

Breaking Down the Barriers to Disability Benefits

Disability Benefit Advice Needs in Wandsworth

Disability and Social Care Advice Service
Research Project report, June 2017



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Executive summary

This report identifies the barriers faced by disabled people in the borough of Wandsworth in accessing disability benefits, and the reasons why so many applicants choose to disengage from the process.

The report draws on evidence gathered in early 2017 from a survey of 110 Disability and Social Care Advice Service (DASCAS) users, 12 qualitative interviews and supporting statements provided by external organisations and charities that deal directly with specific groups of disabled people. The research project was funded by Wandsworth Borough Council.

The research investigated ways to dismantle barriers and assessed the benefits of advice provision and the usefulness of advice and self-help resources. This report makes recommendations for improving the disability benefit system and making the claiming process more navigable.

Key findings:

Barriers that disabled people face in gaining full benefit entitlement:

- Claimants find the application process **too complicated** to manage by themselves: 69% of respondents found the process too complicated to manage without the help of DASCAS.
- Claimants experience **deterioration in mental health** during the claiming process: 62% said the application process made them feel anxious or stressed. This finding was supported by case studies and statements provided by mental health charities.
- Claimants experience difficulties throughout the application process, including problems at the **health assessment** stage.
- An individual's disability may operate as a barrier to engagement, with low literacy levels and not having English as a first language identified as particular obstacles.

Reasons for applicant **disengagement** from the claims/appeals process:

- The research identified **lack of confidence among disability benefit claimants in their ability to navigate the appeals process** successfully by themselves:
- 4% of those surveyed said they would not appeal if their initial claim was unsuccessful; 7% said they were not sure if they would appeal

- Only 13% said they felt confident in formatting an appeal without the help of DASCAS.
- Respondents reported negativity about the outcome, stress, anxiety, disillusionment and apathy as reasons why they might disengage from the claiming and appealing process.

How advice and information services could best help:

- 33% of respondents said that a written information pack or advice guide would have helped
- 12% said that online support would have helped
- 28% said a telephone advice service would have helped
- 32% said that none of these would have helped and instead stated that they needed the face to face expertise of DASCAS to help them to navigate the process.

While many service users are reliant on services like DASCAS to help them to navigate the system, there may be scope for the development of self-help resources to complement this, targeted at those who may be better able to help themselves. The report emphasises, however, that the provision of a self-help resource is not a viable substitute for face-to-face, expert advice in most cases.

The report also demonstrates the link between receiving advice and improvements in the client's health and well-being:

- 79% of those surveyed stated that receiving help from DASCAS made them feel less anxious or stressed.

Recommendations:

- Government/DWP: Simplify the application process and reduce the length of application forms
- Government/DWP: Improve the accuracy of health assessments – get it right first time – and end repeat assessments for the chronically ill
- Government/DWP: Ensure reasonable adjustments are put in place for claimants with mental health issues
- Wandsworth Council: Empower people, organisations and advice services to continue to provide support to those who need it most

- DASCAS: explore the provision of self-help resources that can be made available in hard copy format and on-line to assist people with the disability benefit claims process

Matthew Stocks

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Citizens Advice Wandsworth

Introduction to DASCAS

Citizens Advice Wandsworth's Disability and Social Care Advice Service (DASCAS) provides independent advice about benefits and services to disabled residents of the London Borough of Wandsworth. The service is for people with disabilities and the relatives and friends who care for them. The DASCAS team of staff and volunteers offers telephone advice, home visits or office interviews.

The primary role of DASCAS is to improve the lives of disabled people in the borough through encouraging uptake of disability benefits and supporting claimants throughout each stage of the application process.

In 2016/17, DASCAS:

- Dealt with 4,168 incoming enquiries.
- Successfully helped clients gain £1,834,590 in benefits.
- Completed disability benefit assessments for 1,039 clients.
- Helped 169 clients with advice on benefit tribunals.

