- Advocacy support with employment issues: "It's brilliant to find someone is on your side when struggling at work."

Doing my job to my best ability

When we asked people for positive comments they commonly said words to the effect that "when the package of support meets your needs, AtW is fantastic and enables you to do your job without your disability getting in the way."

Most people said that without AtW support they either couldn't do their job at all, or as effectively. They wouldn't be able to reach their potential in the workplace and would experience significant disadvantage in career progression. "With Atw I got to excel in my job, rather than being left on the dump."

Better quality of life

Many respondents commented that being able to work had a positive impact on their wellbeing. They noted the positive impact on their confidence, as well as the financial, social and physical benefits of working. They valued the ability to have a job, pay taxes and support their families, as well as the ability to feel included in society by playing a worthwhile role.

"This scheme is brilliant and makes it possible for me to work - it helps me retain my independence, support other people and reduces the daily stress and frustrations of having a disability. Having moderate-to-severe hearing loss makes life very difficult. ATW helps make my life and job easier and I really depend on it to keep me in a job which provides my livelihood."

Promoting equality and independence

Respondents also reported that, thanks to the intervention of AtW, their employers were better able to understand and meet legal duties under the Equality Act 2010 to make adjustments to accommodate their disability. As a result, they felt better able to succeed in the workplace on a level playing field with non-Deaf and Disabled workers.

"It allows you to stay in control of your own life and get your needs met better without feeling like you have to be beholden to your employer. It promotes true equality and independence in a way that is almost unique for the average Deaf and Disabled person."

Key data on changes to AtW

"Access to Work was effectively taken away from me due to the changes."

Reduced support

- 1. 46% of respondents said there had been changes to their AtW package. Only 3% mentioned that this change involved an increase in their support
- 2. 43% said the changes impacted adversely on their ability to do their job
- 3. More than half did not know the reason for the changes
- 4. 55% of those experiencing changes were Deaf or non-hearing, the vast majority of whom worked full time
- 5. The majority (one third) of those experiencing changes received just 0 -5 hours of support per week. Only around one in ten received more than 30 hours of support per week
- 6. The most common type of change mentioned was a reduction in support worker hours (48 respondents)
- 7. The changes were not only financial. A great number of respondents said they effectively lost support because the processes for claiming AtW have become so onerous and protracted that the scheme was no longer a viable form of employment support.
- 8. Over 50% of respondents found AtW difficult to claim or use, with one in four reporting severe difficulty.

Impact of changes to AtW

We invited free text responses from respondents with regards to what the changes amounted to, what the reason for the changes were, and what impact the changes had had on their ability to do their job. These responses were subjected to thematic analysis.

 41 respondents said the changes had impacted on their productivity at work or their ability to perform their job to the required standard

- 36 said they had lost the ability to communicate, which affected their attendance at meetings, training, using the phone, attending conferences. Several mentioned loss of career opportunities and career progression
- 19 mentioned the personal impact of the changes in terms of stress and an adverse effect on health, self-esteem and confidence
- 10 reported anxiety about being able to hold down job or remain in employment
- 9 said they had had to turn down work or that their income had dropped due to the changes
- 10 mentioned that the changes placed an undue burden on their employers
- 11 reported having extra workload either because of excessive AtW bureaucracy, or having to deal with agencies, ie loss of admin support from AtW

Reasons for changes

A large proportion of respondents did not know why that package had changed. Only 3 people said that the reason for changes was a reduction in their need for support. An analysis of what respondents were most frequently told by AtW advisers reveals that:

- Cost cutting, savings to the public purse, cost effectiveness were the most commonly used phrases to justify reductions in support. "New rules" were often mentioned, but not explained.
- Underusing their AtW package the previous year was the second most common justification made by AtW advisers for reducing support hours or budget upon reassessment. This applied even if the reason their support award had not been used in full was due sickness absence or a holiday.
- The imposition of technology to replace a human support worker was often mentioned, even when this meant support was effectively lost.
- "Reducing fraud" There appeared to be a more stringent assessment of need for support. Eg having to prove need for wheelchair by providing an NHS letter; disputes over the need for taxi transport; dispute over a Deaf person's inability to use the phone.

- "Minimum standards". Some people were told AtW now only provided support "to a minimum standard", therefore they had to make do with a substandard package. Examples include Deaf customers having to use an underqualified Communication Support Worker rather than a fully qualified BSL interpreter.
- **Permitted Work Rules** Two people working under ESA Higher Level Permitted Work Rules were told their AtW had to stop or be paused after 52 weeks. This is despite the fact they were in the ESA Support Group so had no 12 month time limit on Permitted Work.

Discussion of changes to AtW

1. Cutting by stealth

"The cost effectiveness model seems more vital to Access to Work instead of addressing my personal needs and what I require to deliver in my job".

Since publication of the Sayce report in 2011, AtW has been aiming to support more Deaf and Disabled people in, and into, employment but within a finite budget. Measures have been sought to spread the budget more thinly, by bringing down the average value of awards as well as reducing the maximum value of awards.

The findings from this survey suggest that the main adverse impact of changes to AtW result from the "shaving off" of low and middle value awards, as much as from the reduction of high value awards.

