

RESEARCH REPORT

# Deaf and disabled performing artists' experiences of the UK government's Access to Work scheme



Dancers on stage. Photo credit: Chris Parkes Photography

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## Table of Contents

<b>A note about terminology .....</b>	<b>2</b>
<b>Foreword .....</b>	<b>3</b>
<b>Introduction.....</b>	<b>5</b>
<b>The key messages from this research .....</b>	<b>6</b>
<b>Summary of the research findings .....</b>	<b>7</b>
<b>About Access to Work.....</b>	<b>12</b>
<b>Research methodology .....</b>	<b>14</b>
<b>Full findings.....</b>	<b>16</b>
<b>Discussion .....</b>	<b>33</b>
<b>Conclusion .....</b>	<b>35</b>
<b>References .....</b>	<b>36</b>

### A note about terminology

In this research report I use terminology advocated by UK disabled people’s organisations. The term ‘disabled people’ is preferred to ‘people with disabilities’. Many Deaf people consider themselves part of ‘the Deaf community’ and capitalise ‘Deaf’ in order to emphasise their Deaf identity. Some people with long-term health conditions fall under the Equalities Act 2010 definition of a disabled person but would not use the term ‘disabled’ to describe themselves. For brevity’s sake, throughout this research I use ‘disabled people’ as shorthand for Deaf people, disabled people and people with long-term health conditions.

In the world of freelance performing artists, a ‘job’ is a piece of work - such as a gig or an acting role - that could last from a few hours to a few months.

## Foreword

This research was conducted in the summer of 2019 for my MSc dissertation at the London School of Economics and Political Science (LSE).

I am deeply grateful to the performing artists and staff of arts organisations who gave up their time to participate in research interviews. Thank you also to the many individuals and organisations who gave me advice about the research and shared my call-out for research participants.

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“Without AtW, I couldn't work. Straightforwardly, I wouldn't work.”

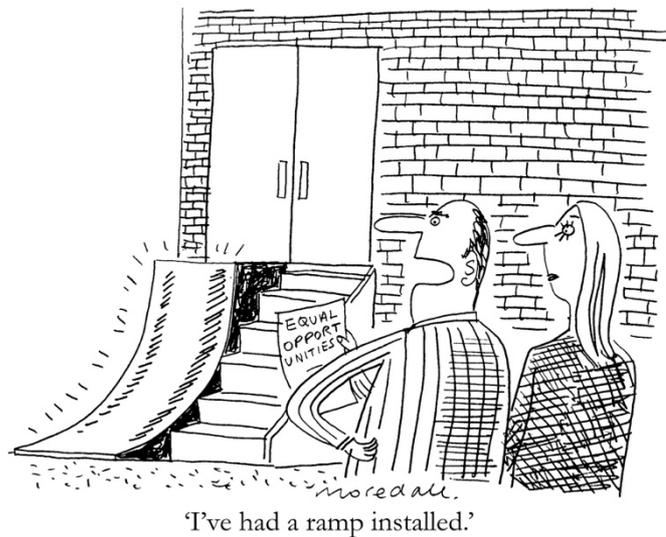
Marie<sup>1</sup>, performance artist

“They call us ‘customers’. If we were customers, we'd shop elsewhere.”

David, freelance musician

“It's definitely stressful. I have cried on a number of occasions.”

Rachel, who manages AtW applications at a dance company



CartoonStock.com

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<sup>1</sup> All names are pseudonyms.

## Introduction

There are 7.6 million disabled people of working age in the UK, and the number is rising. But only 51.7% of disabled people of working age in the UK are in employment, compared to 81.7% of people without disabilities: a disability employment gap of 30 percentage points (House of Commons Library, 2019).

Since the 1990s, successive governments have introduced welfare reforms designed to encourage disabled people into work, with limited success. At the same time, the labour market has shifted away from the traditional model of full-time salaried employment, with a significant rise in people doing **non-standard work** (such as self-employment, zero hours contracts, temporary jobs or agency work) which tends to be flexible, precarious and badly paid. Disabled people are part of this trend: statistics show a rapid increase in disabled people entering non-standard work between 2008 and 2018 (Clarke & Cominetti, 2019).

Access to Work (AtW) is a government programme which offers advice and funding to help disabled people to overcome barriers to work. The stated purpose of AtW is to help people to work and progress in their careers. However, there is little evidence about how people in non-typical work situations are experiencing AtW. With more and more disabled people entering non-standard work, how is AtW responding to their needs?

This research project examines how AtW is being experienced by people doing atypical work, through the lens of disabled people who are working as **performing artists** (actors, musicians, dancers, etc). Performing artists are an interesting and pertinent example of people in non-standard work, because their working lives are typically characterised by self-employment, unpredictability, low incomes and a sense of vocation.

I carried out in-depth qualitative interviews with **10** performing artists, and **four** people who work for arts organisations managing AtW applications on behalf of performers that they have engaged for productions.