Background to the research project

Citizens Advice Wandsworth's DASCAS team has long been aware that some disabled people in the borough do not receive all the benefits they are entitled to. The team felt that local disabled people faced a number of barriers in the way of gaining full entitlement. The DASCAS team was also concerned that many disability benefit claimants disengage from the process, even where it is felt the applicant had a realistic prospect of a successful claim.

The team wanted to understand more about the barriers to accessing full benefit entitlement and the advice that could help them. They wanted to know why people disengage and more about how they could help disabled people to maximise benefit entitlements.

In 2016, DASCAS applied for and received a small grant award of £8000 from Wandsworth Borough Council to undertake a peer research project focusing on these issues.

Research and data analysis

Research methodology



A key feature of the project is that peer volunteers undertook much of the research, two of whom have disabilities and experience with accessing disability benefit advice services. The third volunteer works part-time in the care industry in Wandsworth and therefore had first-hand experience of working with people with disabilities.

The volunteers received training in interview techniques and had a key input in formatting the report and resource material.

The quantitative interviews took respondents through a questionnaire developed on 'Survey Monkey'¹. All of the interviews were carried out over the telephone by volunteers and the Project Leader. The purpose of the questionnaire was to identify why people use DASCAS, why they cannot manage the issue by themselves and what would help them to manage their disability benefit issue without the support from DASCAS.

An ancillary purpose was to demonstrate the value of advice services in supporting disabled people in accessing benefits, as well as demonstrating the link between enhanced well-being and receiving advice. In total, 110 quantitative surveys were completed. The respondents were selected from incoming enquiries received by DASCAS over the period of March-May 2017.

The purpose of the qualitative interviews was to gain a more holistic overview of the respondents' experience of the disability benefit system and from this, an insight into why so many disengage from it and feel disillusioned with it. The qualitative interviews were also designed to highlight some of the systemic failures in current disability benefit arrangements and how these failures can often work to deter applicants from completing the benefit application process.

Several of the interviews were selected to form the basis of case studies, which will be included in the report. In total, 12 qualitative interviews were carried out

¹ www.surveymonkey.net – survey made up of 18 questions (mix of multiple choice questions and questions with yes/no answers): 12 answered by the respondent and the last 6 answered by the interviewer after the survey had finished.

and 7 have been used as case studies. The respondents were selected from clients whom DASCAS Caseworkers and the Project Leader had identified had either disengaged from the application process or whose experiences were felt to give an interesting insight to the challenges faced by disabled people in accessing disability benefits. All respondents had accessed DASCAS services at least once since August 2016.

We also made contact with other organisations that work directly with specific groups of disabled people to see if their experiences matched our findings. These organisations included: Action for Blind, Parkinson's UK, Hestia, Rethink Mental Illness, Together, Wandsworth and Westminster Mind, Wandsworth Carers' Forum, Wandsworth Health and Well-being Hub. Many of these organisations, whilst not providing formal support to disabled people in the disability benefit application process, see first-hand the barriers they face and how the system works in practice. We wanted to draw from the experiences of these organisations and include statements from them to support our findings.

Findings

Barriers to claiming disability benefits

In order to ascertain the barriers disabled people face to accessing disability benefits, a helpful starting point was to ask respondents why they felt they could not manage their disability benefit issue without external support. The findings below were revealed from the survey responses and supported by evidence from the qualitative interviews, as well as supporting statements from external organisations. Some of the responses from the qualitative interviews have formed the basis of case studies, which demonstrate how these barriers operate in practice.

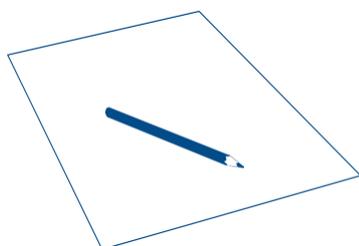
The barriers we identified have been divided into the categories below. It is important to note that some of the categories are interlinked and may overlap.

1) Complexity of the application process

One aspect of the benefit application process that acts as a barrier to engagement is its complexity. Our survey revealed that 69% of those who contacted DASCAS for help found the application process too complicated to manage without advice. The qualitative interview respondents shared this feeling, with many stating that it is “complicated”, “confusing” and “hard to keep up with the changes in legislation”.