Most of our survey respondents reported that the changes to their AtW package was justified by unspecified "new rules" relating to cost effectiveness and protecting the public purse, rather than any specific policy change announced by DWP such as the cap on maximum awards. Phrases such as "funding cuts", "too expensive", "need to make savings" and the "need to reduce fraud" were commonly given by AtW staff when communicated changes to support.

It appears these "new rules" often related to guidance given to AtW advisers on ensuring value for money. The guidance states three principles underpinning AtW awards which clearly offer considerable scope for interpretation:

- Additionality Support should be over and above what a non-Disabled person would require in order to do their job and beyond the reasonable adjustments that an employer is legally obliged to make;
- Meeting minimum need Providing support that meets the customer's minimum needs;
- Cost effectiveness Doing this in the most cost effective way.

The persistence and frequency of inappropriate decision making encountered in our survey suggests staff may be under pressure to find routes to reducing the average value of awards. This was certainly the feeling among many respondents:

"I don't know the reason [for the change] but I feel absolutely sure that AtW employees are now required to try to find all possible reasons to refuse help."

Common routes to reduced support

The guidance on cost effectiveness and meeting only minimum needs was often used to deny essential support.

- Meeting "minimum needs". We heard many examples of "minimum need" guidance being used to justify removing support that was essential in doing their job or progressing in their careers. For example, Deaf people working full time were told they only needed to be able to communicate 3 days in the week and were left without BSL interpretation for the other 2 days in the week. This resulted in their exclusion from meetings and prevented them performing to their full potential. In many cases the support they were denied was not an optional extra but was vital to meeting the requirements of their job: "Without the equipment I am 70% slower than others, even though I'm mentally the same. So my productivity and accuracy are all badly affected."
- **Cost effectiveness**. We even heard a shocking example of the cost effectiveness principle invoked in direct contravention of the purpose of AtW. One respondent said "They cut my support because they said a hearing person could do my job".
- Imposing technological over human solutions. The Value for Money guidance encourages the use of new technology where this provides a cheaper solution in the long term than a support worker to a Deaf and Disabled person's needs. However, we heard many cases where this guidance was applied bluntly and without consideration of its appropriateness in individual cases. "At first when I began a new job they wanted to throw all sorts of technology at me thankfully I have a great employer and we appealed for a more appropriate support package which was about human support". This was a particular problem where AtW staff appeared to have little knowledge or understanding of the role of BSL in communication by Deaf people, and tried to impose technological solutions that are not appropriate.

There also appear to be procedures and mechanisms within the AtW system which facilitate the reduction of support. For example:

• **Frequent reassessment**. Respondents felt that reassessment often occurred, not in response to a change in their needs, but as a vehicle for

reducing their support. "My package met my needs and was great. However due to a change in job title (the same role) they reviewed my package of support and decided that I could use BSL instead of a palantypist so now AtW does not meet my needs at all." Reassessments or reviews were imposed more frequently than necessary, which was not only bureaucratically inefficient but impacted negatively on Deaf and Disabled people's ability to do their job: "They kept allocating 6 months of support at a time which meant I had to deal with "reviews" twice a year. Stressful!

- Reducing support in response to an underused budget. Twenty one respondents said their support worker hours had been reduced because they had not used up all their hours the previous year. Often the reason for the underspend was a period of hospitalisation or a holiday and sometimes the AtW calculation of hours used was disputed by respondents. "I didn't use all of the hours given in the last package but this was due to long term sickness and had I been at work, I would have used them all." This seemed to be an unfair and inflexible way of determining future need for support.
- Reducing eligibility for assessments and repairs for equipment. Some respondents were told that AtW no longer does wheelchair assessments and they would have to have an assessment done privately, or that their wheelchair had to come from the NHS. We also heard cases where AtW refused to carry out replacement or repair of essential equipment, putting customers at enormous disadvantage: "AtW won't pay for repairs to equipment so when it breaks it is as if I had no equipment in the first place - until I can afford to pay for the very expensive repairs." The implication many respondents felt is that they had to make do with second best equipment, or with being excluded from meetings, for example, because ensuring they could perform to their full potential at work was no longer affordable. In many cases the support they were denied was not an optional extra. It was vital to meeting the requirements of their job: "Without the equipment I am 70% slower than others, even though I'm mentally the same. So my productivity and accuracy are all badly affected and I would get sacked at that level of output."
- Restrictions on duration or portability of awards. A commonly expressed frustration was the limitation and inflexibility of an AtW award that did not reflect the real world of employment or self-

employment. This may have been the consequence of changes to assessments in an attempt for greater standardisation. "they like things neatly packaged and clear, but my job varies a lot so the support I need depends on this, also my health impacts on usage too. I can't give them the info in the way they want me to."

It appears that this "box-ticking" approach has increased as a result of the loss of the personalised caseworker system when the call centre was introduced. Respondents felt that awards were of shorter duration and more restricted to specific contracts in recent times. Contrary to recommendations in the Sayce Review, respondents noted that there was less flexibility and portability of AtW awards since the restructuring of 2014. It was more difficult to increase or decrease support in response to changes in health or employment; and more difficult to use an AtW award in a dynamic self-employment market (see case study).