## The key messages from this research

- **AtW is a powerful enabler which helps disabled performing artists to work and pursue successful careers.** This research builds on, and adds to, the existing evidence about the incredibly positive impact of AtW. It shows that AtW can, and does, empower disabled performing artists to work and progress in their careers whereas otherwise they could not.
- **But while the AtW funding itself creates equality, the way it operates creates inequality.** AtW enables people to pursue their careers, but at the same time, it creates a host of practical and emotional difficulties for disabled performing artists that their non-disabled peers do not experience. Although the intention is to sweep aside barriers and enable full participation on equal terms with non-disabled workers, AtW actually introduces a new set of barriers that disabled performers must overcome before they can access work.
- **AtW does not ‘get’ performing artists.** Although there are some encouraging signs that AtW can work for people in non-standard employment, this research sheds detailed light on a host of problems being faced by performing artists, who are encountering a system poorly designed to meet their particular needs, with negative practical and emotional consequences. Many AtW advisers do not seem to understand the reality of performers’ working lives, and performers face the threat of losing work as a direct result of how AtW operates. This research strongly suggests that AtW is not currently set up to effectively support people like performing artists who are doing non-standard work.

“It [AtW] made me feel a bit small.”

June, actor

## Summary of the research findings

### ***Has AtW achieved its aims of helping disabled performing artists to work and progress in their careers?***

All the performing artists felt strongly that AtW helped them to work as performing artists. Indeed, 8 out of 10 performer participants explicitly stated that without AtW it would impossible for them to work. Moreover, 7 out of 10 of the performers perceived that AtW had helped them progress in their careers as performing artists.

The four staff member interviewees echoed these findings; all agreed that AtW was a “brilliant” fund that enabled disabled performers to work. The three interviewees who worked for specialist disabled arts organisations said that if AtW ceased to exist, their organisations would struggle, because AtW makes up a significant proportion of their operating budgets.

### ***What impact has being able to work and pursue a performance career had upon the performing artists who participated in the research?***

Being able to work was extremely important and beneficial for the performer participants. Many said that being a performing artist was central to their identity. Work gave them a sense of purpose and benefited their mental health. It enabled at least some participants to define themselves as something more than their impairment in the eyes of others.

*“Oh, it’s my sense of pride. It’s part of your worth and your value. [...] I mean, it’s – you have to dig deep sometimes to make sure that you can be who you really are and not who people perceive you to be. [...] But it gives me a sense of pride, and the crowds that come to see the shows, they’ve come to see me because I’m on, and it’s not because I can’t see; they come to see because they really enjoy the show. And I feel there’s a real sense of pride that would absolutely be lacking if I couldn’t work.”*

Brian, musician

Most participants perceived that AtW gave them more control over their careers, for instance, over choosing which job opportunities to pursue. Work also brought financial benefits: more for some than others.

### ***How have participants experienced the process of applying for and receiving AtW?***

All the performing artist interviewees felt that AtW simply does not 'get' performing artists:

*"I think they struggle also with people who do freelance work, as well. They seem to manage better if you have a regular job. But if you're stopping and starting, as actors and performers do, they kind of - that seems to fry their brains."* Mike, actor

Participants experienced a system which is **not well-designed for performing artists**, which can result in the threat of losing out on work. For example, performers reported very lengthy delays, an inappropriate Minimum Earnings Threshold, and an inflexible refusal to increase funds when circumstances change.

Participants experienced a **lack of clarity about the AtW criteria**. There seemed to be little information about 'what you can get' or how to get it, leading to uncertainty and confusion. Participants described the eligibility criteria as "*mysterious*" (Dan) and "*opaque*" (Marie). In turn, this led to the fear of not being able to work, as participants can never know for sure if they have met the criteria for an award.

*"You can't relax and know that, as long as they've got this information, they'll be fine with it. You know. It's like on quicksand."* David, musician

All participants – performers and staff members - had found it **difficult to successfully make an application**. Applying is complicated and takes significant time and effort. Huge

amounts of evidence are required. Participants are constantly chasing up their AtW advisers. A different adviser is allocated to every application, making it impossible to build up a relationship with an adviser; the quality of advisers varies greatly. Repeat applicants have to start from scratch with each new application, even if their situation is unchanged.

*"I mean, it does take a ridiculous amount of time."*

Sue, company manager of a major well-known theatre company

Participants found that applying was more challenging for people with certain impairments. For instance, Dan used to have a serious hand impairment but *"there wasn't a contingency for that, like, if you couldn't hold a pen very well. They want you to sign something; how do I...?"*

Sometimes the process of applying was so difficult that participants had abandoned, or not made, applications. For instance, David (who makes a fresh application for every piece of freelance work he does):

*"I'm going to be really honest with you: sometimes, I don't bother, because it's just... it's more bureaucracy than the day's work that I'm going to do. [...] Because, I think, "That's like four days of admin [on the AtW application] for a day's work."*

The staff member interviewees said that it can take months - even years - to resolve an AtW claim and recoup the costs. All four organisations said they had to cover the costs themselves up front, and then eventually recover the money once the AtW claim is approved. They pointed out that this would probably be impossible for small arts organisations with tight budgets.

Participants perceived a **cost-cutting attitude** underpinning their interactions with AtW. They felt that the system is designed to save money wherever possible. This can have negative consequences when AtW advisers suggest cost-saving measures which are inappropriate.