The complexity of the process means that many people do not attempt to navigate the system alone and instead rely on the expertise of advice services like DASCAS to guide them through it.

2) Length of the application forms



Another common barrier to completing the application is the length of the application forms. Several respondents of the qualitative interviews suggested that the applications forms should be reduced in length and made less repetitive, in order to make the application process easier and less time-consuming.

The length of the forms may be particularly relevant where disabled people are relying on friends/relatives or carers to help them fill in the form, who simply may not have the time to do so. Our survey revealed that 11% of respondents

said help from a friend or relative would have helped them to manage their issue without the help of DASCAS, while evidence from the qualitative interviews suggested that in some cases their friend or relative may not have time to provide the help that is needed.

Disabled people often rely upon carers in the community to help fill in forms. There are over 19,000 carers in Wandsworth, with 2,876 carers caring for between 20-50 hours per week and 3,915 caring for over 50 hours per week².

One Trust, a disability charity in Wandsworth which provides support to carers, have noted that, due to the length of the application forms, many carers are unable to help their clients to fill them in as they do not have time to do so alongside their carers' duties.

Evidence from the qualitative interviews suggested that some people might give up with their application due to the length of the forms and instead turn to external support from advice agencies like DASCAS.

3) Problems navigating the application process

Difficulties in navigating a system that is often perceived as unfriendly and weighted against the claimant presents another barrier to engagement with the application process. Nadine's story, below, highlights the things that can go wrong throughout the process and the frustration this can cause to claimants:

Nadine received a letter explaining the Disability Living Allowance (DLA) to Personal Independence Payment (PIP) changeover in November 2016 and inviting her to apply for PIP. In the past, she found communication with the Department for Work and Pensions (DWP) difficult and so she requested an application form rather than applying over the phone.

She described how the form felt vague and formulaic and didn't give her an adequate opportunity to fully outline her conditions. She also felt the form did not take into account the fact that her condition constantly fluctuated – on good days, she is able to leave the house and even volunteer, but when her condition is at its worst, she is housebound and in large amounts of pain.

² Figures taken from the Joint Strategic Needs Assessment report 'The Wandsworth Story 2017-18' by the Business Intelligence Team.

Once her form had been sent off, an Atos assessment was automatically generated for the next possible date. Unfortunately, her conditions also mean she suffers from memory loss and as a result, she missed her appointment. There was no automated message to remind her of her appointment which she felt was wrong, as many disabled claimants suffer from memory problems and the introduction of such a service may lead to a decrease in missed appointments. She was told she had to give a reason for missing the appointment and that this would be considered.

In the meantime, she has been left feeling anxious about what will be decided.

Nadine's case study raises a number of examples of top-down policy making and a system that has not been designed from the perspective of the user. Not only do assessments and claim forms often disadvantage claimants whose conditions fluctuate with variable impacts on day-to-day activities, but a lack of basic facilities such as an automated text message appointment reminder may lead to more missed appointments.

4) Problems with health assessments



The health assessment is another point in the application process at which things often go wrong, which in turn may lead to claimants losing out on money they may be entitled to.

The Citizens Advice response to the government's Health and Work Green Paper, *Halving the disability employment gap*, states that 'over the past 5 years, the most prevalent benefits issue for Citizens Advice face-to-face clients have been Employment and Support Allowance (ESA) and PIP, and the need for advice has been exacerbated by persistent and wide-scale problems with assessments for both these benefits³. The marked upward trend of appeals increasingly being found in the claimant's favour (64% for ESA and 70% for PIP⁴) is further evidence that things are often going wrong at the health assessment stage.

³ 'Halving the disability employment gap' – Citizens Advice report: 18 April 2017

⁴ <https://www.gov.uk/government/statistics/tribunals-and-gender-recognition-certificates-statistics-quarterly-january-to-march-2017-and-2016-to-2017>

It is also clear that a bad experience with health assessments may act as a barrier to re-engaging with the application process. 13% of respondents to our survey had previous negative experience of claiming benefits and cited this as a reason for needing help from DASCAS.