Conclusion: Respondents with high value awards had been very adversely affected by the "30 hour rule", and were very concerned about the effect of the forthcoming cap on maximum awards. However, our survey indicates that the majority of customers disadvantaged by changes to AtW have low and average value awards. Respondents' reports suggest that "value for money" guidance issued by DWP is being interpreted and applied in decision making by inadequately trained advisers with insufficient understanding of their clients' needs, and in response to pressure to make savings. While the stated AtW policy only justifies a cap on high level awards, the practices of AtW advisers have the effect of rationing low and average value awards too. The erosion of low and average value awards has a significant adverse impact on Deaf and Disabled's people's ability to sustain work, perform to the standards expected, and to progress in their careers.

2. "Jumping through hoops": administrative barriers to AtW

"Access to Work is no longer person centred."

For many respondents, the "changes" to AtW were synonymous with a greatly increased administrative burden. Most found that AtW was harder to claim, advisers were less likely to understand their needs, and they found themselves spending much more time challenging wrong decisions.

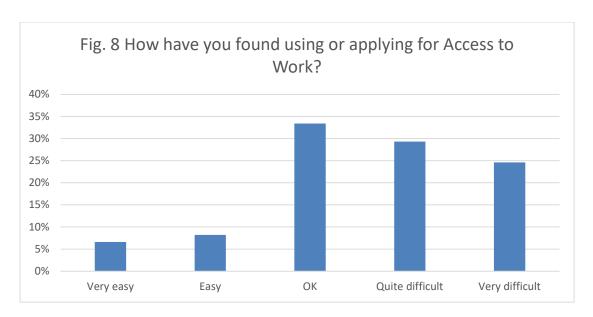


Fig. 8 shows that only 15% of AtW customers in our survey found it easy to apply for, or use, AtW. Over a half of respondents found the process difficult to use, with one in four reporting severe difficulty with AtW.

The Call Centre

Before the "call centre" system was introduced in 2014, AtW customers would maintain ongoing relationships with a single AtW Adviser, or small group of Advisers, who knew and understood their circumstances. Under the new system, each call appears to be randomly allocated to an adviser who has little or no information about their individual circumstances. "16

The WPSC inquiry found that the call centre system was particularly problematic for customers with certain impairment types, particularly those who required support to receive a telephone call, for example Deaf people who use BSL and therefore require an interpreter, and people with learning difficulties or autism who might also need a Support Worker to be available.

Our survey found little evidence of improvements to the call centre service since the WPSC findings and recommendations were accepted by the then Minister. An email service for Deaf customers was launched in December 2014 and welcomed but it does not appear to be operating effectively.

"Contacting AtW is worse than ever, they're slow by email and I won't phone them because NGT (text relay service) is horrendous and mistakes get made and I get blamed. I miss having a named advisor... having to explain

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¹⁶ WPSC (2014) Changes to Access to Work

EVERYTHING to every single person EVERY time is really stressful and actually traumatic..."

The consequences of the new call centre system for all AtW customers were:

Loss of personalisation and expertise

"It used to be good, I could email a case worker. Case workers are no longer available." The new call centre structure has entailed the loss of the caseworker system. Under the previous system, advisers developed personalised knowledge of the customer's needs over time, including their communication needs, and customers knew who to turn to with queries or changes to their requirements. This allowed for a person centred model of assessment and support. Now, as one respondent said, "It is luck of the draw if you get an adviser with knowledge of autism."

Around a 100 new staff members were recruited for the call centre restructuring. Initially problems with lack of Deaf and disability awareness among staff could be explained by lack of experience. However, these problems appear to be on-going. A respondent felt that "staff are no longer experts but low paid workers with a script programmed to make things hard to claim."

• Communication delays and inefficiencies

"I no longer have a local AtW officer to advise me. I have to use a general email address and it takes a long time to get an appropriate response, that is if you do get a response. So, I can't get anything 'simple' resolved quickly, it's very frustrating." Even when the email facility was offered, it was felt that the new chains of communication which have replaced direct contact with an adviser function poorly. This makes communication processes longer and more difficult. "It's quite difficult when ... trying to contact them to query anything or get relevant advice due to the difficulty of contacting the right person or department." "It's sometimes difficult as the case worker changes too frequently and time is wasted having to repeat the same information."

Increased bureaucracy

"AtW is taking more time than my job". The WPSC criticised the outdated paper-based processes used by AtW. Many respondents to our survey complained about having excessive paperwork to deal with. Certainly, many would welcome an online portal for claims and payment processing to replace the paper-based system. However, the comments we received related not only to the medium of communication but to a perceived increase in the frequency

and complexity of form filling: "Too many questions and forms to fill over and over again - do they not keep my details on file?"

It is possible that this perceived increase in bureaucracy is linked to the higher frequency of reassessments, a drive for standardisation, and to restricted award duration and portability (see above) and to the tighter eligibility criteria for assessment and repairs of equipment.

Its adverse impact on respondents was one of the most common issues they raised. We heard many reports similar to this one: "Last time I applied, the process was so protracted that I was put off from doing it again." And this: "I've spent so much time dealing with ATW that I've actually had less time to do my job. Some days I spend more time on ATW than on my job itself."