Participants experienced notable **inconsistency**. For example, Sara was playing a role in a theatre production alongside another Deaf actor. She had received funding for BSL interpreters for this job; her colleague (with identical access needs) had not:

*“They’ve said yes to me but not to her, so why are they treating us differently? We both need that AtW. So I would like to know why has she not got a budget for this production yet I have?”*

All of the performer participants said AtW had a **negative impact on them emotionally**. The threat of not being able to work (e.g. because they had not met the Minimum Earnings Threshold) created frustration, anxiety, and even fear. Participants loved their work and had a strong desire to keep working. The uncertainty - caused by unclear criteria and inconsistency – made participants feel like they were continually *“asking permission to do your job”* (Marie). The arts organisation staff participants, too, found AtW stressful; one even said it had reduced her to tears.

Several of the performers disliked the **inequality** of having to *“jump through hoops”* (as Amy, Dan, Brian put it) to be able to work, unlike their non-disabled counterparts. Participant June had been asked to provide letters of recommendation from the theatre company that had engaged her for a show, explaining why they wanted to hire her:

*“I felt a bit like, ‘oh, okay, so...’ I mean, a hearing person can just get a job, but then I cost more so I have to be really worth it to be able to pay me to work. It felt a bit – it made me feel a bit small.”*

AtW advisers appear to have a large amount of discretion when deciding whether to make an award. Interestingly, the data suggest that people who are more **persuasive**, confident or who have social privilege appear to achieve better outcomes from their AtW applications.

## ***How do participants perceive the government's attitude towards AtW?***

There was a strong feeling among all participants, especially from those who had used it since before the reforms in 2011, that AtW had been 'cut' and tightened up in the last few years. Most participants spontaneously remarked that AtW is deliberately designed to be off-putting, perhaps to save money:

*"I think they make it so complicated to put people off from having it."* June

Participants regarded AtW as a "well-kept secret" which hardly any disabled people or arts organisations knew about. Some felt this was deliberate.

*"And it's a deliberately well-kept secret. Because I think that if people knew about it more people would claim, and therefore more money would be used from the pot."*

Tom, actor

Several participants placed AtW in a wider context of government cuts and attitudes towards disabled people:

*"And it does feel like they're not on our side."* Mike, talking about the government

## About Access to Work

### What it is for

The stated purpose of AtW is to provide practical assistance to people who are disabled or have a physical or mental health condition that makes it *“hard for you to do your job”* (Department for Work and Pensions, 2019). The types of costs covered by the scheme include specialist equipment, travel to work, sign language interpreters, support workers or mental health mentors. Last year, 33,860 people received AtW payments (Department for Work and Pensions, 2018).

### Eligibility

AtW is open to employed people, self-employed people, and people who want to start work. AtW is not an entitlement; it is a discretionary grant. The size of the award depends on the individual person’s needs and work situation. No individual customer can receive more than £59,200 of AtW funding per year (the ‘cap’). The duration of an award can vary from a few days to three years.

It is possible for someone to hold more than one AtW award at the same time: for instance, an ongoing award for their day-to-day freelance work, and a separate award to fund the costs of a short-term intensive piece of work such as a theatre show or a music tour.

People are (at the time of writing) allowed to nominate a third party to manage their AtW application on their behalf. Some performing artists do this when they are engaged by an arts organisation for an acting job, a tour, or dance production. A member of staff at the organisation will take over the application for them. In practice, it appears that only large or specialist disabled arts organisations really have the capacity to do this.

## **Recent reforms to AtW**

In 2011, Liz Sayce was asked by the government to review disability employment support (including AtW); she recommended AtW be greatly expanded, and inefficiencies within it addressed. In response, the government made major changes to AtW, including creating a dedicated mental health service, but most of the reforms seemed to focus on cutting costs. Applications are now routed through a central call-centre and randomly allocated to an adviser, rather than the former personalised caseworker approach. The aforementioned ‘cap’ on individual entitlement was introduced, saving £3 million, along with a limit on how many British Sign Language (BSL) interpreter hours Deaf people were allowed (the so-called ‘30-hour rule’).

## **Existing evidence about the impact and effectiveness of AtW**

In the past five years there have been three notable research reports about AtW: a House of Commons Work and Pensions Select Committee investigation (2014), a survey and report by the grassroots campaign group StopChanges2AtW<sup>2</sup> and the campaigning organisation Inclusion London (2017), and DWP-commissioned qualitative research (2018) which investigated how well AtW processes were working and where it was adding value.

All three reports showed that AtW was valued by its users, who felt it had a very positive effect on their ability to work – which in turn was beneficial for their personal wellbeing. However, all three reports identified multiple issues with AtW which were having adverse effects on disabled people, such as complex bureaucracy and lengthy delays. These reports focused mainly on the experiences of people in traditional, salaried employment.

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<sup>2</sup> StopChanges2AtW was formed in 2014 by a group of AtW users and BSL interpreters to campaign against the reforms to AtW

## Research methodology

Qualitative data were gathered through **semi-structured in-depth interviews** with **10** professional performing artists, and **four** people who work for arts organisations, managing AtW applications on behalf of artists. I thematically analysed the interviews and identified a number of strong themes.

The research participants were recruited via word of mouth, Twitter, and with the help of organisations including Equity, the Musicians' Union, the National Theatre and others. The interviews were anonymous and confidential; all names used are pseudonyms.