Rossita's story below is an example of how the assessment process can go wrong, causing claimants to potentially lose out on money to which they are entitled:

Rossita moved to the UK when she was 15 years old. She worked several jobs until her partner fell ill and she took on the role of carer. Her own health took a turn for the worse as it was discovered she was HIV+ and she later developed osteoporosis. She needed the help of the disability benefit system as her illnesses made it impossible for her to work.

She found the process of applying for ESA to be daunting due to the length of the forms, but in spite of this, she managed to fill out the form by herself and was successfully awarded the benefit.

However, it wasn't until she began a claim for PIP that her experience with the benefit system turned sour. As with nearly everyone who claims PIP, she was invited to an assessment centre. It was here that Rossita alleged she experienced humiliating discrimination by the receptionists due to her being both transgender and an EU citizen. She described how she felt she had 'been written off before the assessment even began'.

During the assessment, Rossita claimed the assessor had an alarming lack of knowledge about her conditions and appeared to be unsympathetic towards how her conditions affected her on a day-to-day basis.

As well as being unknowledgeable about and unsympathetic toward Rossita's illnesses, Rossita claimed the assessor went off at tangents and asked her seemingly irrelevant questions. She remarked: "The assessor spent the majority of the assessment asking about my dogs and how I was able to look after them with my disability. None of the questions I had been advised would come up did come up."

Rossita complained to ATOS about the assessment, but they refused to acknowledge any wrongdoing. The DWP, however, treated the complaint more seriously and stated they would investigate the situation.

In the meantime, Rossita is lodging an appeal against the decision not to award her PIP. This could take several months. She is naturally nervous about going to the tribunal but does not want to give up. She stated: "I know what I am entitled to and I am not going to let a bad experience deter me."

Rossita's experience may be unusual, but the unprofessionalism displayed during the assessment draws attention to a wider concern about the quality of ATOS assessments. A National Audit Office report into the work of three of the government's assessment providers (ATOS, Maximus and Capita) showed that in the two regions in which PIP assessments are carried out by ATOS, eight and nine per cent of assessments did not meet the necessary standards⁵.

Rossita's concern about the quality of assessments is one that was shared by a number of respondents in the qualitative interviews. One interviewee, when asked how he thought the health assessments could be improved, said: *"Health checks should be more thorough and have regard to the full medical history of the claimant rather than just a synopsis."* He also stated that, at present, assessments feel *"rushed"* and *"impersonal"*.

It is often felt that medical evidence isn't fully taken into account at the assessment stage and claimants are often unsure about what evidence to submit and when. The importance of sufficient medical evidence submitted at the right time cannot be overstated. On appeal, hearing medical evidence was the major reason for overturning DWP decisions about PIP.

The Research and Campaigns team at Citizens Advice Wandsworth has developed a resource for Wandsworth residents to help format a complaint about a DWP health assessment⁶. It is important that disability benefit claimants are aware that an avenue of redress is available where assessments fail to meet the required standards and that complaints will, in every case, be taken seriously.

5) Stress and anxiety

Stress and anxiety are another two major barriers faced by disabled people in managing their disability benefit issue by themselves. 62% of survey

⁵ Statistics available at <http://www.disabilitynewsservice.com/atos-maximus-and-capita-forced-to-admit-assessment-failures>

⁶ Resource available at <https://cawandsworth.org/self-help>

respondents said that the application process made them feel anxious or stressed and cited this as a reason for needing support from DASCAS.

Luisa's story, below, demonstrates how the application process can have an adverse impact on the claimant's mental health. Her story also shows how advice services can positively intervene to transform client outlook for the better and consequently, improve their health and well-being:

Luisa's experience with accessing disability benefit advice services began in late 2016. She expected her DLA to come up for review in January 2017, and was surprised when she received a letter from the DWP stating that the benefit would be changing over to PIP.