It is extremely concerning to hear reports like these: "Bureaucracy has greatly inhibited my ability to work effectively, including great stress from threats of legal action from unpaid interpreters!"

Poor information and signposting for new and existing customers

Many respondents we heard from struggled both to make initial contact with AtW and also to obtain information and guidance following their initial assessment or award. Examples included:

- Poor signposting for new applicants. One person expressed the feeling that "they don't want you to contact them, the barriers to initial contact are eye-watering!" Another explained her advantage in having knowledgeable employers: "I found the system quite straightforward, but I only knew about it in the first place because I had a very pro-active boss in this regard. Had she not been so well informed and supportive I may not have known about the scheme."
- No continuity in communication following an award. The communication difficulties brought about by the call centre system appear to have left AtW customers unable to obtain simple guidance on how to use their award or report changes. This created great uncertainty when there were changes in their circumstances to report, as in this case: "I have no idea how to get hold of someone to ask questions, tell them I have moved or to discuss how to prepare for renewal and how to explain /deal with a planned break in working a few months which will affect my overall income which is now considered when support is reviewed." This situation was very

commonly reported by self-employed customers in particular: "As a freelancer... I have been given very little guidance on how my award can be used - some months I use it more than others. I finally got an answer on my 3rd phone call that this did not have to be 14 hours per month, but more an annual budget. I don't understand why it was so difficult to get a straightforward answer."

• No notification of when an award is ending. In several cases people found their award had been stopped without notice; they were not told when their award would run out, or they only found out their support had been reduced when BSL agencies contacted them to claim unpaid fees. Customers have been told it is now AtW operational policy not to contact them when their package is due for renewal. "I have just found out that my A2W fund was stopped and not renewed. I wasn't aware of this, so a reminder that the scheme is due to end would be useful as I now need to apply again instead of having a renewal."

Many respondents described dealing with AtW as akin to "jumping through hoops". This situation has persisted long after the new call centre was established in 2014 and can no longer be explained by transitional difficulties.

We heard of many cases where administrative and communication barriers were so severe that they affected Deaf and Disabled people's ability to remain in work. Some respondents found that it took them so long to apply for AtW that they had to start a new job without support in place and their need for support was then put into question.

"The process for claiming is too complicated and I have ended up out of pocket because it is too difficult to navigate."

"Access to Work isn't working because it is no longer possible to apply in a timely fashion. Cutting staff has cut availability."

"Getting support from AtW takes too long. I started the process 3 months in advance [of a new job] only to be told ... that my award had finally been granted a WEEK after the date I needed that support."

Conclusion: The administrative restructuring of AtW in 2014 has affected the accessibility and operation of AtW to the point where the programme is sometimes not fit for purpose. Inefficiencies and delays in communication, poor disability awareness among staff, and the loss of the personalised case worker system have all contributed to greatly reduced levels of customer

service. This loss of service impacts directly on the viability of the AtW programme for Deaf and Disabled people striving to remain in work.

3. Compounded difficulties for Deaf/BSL customers

Deaf customers are one of the groups worst affected by changes to AtW. They are typically disadvantaged both by the "value for money" reforms which have sought to limit expenditure on BSL interpreters, as well as by the administrative restructuring with its accessibility issues and the loss of a personalised relationship with a Deaf-aware adviser.

Inaccessibility of AtW processes

The call centre system, based on telephony and launched in 2014, was originally inaccessible to Deaf or hearing impaired customers.

"ATW expected me to use a telephone to contact them for my initial contact which is a ridiculous expectation for a profoundly deaf person! It took several calls using Text Relay before I was given an email contact. I also had to continually remind the ATW adviser of my claim as emails were not always answered."

The more recent email facility for Deaf customers appears to be functioning poorly, with unacceptable delays in response times. DWP recently announced the launch of a BSL video relay service. This should bring a welcome improvement in communication for Deaf AtW customers.

The recent policy of regular reassessments leads to unnecessary bureaucracy for a customer group whose condition and needs are fixed: "Why do I need to explain my deafness and needs again and again - it isn't going to change!"

Lack of Deaf awareness in policy design and implementation

The drive to bring down the costs of BSL interpreting appears to have been carried out without a full understanding of the role of BSL as a first language, Replacing a fully qualified BSL interpreter with a cheaper, trainee Communication Support Worker frequently results in Deaf employees being unable to do their job. Nor can Deaf people needing full time BSL support employ a single full time support worker for BSL interpreting because of the need to employ different interpreters in different professional contexts, according to their specialism, eg in finance, or law, or education. This meant the 30-hour rule was untenable for many Deaf people.

Most Deaf respondents reported encounters with AtW advisers who did not have sufficient awareness of Deafness and hearing difficulty to understand their needs:

"Advisors appear to have very limited knowledge & understanding of how specialist equipment supports a deaf person. Hence the whole process takes too long & becomes much more stressful to deal with. I think this could be avoided with more training & understanding. Not just filling in forms & ticking boxes. Unless you have support of an experienced person, it makes life extremely difficult."