The 10 performer participants – **Mena, June, Sara, Mike, Marie, Dan, Amy, Tom, Brian and David** - had the following characteristics:

- Five were actors, four were musicians and one was a performance artist.
- Nine earned their performance income as self-employed freelancers. The performing artist, Marie, ran her own business through which she carried out her performance work, and paid herself as an employee.
- Their work and income was unpredictable (except for the performing artist, whose income was a regular salary but whose creative work was unpredictable)
- Three were Deaf, two were blind, and the rest were wheelchair users with a range of disabilities.
- All participants were already disabled when they began their performance careers.
- Five were men and five were women; two were Asian, the others were white.

I also interviewed four people who work for arts organisations:

- **Sue**, company manager of a well-known major theatre company; she manages AtW applications on behalf of disabled actors who are cast in shows.
- **Rachel** works for a dance company whose work features disabled and non-disabled dancers; she manages AtW applications on behalf of their disabled dancers (most of whom they employ on full-time contracts).

- **Emma** works for a theatre company of disabled artists; she manages AtW applications on behalf of their actors. In contrast to Rachel's organisation, their actors are not on full-time contracts but are engaged (on either a PAYE or self-employed basis) for productions lasting from a couple of days to several weeks or months.
- **Joanne** works for a Deaf theatre company. Unlike the other participants, she does not manage AtW applications on behalf of actors who are engaged by the company; the actors manage their own applications. But as a hearing person she often speaks to AtW on behalf of Deaf performers, where an interpreter is not available, as they cannot make those telephone calls themselves.

## Full findings

### ***Has AtW achieved its aims of helping disabled performing artists to work and progress in their careers?***

#### **THE PERFORMING ARTIST PARTICIPANTS:**

##### *It would be impossible to work without AtW:*

All the performer participants were very supportive of AtW as a concept and valued it hugely. All felt strongly that AtW helped them to work as performing artists. Indeed, 8 out of 10 performer participants explicitly stated that without AtW it would impossible for them to work. For example:

- Marie<sup>3</sup> is a performance artist who requires funding for taxis to and from work, as she is unable to use public transport due to her impairments. She also needs full-time support workers to assist with frequent seizures, pain, etc.

*“Without AtW, I couldn’t work. Straightforwardly, I wouldn’t work.”*

- Amy, a musician, needs a driver to transport her and her gear<sup>4</sup> to gigs, as she cannot drive herself (because she is blind):

*“It means I can work. Without that driver support worker funding I can’t do it. I can’t expect someone to do that for nothing.”*

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<sup>3</sup> Names are pseudonyms.

<sup>4</sup> Musical amplification equipment: speakers, microphone, cables, stands, etc

- June is a Deaf actor who was hired for a theatre production. Although she can lipread, she needed BSL interpreters in rehearsals:

*“...people shouting out their lines and I’m trying to read the script... so I need another person standing next to me to be able to point to the script so I can follow the script. And also, sometimes the director gives you a load of information, and I need to write down a note, but I can’t write down and watch the interpreter because my eyes can only do one thing.*

*With that theatre job I did in [name of theatre] they wouldn’t be able to afford me without AtW, so I had to apply for AtW.”*

It was clear that the cost of the assistance provided by AtW would be too much for participants to afford themselves. For instance, Tom said taxi journeys can cost £60 a day, and June had been awarded £15,000 for interpreter costs.

*AtW has helped participants to progress in their careers:*

7 out of 10 of the performers perceived that AtW had helped them progress in their careers as performing artists. I did not define ‘career progression’ for them; they defined it for themselves in various ways: opening up more opportunities; speeding up the process of getting work; ‘building up’ an impressive body of work over the years; working more often; earning more money; or progressing to high-profile work (e.g. performing at the Kennedy Centre in Washington DC, playing a lead role in a world-famous theatre).

For example, Dan had successfully applied to increase his allocated support worker hours and was allowed to hire the specialist support worker he wanted, an expert in the music technology he deploys in his performances:

**Dan:** *Having [name of support worker] on board, I've just said yes to absolutely everything. Because I can. And the amount that I've earned from performing in the last 12 months, compared to what I earned in the years previously, it just doesn't even compare. And those big gigs: without AtW, they're not possible. [...]*

**Interviewer:** *It sounds like [AtW] has helped you – putting words in your mouth here, but it's helped you progress in your career, whereas –*

**Dan:** *Massively, yeah.*

**Interviewer:** *- perhaps the progression would have been more challenging if you hadn't had AtW?*

**Dan:** *Yeah.*

## **THE STAFF PARTICIPANTS:**

The four staff member interviewees echoed these findings; all agreed that AtW was a “brilliant” fund that enabled disabled people to work as performing artists. The participant who worked for a major well-known theatre company said that they would cast disabled people in roles regardless of whether AtW existed, because they could absorb the extra costs; in contrast, the three interviewees who worked for specialist disabled arts companies felt that if AtW ceased to exist, it would have a huge negative impact on their organisation, because AtW makes up a significant proportion of their operating budgets.