She began to research PIP and found the media coverage of the negative experiences of people claiming the benefit to be upsetting and anxiety inducing. She started to look for help online, and whilst she found some of the information to be helpful, the sheer volume of material added to her confusion and mounting anxiety. She contacted the PIP helpline and was asked a line of seemingly impersonal and irrelevant questions. This was followed by a claim form, which was sent to her address for her to complete.

Despite being used to filling out DLA forms for both herself and her disabled daughter, she found the length of the PIP form to be daunting. She described how the form felt impersonal and didn't give her an opportunity to fully explain her condition or circumstances – rather, it felt like an exercise in ticking boxes and fulfilling criteria. Her anxiety had, at this point, reached unmanageable levels and it was at this point that she decided to seek help from her GP.

Her GP was very understanding of Luisa's situation, having seen several other claimants in similar states of worry and anxiety due to the DLA to PIP changeover and the uncertainty that it brought, and so she suggested that Luisa contact DASCAS. Luisa was initially anxious about this but once she got in touch with a benefits caseworker, she felt calmer and reassured.

A home visit was arranged and a DASCAS caseworker assisted Luisa with filling in the forms. Luisa described how the DASCAS caseworker, with their knowledge and expertise, was able to fill in the form in a way that

she could not do by herself. Once the form had been filled out and sent off to the DWP, along with medical evidence from her GP, the next stage was to await a letter that would most likely invite her to an assessment centre.

Luisa was delighted however when she received a letter informing her that, based on her application form and medical evidence, she had been awarded PIP for the next four years. She describes how she couldn't have done it without the help of DASCAS, and whilst she can't help but think about what might be in store in four years' time, she is doing her best to live in the moment.

Caseworkers at DASCAS have long been aware of the negative impact that navigating the welfare benefit system can have on clients' mental health and this is an experience that is shared by other organisations. An Independent Mental Health Advocate we contacted at Rethink Mental Illness commented that she 'regularly hears from clients who feel their mental health deteriorates under the stress of having to deal with benefit applications, changes to benefits, providing evidence to support their claim and attending assessments or interviews to comply with the conditionality of their benefits'.

A spokesperson at mental health charity Together stated that helping their clients to fill out benefits forms is 'a common support need' and that their clients 'have a massive anxiety around this'. Wandsworth and Westminster Mind have also had similar experiences stating that 'Wandsworth clients have tended to present with feelings of confusion and anxiety over letters from DWP (calling them in for face-to-face assessments) or being matched with a work coach, despite being clearly not ready/fit for work'.

Currently, the DWP's lack of reasonable adjustments and considerations to make the process a simpler and less stressful experience is having an adverse impact on claimants with mental health issues.

Receiving advice can improve clients' well-being by reducing stress and anxiety levels: 79% of survey respondents said they felt less anxious or stressed after receiving help from DASCAS. This is consistent with Citizens Advice national figures that 4 in 5 people feel less stressed, depressed or anxious after receiving

advice⁷ and is further evidence of the link between receiving advice and improved health and well-being.

6) Disability prevents engagement

Disabilities and health conditions can have a multitude of effects on people's everyday lives and some of these may impact on their ability to engage with the disability benefit application process.

For example, 37% of respondents reported that they struggled with reading or writing and in many cases this was due to their disability. Dyslexia, arthritis and Parkinson's disease were the main disabilities cited that made it particularly difficult to fill in application forms without external support. Having a visual impairment will also often act as a barrier and those who are visually impaired will clearly need outside support to help them fill in forms. One man we spoke to, for example, could not read the application form due to blurred vision as a result of his diabetes.

Scarlett's story demonstrates how the side effects of disability can act as a barrier:

Scarlett has a slipped disc as a result of an accident she had in 2016. She contacted DASCAS for help with her application and was successfully awarded PIP. However, she faced a number of difficulties throughout the application process. She described how she felt the process was not very user friendly and when she called to request a form, she had to wait on the phone for about 20 minutes.