The 30 hour rule led to severe cuts to BSL pay rates for full time customers of BSL. We heard of a case where a package of 37.5 hours of qualified interpreters' support at £35 per hour was reduced to £18 per hour as part of the 30 hour guidance. This led to loss of employment after three months as the pay rate was unsustainable.

Even now that the 30 hour rule has been abolished, respondents reported a wide range of pay rates among colleagues for BSL interpreting, from £18 to over £40 per hour.

A recent Freedom of Information request response (FOI 876) stated that "Access to Work does not have set pay rates for BSL/English interpreting and CSW support for Deaf and deafblind people. Access to Work advisers, in discussion with the customer would establish both the level and type of support required and source this from within the area where they are working and do so on the best value for money basis".

This was not the experience among our survey respondents. Deaf people are being pressured to accept a mixture of interpreting and CSW hours rather than solely interpreting hours, despite the fact that their needs can only be met by qualified interpreters.

Some respondents told us they had managed to negotiate a higher rate for interpreting after challenging their award. But this leads to a perception of unfairness:

"I had a bit of a battle with AtW due to the variation in prices. One of my colleagues works in the same room, same building, but less senior, yet I get much less per hour for interpreters compared with them. It's not fair and doesn't make any sense to me"

Future implications for BSL interpreting

DWP is implementing centralised commissioning for BSL interpretation via the national framework agreement launched in April 2016. This may help to establish clarity and consistency over BSL pay rates. However, the National Union of British Sign Language Interpreters (NUBSLI) has warned that the national framework agreement will result in worsening terms and conditions and an erosion of fees for BSL interpreters. A survey of registered BSL interpreters in 2015 found that a quarter were planning to leave the profession, with the vast majority citing uncertainty in the profession as the cause of this action. NUBSLI is concerned that an under-valued and deskilled BSL interpreting industry will not be able to provide full access to employment for Deaf people, as well as undermining Deaf people rights and inclusion in society more generally.

The new cap on the maximum value of awards at £40,800pa was introduced in October 2015 and will not fully affect existing AtW customers until 2018. None of our survey respondents had therefore had their award capped under this policy, although several people reported increased anxiety at the impact of the capping policy at their next reassessment.

The cap is projected to affect 200 AtW customers, of which 90% are in the Deaf/hearing loss category. It is predicted to save 3% of the total AtW budget, and to enable an extra 982 people to be supported by AtW on average awards of around £3,000.

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¹⁷ NUBSLI (2015) Survey of BSL interpreters' working conditions

Conclusions

StopChanges2AtW has been monitoring changes to the AtW programme since 2012/2013. Towards the end of 2015 we surveyed 320 AtW customers to assess whether and how the administrative and policy developments in the AtW programme have continued to affect their working lives.

It was clear from our survey that AtW is still not working the way it did before 2014 for most of our respondents. In too many cases, on-going changes have led to loss of opportunity, loss of equality, and loss of independence in work, as well as in the rest of their lives.

The findings of this survey spell a strong warning. An apparent agenda of cost cutting rather than investing to save is putting Deaf and Disabled people's jobs and livelihoods at risk. If this trend continues we will see reduced diversity in the UK workforce, and an increase in the numbers of Deaf and Disabled people claiming out of work benefits.

AtW has the potential to transform lives for Deaf and Disabled people. It should be central to this government's attempts to build a country that works for everyone.

A national treasure

We heard from Deaf and Disabled people working in the not-for-profit, government, private, education and health sectors. Most of them worked full time and 60% were Deaf or non-hearing.

Despite the distress and disadvantage caused by the restructuring of AtW, most respondents still placed a high value on the scheme. They credited AtW with removing the disadvantages that prevented them from holding down a job, or achieving their full potential in work. They spoke of the enhanced wellbeing that came with work: the sense of purpose, inclusion in society and financial independence. In the best cases, AtW did not just provide equipment or support workers but helped to broker better understanding and adjustments by employers.

A good package of support from AtW was characterised by the security of award length to allow people to focus on doing their job, and the flexibility to respond to changes in role or employer. This seemed to result from a

combination of expertise with a person-centred approach among AtW assessors.

Rationing of support

However, almost a half of our respondents had experienced changes to their AtW package which had impacted negatively on their work, mostly by reducing their standard of work or their productivity. In some cases, the changes had led to loss of income or employment; and in many cases they caused anxiety about job sustainability and personal distress. Deaf people and those with hearing loss were hit far worse than other impairment groups in our survey sample.

The majority of respondents whose support had been reduced received less than 5 hours of support per week. Of those who were given reasons for the reductions to their support package, the majority mentioned "cuts" or "cost-cutting". The most common reduction was a cut in BLS interpreter hours.

The most common routes to reduced support mentioned by respondents were frequent reassessment; cutting support because of an underused budget the previous year; preference for technological over human solutions even when these did not fully meet needs; reducing eligibility for assessment and repair of equipment; and restrictions on the duration and portability of awards.