*“It allows people to work on an equal level with their non-disabled colleagues.”*

Emma, works for a theatre company of disabled artists

*"I do think it's an amazing system and we wouldn't survive without it. We're already fundraising so much anyway for costs of shows."* Joanne, works for a Deaf theatre company

### ***What impact has being able to work and pursue a performance career had upon the performing artist participants?***

Being able to work was extremely important for the performer participants. Many said that being a performing artist was central to their identity:

*"You can hold your head up high and say, 'I'm a musician' [...] Instead of saying, 'I sit at home, and I'm on benefits so I don't do anything'."* Amy

It gave them a sense of purpose and of contributing to the world:

*"I've had a great career, and it's grown and grown. And my work gives me purpose. It's not the only purpose, and I don't need to earn a great deal to survive, but I like to pay my way. I like to contribute not only financially, but just, you know, whatever."*  
David, musician

Half of the participants reported that being able to work as a performing artist was important for their mental health:

*"I need to work, because if I'm not working, being honest about it, I do have bouts of depression. And they are often triggered by not feeling useful, not having a purpose. So that's why work is important. And that's why AtW is important."* Mike, actor

Work enabled at least some of the participants to define themselves as something more than their impairment, in the eyes of others:

*“Oh, it’s my sense of pride. It’s part of your worth and your value. [...] I mean, it’s – you have to dig deep sometimes to make sure that you can be who you really are and not who people perceive you to be. [...] But it gives me a sense of pride, and the crowds that come to see the shows, they’ve come to see me because I’m on, and it’s not because I can’t see; they come to see because they really enjoy the show. And I feel there’s a real sense of pride that would absolutely be lacking if I couldn’t work.”*

Brian, musician

Most participants perceived that AtW gave them more control over their careers, for instance, over choosing which job opportunities to pursue:

*“It makes me more competitive.”* Dan, musician

Work also brought financial benefits: more for some than others. Typically, participants said they were *“okay but not rolling in it”* (Mike). Those on higher incomes stressed that it had been a long *“journey”* (Tom) to reach that place of relative comfort. All reported that work (and therefore income) was unpredictable, irregular, and uncertain. Some did other part-time work to help make ends meet, such as working in a school, sewing, and hypnosis. Several of the participants pointed out that being able to work meant they paid tax, and they cited this as one of the reasons why AtW is a good thing.

All participants said they had wanted to be performers since they were very young; performing is their passion, their *“vocation”* (David). They love performing.

*“Well, the success is being paid to do what you’d pay to do if you had the money. And that is exactly my life. I am paid to do what I’d pay to do. [...] The politics is crazy. And the travelling and the unsurity, the unsure times you have with finance... But being on stage is still just like a drug, as you know.”* Brian, musician

These findings chime strongly with existing academic evidence that work – particularly ‘good’ work – is beneficial for people’s economic and emotional wellbeing.

## ***How have participants experienced the processes of applying for and receiving AtW?***

### **THE PERFORMER PARTICIPANTS:**

All the performing artist interviewees felt that AtW simply does not ‘get’ performing artists:

*“I think they struggle also with people who do freelance work, as well. They seem to manage better if you have a regular job. But if you’re stopping and starting, as actors and performers do, they kind of - that seems to fry their brains.”* Mike, actor

**Interviewer:** *To what extent do you think they understand your life as a musician?*

**Amy:** *Absolute zero.*

Participants experienced a system which is **not well-designed for performing artists**, which can result in the threat of losing out on work. For example:

- Self-employed AtW users are subject to a minimum earnings threshold (MET) of £6,000 per year. After a one-year grace period, if they subsequently fail to meet the MET they can be forbidden from re-applying for AtW. Several participants on lower incomes were affected by the MET and had found it very stressful.

**Amy:** *They threatened me the first time saying, "If you don't make that threshold we'll take your support off you." And I didn't make the threshold. It caused me so much anxiety. Then she said, "I'm going to make a case for you that you've actually earned*

*more than the previous year, and you are very close to the threshold and make a case that the business is growing."*

**Interviewer:** *So, they did let you keep having the...*

**Amy:** *Yeah. But oh my God, the anxiety that it caused me.*

- Participants felt that the MET is inappropriate for performing artists, because much of their ability to earn is due to factors beyond their control: luck, the limitations of their impairment, and the fickle nature of the creative industries.
- Many participants described a tick-box culture of being asked “robotic” (Tom, Amy) questions that were irrelevant for performing artists.

*“You see, the people I talk to, they’re just looking at boxes on a screen; you’ve got to tick those boxes. So the people I’ve spoke to themselves have been okay, but they’re saying no to things, and [...] I’m not matching the boxes on their screen, because a musician’s life is so different.”* Brian

- Some participants received a ‘freelance budget’, such as Mena (an actor) who was given a one-year award for seven hours of communication support a week. This saved people from having to make a fresh application for every single piece of freelance work, which reduces bureaucracy. However, when someone’s workload becomes bigger than they had anticipated, they must either turn down the extra work, or re-negotiate with AtW for a budget increase – not always easy.

*“And I had to say to Access to Work, ‘look, my money’s gone up’. I said, ‘please, please, please’ and they were like ‘no, sorry, we can’t’.”* Sara, actor, who had achieved unanticipated success with a major theatre company

- Participants had to spend all of their agreed award(s) within the agreed period; if not, the size of future awards could be reduced, which could shrink work opportunities. But it will not always be possible for performing artists to fully spend their awards, due to the unpredictable nature of artistic work.

- All participants said that it took too long to receive a decision from AtW - deeply problematic for performing artists due to the short-term nature of their work. For instance, Mena and Sara, both Deaf actors, had been under pressure to book BSL interpreters for rehearsals that were starting imminently; AtW advisors did not seem to comprehend the urgency.