When the form arrived, Scarlett continued to experience difficulties. Pain medication for her slipped disc has resulted in memory problems, which have a profound effect on Scarlett's day-to-day life. One effect of her memory problems and clouded thinking is that it significantly impeded her ability to complete the application form without help. Due to the nature of her problems, she stated that other forms of help, such as online help or a telephone advice service, would not have been useful.

⁷ Figures from a Citizens Advice Impact report: 'Helping people find a way forward – a snapchat of our impact in 2015/16'.

Where an individual's disability makes it practically impossible for them to engage with the process, it is clear that advice agencies will be relied upon to provide the necessary support.

7) Language barriers

Not having English as a first language is another major barrier to accessing disability benefits. 12% of respondents needed help to understand English and 9% said that having help from an interpreter would have helped them to manage their disability benefit issue without the help of DASCAS.

It is therefore not surprising, given the complexity and length of the forms and the absence of a local authority-funded translation service, that those who had a language barrier required external support. However, a lack of internal interpreters within organisations such as CAW and DASCAS means it is difficult to meet the advice needs of this section of the disabled community.

Reasons for applicant disengagement

Applicant disengagement may occur at various stages throughout the application process and takes a variety of forms, including those who give up during the earlier stages of the application process; for example after unsuccessfully attempting to fill in forms by themselves, and those who decide to not challenge a negative decision on their initial application. This section of the report will focus on the latter category, but we have already shed light on some of the reasons for the former throughout our exploration of the various barriers people face throughout the process, all of which may lead a claimant to give up on their application.



Challenging a decision can be a lengthy process and one that can also bring about often months of financial uncertainty and distress for claimants. Before a claimant can proceed to a tribunal, they must go through an intermediary stage known as 'requesting a mandatory reconsideration'. Everyone who receives a negative decision has the right to request a mandatory reconsideration which compels the decision maker to look at the decision again. The statistics related to this stage reinforce the impression that the system is weighted against the claimant:

From a total of 17,400 mandatory reconsiderations that were decided in April 2017⁸ -

- 15,000 were not revised, compared with 2,400 revised in the claimant's favour;
- 12,000 (68 per cent) related to disputes about fit for work assessment outcomes, with only 7 per cent of these resulting in a positive revision in favour of the claimant;
- 16 per cent were disputes about which group the claimant was placed in, with 25 per cent of these decisions being revised; and
- 16 per cent of decisions were made on disputes for reasons where the claimant had not followed the claim procedures - including failing to return the initial questionnaire, failing to provide medical evidence or not attending their assessment - with 22 per cent of these disputes being revised.

There have been concerns raised on the national level about the introduction of mandatory reconsiderations adding to the complexity of the appeals process. The Wheatley Group in Scotland were cited in the Social Security Advisory Committee's report into decision making and mandatory reconsiderations⁹ as noting the following:

"We believe that the majority of our customers find the appeals process extremely daunting and difficult to navigate, and the mandatory reconsideration has only added another level of confusion. Many vulnerable customers have advised that without assistance they would have given up". The Wheatley Group

Part of DASCAS's work is to encourage those who have received a negative decision on their initial application to go through with an appeal; if it is felt they have a reasonable prospect of success. It is clear that on appeal, applicants have a much greater chance of having a decision being found in their favour. The latest government statistics¹⁰ reveal the following:

⁸ <https://www.gov.uk/government/statistics/esa-outcomes-of-work-capability-assessments-including-mandatory-reconsiderations-and-appeals-june-2017>

⁹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/538836/decision-making-and-mandatory-reconsideration-ssac-op18.pdf

¹⁰ <https://www.gov.uk/government/statistics/tribunals-and-gender-recognitions-certificates-statistics-quarterly-january-to-march-2017-and-2016-to-2017>

- 64 per cent of PIP cases were overturned;
- 70 per cent of ESA cases were overturned;
- 61 per cent of disability living allowance cases were overturned.

While it was encouraging that 86% of those surveyed said they would appeal a decision if their claim was unsuccessful, a worrying number of claimants give up once they receive their first decision, even where it is felt they had a reasonable prospect of success. 4% said they would not appeal if their application was unsuccessful and 7% said they were not sure if they would appeal.