Respondents with high value awards were worried about the effect of the forthcoming cap on maximum awards. The impact of the cap was not captured in our survey because the majority of AtW customers affected would have transitional protection until 2018. However, our survey indicates that the majority of customers disadvantaged by changes to AtW have low and average value awards. Respondents' reports suggest that "value for money" guidance issued by DWP is being interpreted and applied in decision making by inadequately trained advisers with insufficient understanding of their clients' needs. While the stated AtW policy only justifies a cap on high level awards, the practices of AtW advisers have the effect of rationing low and average value awards too. Yet the impact of this is not being monitored by DWP.

While the effects of the cap are of great concern, the erosion of low and average value awards has an equally significant adverse impact on Deaf and Disabled's people's ability to sustain work, perform to the standards expected, and to progress in their careers.

Jumping through hoops

The negative changes to AtW experienced by respondents were not only financial. A great number said they effectively lost support because the processes for claiming AtW have become so onerous and protracted that the scheme was no longer viable. Over 50% of respondents found AtW difficult to claim or use, with one in four reporting severe difficulty.

Our survey found that support was being undermined by a climate of suspicion of fraud and increased "red tape".

For many respondents, the "changes" to AtW were synonymous with the new call centre. Accessibility issues with the call centre appear to remain, especially for non-hearing customers and those with autism, but also for all customers due to the inefficiency of communication processes. A minority of non-hearing respondents found the recent email facility brought improvements in communication but most reported extreme frustration with the unresponsiveness of email communication. The BSL video relay service for Deaf customers announced by DWP had not yet been launched.

The loss of the named local caseworker system under the call centre restructure was particularly regretted. This was associated with loss of condition specific expertise, with inefficient chains of communication, and with greater likelihood of incorrect decision making, bringing with it protracted negotiation and dispute over AtW awards, impacting on respondents' ability to get on with their job.

Respondents reported very poor information and signposting with AtW. This affected new customers who faced barriers to engaging with AtW. It also affected existing customers who frequently didn't know how to make basic queries, obtain advice or report changes once their award was in place.

There was a perception of increased "paperwork" in the AtW process. This may be alleviated by the planned digital portal to replace the outdated and inefficient paper-based processes. However, to our respondents it felt as though more barriers had been put in their way. It may be that the increased frequency and complexity of form-filling is a feature of bureaucratic changes to AtW which will be retained on the digital platform.

The administrative restructuring of AtW in 2014 has affected the accessibility and operation of AtW to the point where the programme is sometimes not fit for purpose. Inefficiencies in communication, poor disability awareness among staff, and the loss of the personalised case worker system have all contributed

to greatly reduced levels of customer service. This loss of service impacts directly on the viability of the AtW programme for Deaf and Disabled people striving to remain in work.

Added barriers for Deaf customers

Deaf customers experienced combined disadvantages from changes to AtW. The call centre system remains poorly accessible to them. They have been targeted for reductions to high value awards, initially through the 30 hour rule, now by the cap on maximum awards. They also experience inconsistency in pay rates for BSL interpreters which are seen as arbitrary and unfair and pressure to use cheaper, unqualified communication support workers who cannot fully meet their needs. While a new commissioning framework for BSL services aims to standardise pay rates, there is concern that this will drive down pay and conditions for BSL interpreters and undermine the quality and sustainability of the profession.

Changes to AtW are not evenly spread among all customers. 90% of those targeted by the new capping policy are Deaf. StopChanges2AtW believes this will discourage employers from employing Deaf people, increase the likelihood of discrimination against them, and reduce equality of opportunity among this group. If fewer Deaf people are in employment this may damage relations between Deaf and hearing people, as well as impacting on Deaf people's rights to participate in the economy and society and to have choice and control over their lives.

A perverse agenda

Often the crucial difference between a Disabled person in receipt of social security benefits and a Disabled person in work is the availability of aids, adaptations and support that enable them to enter and progress in the workplace. Some of our respondents felt this key enabling principle of AtW was being eroded:

The impact of the changes has been severe stress, affecting my physical health. My confidence, self-esteem and motivation are all affected... I have to work much harder than hearing people to sustain work. Access to Work do not realise if disabled people are not given the support required to sustain work they then become another statistic on the dole.

The fact of the significant and very real barriers faced by Deaf and Disabled people in their working lives seems to have become lost to AtW policy makers. Respondents often expressed the feeling that the overarching purpose of the AtW changes was, not to enhance the support it offers, but to encourage less dependence on the State by Deaf and Disabled people, by "treating us like scroungers", and to increase surveillance against fraud. This is a sad and negative development in the Deaf and Disabled people's movement for change.

A partnership for change

StopChanges2AtW welcomes the government's focus on increasing the numbers of disabled people in work. We welcomed the announcement in Autumn 2015 of increased funding for the AtW scheme; the planned operational improvements to access and the announcement of specialist teams of support.

We wish to partner with the government in fixing the broken aspects of AtW outlined in this report. AtW has a track record of success and value for money and should be the key plank of disability employment policy going forward. We wish to see its future secured, not just for the sake of existing customers who are being failed by the programme, but for thousands more Deaf and Disabled people whose lives could be transformed through inclusion in the workplace.

Recommendations

1. Commit to an Access to Work programme that embodies the following principles and values:

- 1.1 The aim of AtW must be to level the playing field for Deaf and Disabled people to get into, stay in and get on in the labour market. We are the experts in our access needs.
- 1.2 Support through AtW should focus on our abilities and enable us to fulfil our potential.