*"[I applied] one month in advance [of the job starting]. And then I had to keep reminding them and getting them to get back to me. It was very slow and it was difficult. [...] That person that I was dealing with, they were very defensive. Like, when I was emailing, I said 'I need to book an interpreter really soon because there's not much time'..."* Mena, who eventually had to start the job before receiving the decision from AtW

Participants experienced a **lack of clarity about the AtW criteria**. There seemed to be little information about 'what you can get' or how to get it, leading to uncertainty and confusion. Applicants are simply invited to tell AtW what their access requirements are, without being given any information or examples of what can be funded. Participants described the eligibility criteria as "*mysterious*" (Dan) and "*opaque*" (Marie). In turn, this led to the fear of not being able to work, as participants can never know for sure if they have met the criteria for an award.

*"You can't relax and know that, as long as they've got this information, they'll be fine with it. You know. It's like on quicksand."* David, musician

All performer participants had found it **difficult to successfully make an application**. The main issues were:

- Applying is complicated and takes significant time and effort, which takes time and energy away from working. Participants must provide a huge amount of information and evidence and spend a lot of time 'chasing' AtW. They find this stressful; so much

so that several participants had on occasion handed over their applications to a staff member at the organisation that had engaged them, to manage it on their behalf<sup>5</sup>.

*“So, it's always chase, chase, chase. I'm meant to be working. I'm not meant to be chasing Access to Work. I'm meant to be getting on with my job.”* Amy, musician

- Repeat applicants have to start all over again with each new application, even if their disability and access requirements are unchanged. Participants found this inappropriate and a frustrating waste of time. For example, musician Brian – who has been using AtW for 20 years - was recently told to provide multiple pieces of evidence to prove he was still a travelling performer, including photographs of him outside a Travelodge and on a ferry.
- Whereas each AtW customer used to have a dedicated caseworker, now, customers experience a different advisor each time they apply, meaning they have to explain their situation afresh every time:

*“Even having conversations, having to do that each time with a new person, obviously it adds labour and wastes time and energy and doesn't feel very effective.”* Marie, performance artist

Related to this, participants felt that the quality of the advisers varied, and some were more helpful or understanding than others; but since they are randomly allocated, *“it's the luck of the draw”* (David).

- Sometimes the process of applying was so difficult that participants had abandoned, or not made, applications. For instance, David (who makes a fresh application for every piece of freelance work he does):

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<sup>5</sup> This appears to only be feasible when the company is a specialist disability arts organisation or a large mainstream organisation. Interviews with staff members who handle AtW applications on performers' behalf revealed that they, too, find it time-consuming and stressful.

*"I'm going to be really honest with you: sometimes, I don't bother, because it's just... it's more bureaucracy than the day's work that I'm going to do. [...] Because, I think, "That's like four days of admin [on the AtW application] for a day's work."*

- Participants found that applying was more difficult for people with certain impairments. For instance, Dan used to have a serious hand impairment but *"there wasn't a contingency for that, like, if you couldn't hold a pen very well. They want you to sign something; how do I...?"* He also told a story of a blind friend who tried to apply, but gave up when they insisted she fill in forms.

Participants perceived a **cost-cutting attitude** underpinning their interactions with AtW. They felt that the system is designed to save money wherever possible. This can have negative consequences when AtW advisers suggest cost-saving measures which are inappropriate. For instance, many participants had been required to 'shop around' for quotes and choose the cheapest supplier no matter what. David, a wheelchair user, had been told to use Addison Lee to travel to a workshop because they were the cheapest taxi firm:

*"So I just went back, and I said, 'Addison Lee don't have accessible cabs'. They have one or two, and they don't guarantee it. [...] I can't be unreliable at a school where you've got 30 kids waiting for you. You've got to be early."*

The cost-cutting atmosphere contributed to a sense that AtW advisers were purely reactive, rather than proactively suggesting more ways that they could help customers:

**Interviewer:** *It sounds like it's about money, that they're concerned about ...*

**David:** *Oh, yeah. There's never a... I don't recall, any time, them saying, "Could we have helped you more? Was there anything [else] that we could help you with?"*

Participants experienced **inconsistency**. Here are three examples.

- Mike had applied for help with an acting job away from home. He needed funding for the extra cost of wheelchair-accessible accommodation. AtW initially refused to cover this cost, so he got his union involved:

*“And [Equity] got in touch [with AtW] and suddenly ‘Oh yes, we’ll pay for your accommodation’. So - and that’s the thing: sometimes I don’t think they know their own rules, because it seems to change all the damn time...”*

- Sara was playing a role in a theatre production alongside another Deaf actor. She had received funding for BSL interpreters for this job; her colleague (with identical access needs) had not:

*“They’ve said yes to me but not to her, so why are they treating us differently? We both need that AtW. So I would like to know why has she not got a budget for this production yet I have?”*

- Participants Mena and June were both Deaf actors and first-time applicants who needed interpreters in order to work. One was told to supply a business plan, the other was not.

All of the participants said AtW had a **negative impact on them emotionally**. The threat of not being able to work created frustration, anxiety, and even fear. Participants loved their work and had a strong desire to keep working.

*“Well, when I first heard about this ‘£5,000 before you can claim it’ rule, or whatever you want to call it, that scared me, and I honestly thought I wasn’t going to be able to do the [acting] job I’d got. I’d got the job, and I thought I wasn’t going to be able to do it for that reason. Because I thought I wouldn’t make enough. It worked out OK in the end, but I really was scared.”* Mike, actor

In addition, uncertainty - caused by unclear criteria and inconsistency – made participants feel like they were continually “asking permission to do your job” (Marie).