1.3 It should not:

- Place Deaf and Disabled people at financial risk
- Disadvantage Deaf and Disabled people in the work-place
- Impose inappropriate support
- Normalise inequality
- Subject Deaf and Disabled people to hostility and discriminatory attitudes

2. Place AtW at the heart of the government's strategy to increase the numbers of disabled people in work.

"Improving Lives: the work, health and disability green paper" contains few mentions of Access to Work and yet its effectiveness at supporting Deaf and Disabled people to get into, stay in and get on in employment is well evidenced, while investment in the programme produces a return for the Treasury. Improvement and expansion of the Access to Work programme must be a central part of proposals to reduce the disability employment gap.

3. Equip AtW to enable Deaf and Disabled jobseekers to move into work

- 3.1 Give an indicative support package to new customers at job application stage so they can reassure prospective employers of their ability to meet job requirements.
- 3.2 Revise rules which limit support to 52 weeks for Higher Level Permitted Work customers. There are no longer time limits for Higher

- Level Permitted Work under current ESA and Universal Credit regulations.
- 3.3 Expand the availability of AtW to Deaf and Disabled people gaining experience through volunteering and other forms of work experience beyond the current regulations which limit support to specific internships, trainee and placement initiatives. This could also benefit Deaf and Disabled people in self-employment who are prevented from opportunities to work to build their businesses by the viability model currently operated by AtW.

4. Improve job security and stability for Deaf and Disabled people in work through:

- 4.1 Reduce target waiting times for agreement of new packages to four weeks maximum. Delays keep employers waiting unreasonably and put AtW customers' jobs at risk.
- 4.2 Reduce frequency of reassessments for those with lifelong or chronic conditions and stable employment. To avoid insecurity and instability, reassessments should only be triggered by a change in support needs or for conditions expected to change over time.
- 4.3 Increase the length of AtW awards, especially for self-employed workers, to allow stability in work and minimise the loss of productivity and risk of job losses caused by reassessments and incorrect awards.
- 4.4 Advisers should not reduce AtW awards when people under-use their budget the previous year for a reason unrelated to changing needs, for example sickness absence or hospital leave.
- 4.5 AtW should bear full financial responsibility for repair or replacing of equipment it provides for as long as the customer is eligible for support.
- 4.6 Increase the portability of AtW packages, especially for the selfemployed, to allow them to take up employment opportunities without delay and to avoid barriers to taking up short term contract work where the wait time makes it unviable.
- 4.7 Review the system for providing and maintaining wheelchair equipment so that wheelchair users are not disadvantaged at work by unnecessarily lengthy and frustrating processes.

5. Introduce digital systems to improve delays, reduce inefficiencies and tackle fraud

- 5.1 An online claims system for AtW would protect both customers and support staff from fraudulent activity and reduce the rate of delays due to missing forms.
- 5.2 Online payment processing would reduce delays and incidences of payments missing in the post.

6. Improve communication with new and existing customers and employers

- 6.1 Notify customers three months before their award ends, and again one month before, to allow sufficient time for reapplying without interrupting their employment.
- 6.2 Provide auto alerts to customers whose claims have exceeded their monthly allowance
- 6.3 Respond to all call centre inquiries within 48 hours.
- 6.4 Inform customers in writing about any changes to AtW awards, eg changes to BSL pay rates, giving clear reasons for any changes.
- 6.5 Provide clear information on how to contest decisions and make complaints.
- 6.6 Bring back the named caseworker system and allow AtW customers to have direct contact with their caseworker at all stages of their award.
- 6.7 Systems to be established so that customers can communicate directly with AtW in ways that meet their access requirements including BSL, electronically, easy read format and face to face visits or via a third party if that best meets the customer's needs. Access needs to be recorded and respected by AtW staff at all times when making contact.
- 6.8 Improve signposting, information and guidance to new customers and employers.
- 6.9 Customer service standards for AtW staff to ensure positive communications and reverse the trend of treating customers as burdens on the taxpayer.

7. Improve decision making in AtW through:

- 7.1 Deaf and disability training for AtW staff should be delivered by Deaf and Disabled people's organisations and based upon the social model of disability.
- 7.2 Improve staff guidance on Minimum Needs to ensure that AtW packages fully meet all Deaf and Disabled people's employment support needs. Deaf and Disabled people should have choice and control over the support they need and should not have inadequate or unqualified support imposed on them.
- 7.3 Support needs of customers to be taken into account above arbitrary targets for time-limiting awards. There needs to be recognition of the value of ongoing support in enabling Deaf and Disabled people to stay in and get on in employment across all impairment groups including mental health support needs and neuro-diversity.
- 7.4 Advisors to be open to customer choice in meeting support needs rather than imposing a one size fits all approach through contracted services.
- 7.5 Review to be carried out into the interpretation of the 80/20% ratio with specific relation to the support needs of people with learning difficulties/disabilities in different job roles.
- 7.6 Improve transparency in decision making by consulting with Deaf and Disabled People's Organisations on all changes to staff guidance and communicating it with customers.
- 7.7 Improve staff training in decision making and interpretation of guidance to ensure consistency and reduce the need for complaints.
- 7.8 Have a clear standardised system for calculating support which is consistent and fair, to ensure full transparency and stop the discrepancies between awards.