The cost-cutting aura was unpleasant for some:

*“It’s a hard-enough ride [being blind] without AtW trying to make you feel like you’re some kind of beggar trying to...” Brian*

Several participants disliked the **inequality** of having to “jump through hoops” (as Amy, Dan, Brian put it) to be able to work, unlike their non-disabled counterparts. Participant June had been asked to provide letters of recommendation from the theatre company that had engaged her for a show, explaining why they wanted to hire her:

*“I felt a bit like, ‘oh, okay, so...’ I mean, a hearing person can just get a job, but then I cost more so I have to be really worth it to be able to pay me to work. It felt a bit – it made me feel a bit small.”*

Interestingly, the data suggests that people who are more **persuasive**, confident or pushy appear to achieve better outcomes from their AtW applications. Musician Dan learnt how to play a unique piece of music technology adapted for his impairment. A lucky break resulted in his performance career “exploding” and he was unable to accept every gig. He persuaded AtW to dramatically increase his support worker budget from 12 to 30 hours a week, and to allow him to employ a particular support worker who was an expert in this technology. He remarked, “I wanted to push my luck, and the adviser was on side”. This led us into a fascinating discussion about whether he thought his personality had impacted upon AtW decision-making:

*“Yeah, there’s this thing with me and my partner of 15 years, she pointed this out to me. She’s like – my brother blagged his way into something – a concert somewhere – and my partner was like, “you guys are so fucking [inaudible], you talk people into fucking anything” and I was like “really?” and she was like “yeah, you guys – do you*

*not notice how you always get your own way?” and I was like, “well, I’m just working hard”; she was like, “no”. And I became more aware of how persuasive I can be, and that in itself is a kind of privilege. And if I didn’t know how to fight the fight, and use the right language to push these applications... [When I talk to AtW] I know I’m going to be super persuasive about it and that’s fine. Yeah, so that’s a big factor in how I get to do what I want to do.”*

Dan perceived that he had privilege:

*“...if it wasn’t for the fact that I’m disabled, I’m ticking all the boxes. I’m a white, cis gender, straight, middle class dude with a big loud voice, and I don’t mind cracking the whip. I’m loaded with privilege, except for this one thing.”*

In contrast, musician Brian’s freelance budget of 20 hours a week for a support worker is not sufficient to cover the costs of all the gigs he is offered, but he did not want to ask for an increased budget - even though it meant he was sometimes turning down work:

*“I want to be independent [inaudible] earnings and doing most of this myself, but that’s not the way to play it – I don’t [inaudible] how to play the game. [...] I’ve tried my best to not go and – I mean, I could turn round and justify, easily, 30, 40 hours for this, but I – I’ve left it at my 20.”*

### **THE STAFF PARTICIPANTS:**

It was a similar story for the ‘third parties’ who managed AtW applications on behalf of artists. The four interviewees who worked for arts organisations reported major difficulties with the process of applying for AtW. While the process can sometimes be very smooth, usually this is not the case.

*“You have to make a massive fuss.”* Joanne, works for a Deaf theatre company

Like the performing artists, the staff members felt that AtW does not 'get' the performing arts. They pointed out that arts projects can change unexpectedly if funding arrives or is withdrawn at the last minute, but AtW some advisers did not understand this. Participants had also experienced inappropriate rules and restrictions, such as AtW refusing to cover the travel and accommodation costs of support workers on tour, or refusing to pay for accessible accommodation for out-of-town actors:

*"I mean, I have had case workers say, 'Why can't you just employ somebody from London? You don't need to employ this person from Manchester'. So, not realising that actually, acting, you're choosing somebody for a specific role."*

Sue, works for major well-known theatre company

The staff members described AtW as a *"battle"* that takes up a lot of their time. It can take months - even years - to resolve a claim and recoup the costs. All four organisations said they had to cover the costs themselves up front, and then eventually recover the money once the AtW claim is approved. They pointed out that this would probably be impossible for small arts organisations with tight budgets.

All four interviewees perceived that AtW has become more difficult to use and stricter:

*"It's more and more difficult to get through the red tape."*

Emma, works for a theatre company of disabled actors

Interviewees described continually chasing AtW and not receiving responses to voicemails or emails. This can drag on for months. There is a six-month cut-off for payments, but often the delay has been caused entirely by AtW and is not the organisation's fault.

The participants found applying to AtW frustrating, time-consuming and stressful.

*“I mean, it does take a ridiculous amount of time.”* Sue, major theatre company

*“I am bringing in money into the company and if something goes wrong, then I feel like I've kind of let the company down by not bringing that amount of money in that we thought we might get. It's definitely stressful. I have cried on a number of occasions over certain incidents where I just feel like it's all kind of come up to a boil too much.”* Rachel, works for dance company of disabled and non-disabled dancers

Two of the staff members had been told very recently that AtW will soon no longer allow third parties (i.e. staff members of arts organisations like them) to manage AtW applications on behalf of individuals. They are worried about this and expect it to be highly problematic.