8. Remove the cap which discriminates against Deaf and Disabled people with high support needs and in senior job roles.

For as long as the cap/transitional cap is in place to ensure that:

- 8.1 Customers are contacted in good time before they reach the cap to avoid using assistance/support that they cannot then pay for.
- 8.2 One-off costs towards the cap are not counted for example the cost for purchase of a wheelchair will significantly reduce the amount of

support costs that are available within that year to the point of making employment unviable.

9. Review the current guidance on self-employment 'business viability'

- 9.1 Consult with Deaf and Disabled people about the barriers to selfemployment presented by the current AtW guidance. Selfemployment can have many benefits for Deaf and Disabled people due to increased flexibility, however the inflexibility of AtW guidance on self-employment prevent them from taking this up.
- 9.2 Review the current 'business viability' threshold of £5876.00 turnover which creates a barrier for Deaf and Disabled people in low paid and/or part-time self-employment.
- 9.3 Extend the start up period where the turn-over threshold is not applied. Currently this is set at 12 monthsbut it often takes far longer for a business to be established, especially for Deaf and Disabled people who may require longer due to the additionl barriers we face.
- 9.4 Ensure that the guidance takes sufficient account of periods of ill health/disability-related absence from work. This is a crucial factor that may affect, and repeatedly affect, Deaf and Disabled people in self-employment (especially if sole trading).
- 10. Put Deaf and Disabled people back at the centre of the AtW process. Consult with StopChanges2AtW, and other user-led organisations of Deaf and Disabled people on any further revisions to AtW policies or operational changes to AtW processes.

11. Address the disproportionate impact of changes to AtW on Deaf/deaf, deafened and hard of hearing customers

- 11.1 Ensure that where interpreting support is required, Deaf AtW customers are always supplied with fully qualified RSLI interpreters unless the customer agrees that a trainee SLI is fully able to meet their communication support needs.
- 11.2 Consult with and seek feedback from Deaf/deaf, deafened and hard of hearing customers on developments with specialist teams and the planned video relay service for BSL to ensure it is fully meeting their access requirements.

- 11.3 The use of new technologies should only be offered as a choice or as part of a mixed package not as a substitute for other types of support for cost saving reasons. They must fully meet access needs.
- 11.4 Do not introduce a Framework Agreement for interpreting services in AtW as this will undermine customers' choice and control and risk the sustainability of the interpreting profession. Consult with the National Union of British Sign Language Interpreters (NUBSLI) to ensure any future changes are feasible.

Appendix 1 - Schedule of survey questions

Preamble to the survey

This survey is being conducted by the campaign group <u>StopChanges2AtW</u> to discover more about the current levels of AtW service being received. This will help us see how changes made/being made are affecting/have affected Deaf and Disabled people using the scheme. Please see our information sheet below for more information.

1. Which "Primary Medical Condition" do you claim AtW for? (Based on AtW Categories)

Missing/unknown

Arms or hands

Legs or feet

Back or neck

Stomach, liver, kidney or digestion

Heart, blood, blood pressure or circulation

Chest or breathing

Difficulty in hearing

Difficulty in seeing

Difficulty in speaking

Learning disability

Progressive illness

Dyslexia

Epilepsy

Diabetes

Mental Health condition

Cerebral Palsy

Spina Bifida

2. How long have you been receiving AtW support?

- 0 1 year
- 1 2 years
- 2 3 years
- 3 5 years
- 5 10 years

10 years or more

3. How many hours do you work?

- 0 5 hours
- 5 10 hours
- 10 15 hours
- 15 20 hours
- 20 25 hours
- 25 30 hours
- 30 35 hours
- 35 40 hours
- 40 hours or more

4. How many hours support do you receive from AtW?

- 0 5 hours
- 5 10 hours
- 10 15 hours
- 15 20 hours
- 20 25 hours
- 25 30 hours
- 30 35 hours
- 35 40 hours
- 40 hours or more

5. What type of support do you receive? (Add all that apply)

BSL/English Interpreter

Job Aide

Travel buddy

Job coach

Mental Health support service

Lipspeaker

Deaf blind interpreter

Note taker

Electronic note taker

Equipment

Other

6.	Has your AtW p	ackage changed?	If yes,	has your	job	changed
(PI	ease give details	s)				

Yes

No

Not sure

Other

7. Have these changes affected your job?

Yes

No

Not sure

Other

8. Do you know why your package has been changed?

Yes

No

Not sure

Other

9. Which sector do you work in?

Not-For-Profit

NHS

Social Service

Government

Private sector

Own business

Other

10. What is your current job?

11. Have you found applying or using AtW:

Very easy

Easy OK Quite difficult Very difficult Other

- 12. Please tell us something positive about the scheme or any recent changes there have been:
- 13. Please tell us something about the scheme that you think could be improved.
- 14. Would you be happy for your experiences to be shared as a case study?

Yes No Anonymised only

15. Is there anything else you would like to add?