*“They're changing the rules about speaking to a third party. They say they will now want to speak to the claimant directly. Which is obviously problematic. Particularly for deaf people – AtW say there is video relay available, but it doesn't work. If the person is there physically present with me then they can call AtW, give permission for me to talk to the caseworker, then hand over the phone. But with actors who are based around the country, this is simply not going to be possible a lot of the time.”*

Emma, works for a theatre company of disabled actors

### ***How do performer participants perceive the government's attitude towards AtW?***

There was a strong feeling among the performing artists, especially from those who had used it since before the reforms in 2011, that AtW had been 'cut' and tightened up in the last few years:

*“Well, it [AtW] was good in those days. It's just that with government cuts, 'we're not doing this now. We don't fund that. We're not going to help you with that. We're not going to fund you'.”* Amy

Most participants spontaneously remarked that AtW is deliberately designed to be off-putting, perhaps to save money:

*“I think they make it so complicated to put people off from having it.”* June

*“I wouldn’t put my name against this because it’s not provable, but I have a very strong feeling that the process has been deliberately - feels like it’s been deliberately been made complicated and hostile. There is a hostile environment. So you have to really know your rights and be solid of your rights within that.”* Marie

Participants regarded AtW as a “well-kept secret” which hardly any disabled people or arts organisations knew about. Some felt this was deliberate.

*“And it’s a deliberately well-kept secret. Because I think that if people knew about it more people would claim, and therefore more money would be used from the pot.”*

Tom

Several participants placed AtW in a wider context of government cuts and attitudes towards disabled people:

*“And it does feel like they’re not on our side.”* Mike, talking about the government

Two participants noted that AtW is operated by the DWP, which also administers welfare benefits:

*“I’d try and move it [AtW] away from the Department for Work and Pensions, because they’ve got an agenda. They’ve got a political agenda which is horrible.”* David

The findings indicate a deep-rooted suspicion of the government's intentions towards AtW, which is perhaps unsurprising given the literature showing that welfare reforms have led to a breakdown of trust between disabled people and the government, particularly the DWP.

## Discussion

These research findings strongly suggest that AtW is not currently set up to effectively support people doing non-standard work. This is despite the fact that a 'self-employment specialist team' was established within AtW in February 2015 (House of Commons Work and Pensions Committee, 2015). Only one research participant mentioned the specialist team: this suggests that either their applications were not being dealt with by that team – in which case AtW should improve how applicants are referred into that team – or they were, and therefore the team is not able to effectively support self-employed performing artists.

The findings indicate that AtW advisors can exercise a large amount of discretion in their decision-making. Discretion is wielded by advisors who the participants perceived to be stressed, overworked and poorly trained. It seems feasible that advisors are under internal pressure to cut costs. Moreover, discretion seems to favour applicants who have social privilege or persuasive personalities.

Discretion could also have positive outcomes. Many of the participants who had failed to meet the Minimum Earnings Threshold said that their advisor had used their discretion to allow them to keep claiming AtW. The absence of a definitive 'list' of what can be claimed means there is a chance that a creative, outside-the-box application from an artist can be approved if it enables them to work.

The overarching theme of this research is that while the AtW funding itself creates equality, the way it operates creates inequality. AtW literally enables people to pursue their careers, but at the same time, it creates practical and emotional difficulties for disabled performing artists that their non-disabled peers do not experience. Although the intention is to sweep aside barriers and enable full participation on equal terms with non-disabled workers, AtW actually introduces a new set of barriers that disabled performer must overcome before they can access work.

Why does this matter? Because this research indicates that work is incredibly important and beneficial to disabled performing artists. Participants want to continue working, so they have no choice but to continue to use AtW. In a just society, no disabled person would have to 'jump through hoops' in order to step out onto the metaphorical level playing field.

This research also builds on, and adds to, the existing evidence about the incredibly positive impact of AtW. It shows that this policy intervention can, and does, empower disabled performing artists to pursue successful careers. Trends indicate that the numbers of disabled people entering non-standard work such as artistic work will continue to grow; AtW could be a powerful part of their journey. Since levels of disability and non-standard work are growing all over the world, this research suggests that other countries might find an AtW-style intervention beneficial.

## Conclusion

Due to time and resource constraints, this research is necessarily limited in scope. However, I hope it can act as a springboard for future research about the impact of AtW.

My participants belonged to social groups that tend to be closer to the labour market: they had physical or sensory impairments, were mostly white, and only a minority seemed to experience impairment-related pain or fatigue. Future research should build upon this small-scale study and explore the AtW experiences of groups who have a harder time accessing work, particularly people with so-called ‘work limiting’ impairments such as learning disabilities and mental health problems.

It is vital to acknowledge that even a perfectly-functioning AtW could not fully level the playing field for disabled performing artists, because of the wider societal barriers that disabled people face. Participants told many stories of the access and attitudinal barriers they had faced during their careers:

*“You know, I’ve been for parts which have been written for a wheelchair user, where the building wasn’t accessible, for example, and I’ve had to audition in the street with people watching. It was horrible.”* Mike, actor

Reforming AtW would not, of itself, be a complete policy solution. Much more needs to be done to transform society so that disabled workers can fully participate in society on an equal footing with non-disabled people.

Disabled people often say that policy-making should be: *“nothing about us without us”* (Sayce, 2018). In this spirit, I hope that my research, which places the voices of disabled people front and centre, can make a small contribution to the policy landscape.

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