Our research discovered three main reasons why claimants decide not to go through with an appeal. It is important to note that some of the categories overlap and for some claimants, it is a combination of factors that leads to their disengagement.

1) Feeling negative about the outcome

Feeling negative about the outcome was one of the reasons cited by those who said they would not appeal an unsuccessful disability benefit decision. Wendy's story highlights how feeling negative about the outcome can be a reason for disengagement with the process:

Wendy had been on DLA for 4 years, but when it came to the DLA-to-PIP changeover she lost the medium rate of PIP. She decided against challenging the decision as she felt it was unlikely that it would change and she had lost confidence in navigating the system.

She contacted DASCAS regarding reapplying for PIP, but following an assessment by the pain management clinic that deemed she was able to work, she doesn't feel she has the medical evidence to make a successful claim. Despite having arthritis of the neck and an annular tear in her lower spine, she finds herself in a situation where she is forced to look for work despite feeling physically incapable of working.

Wendy is one of many disabled people who disengage from the process due to an under-confidence in their prospects of success. When it feels like the odds are stacked against them, many claimants find the idea of reapplying for benefits or appealing a negative benefits decision to be daunting and distressing.

Wendy has been told she can get back in touch with DASCAS in the future if she decides to follow through with an application. In the meantime, however, her sense of hopelessness has left her feeling unwilling to put herself through the process again.

2) Stress and anxiety

As we have seen, stress and anxiety can act as a barrier to applying for disability benefits. However, it can also act as a reason why clients disengage from the process and choose not to follow through with their application or go ahead with an appeal. 4% said they would not appeal if their benefits decision was unsuccessful and when asked why, some respondents said the appeals process made them feel 'unsettled' and 'anxious'.

Dean's story below highlights how stress and anxiety can prevent people from following through with their application, even where they may otherwise have had a reasonable prospect of success on appeal:

Dean has been diagnosed with ADHD and autism. He applied for PIP but at the assessment, was turned down after scoring zero points. Both he and his wife were confused by the outcome as Dean had presented medical evidence outlining his condition to support his claim. He went through the mandatory reconsideration stage, at which the decision was upheld, but did not want to proceed further due to the anxiety of going to the tribunal.

He got in touch with DASCAS in late 2016 after considering reapplying for PIP. However, prior to his appointment with DASCAS, he started to have doubts. His first experience of going through the assessment process made him wonder why he would put himself through the stress and anxiety of it all again.

Dean's autism means he is particularly susceptible to anxiety and obsessive thoughts. Since being turned down for PIP, he has had to refuse offers of employment due to his anxieties. Given the stress involved in both the application and appeals process, it is unsurprising that Dean decided to not go through with his application.

3) Disillusionment with the system and apathy

Monica's story, below, reveals a simpler explanation for why people disengage from the process – disillusionment and apathy:

Monica suffered a stroke on her right side and as a result applied for Attendance Allowance. She has made good progress in terms of her health, finding she is able to carry out simple tasks for herself, and has also regained normal speech after attending regular group speech therapy sessions.

Her Attendance Allowance was eventually reduced to £54 a week. Despite her daughter being adamant that she challenges the decision, Monica feels reluctant to go through with it. She does not feel up to going through the process of form filling again and says she doesn't want to 'cause any trouble'. She describes how she feels 'disillusioned with the system'.

It is clear that in some cases, clients, due to their circumstances, age or disability, may not want the hassle of going through the application or appeal process. As Monica's case reveals, once someone has become disillusioned with the system and is apathetic about their situation, it can become difficult for family members to persuade them otherwise.

Dismantling the barriers to accessing benefits: the importance of advice provision

Another aim of the project was to identify ways of dismantling these barriers and preventing applicants from disengaging in the future. With this in mind, we asked survey respondents what would have helped them to manage their issue without the help of DASCAS.

33% said that having a written information pack or advice guide would have helped and only 28% said a telephone advice service would have helped. The figures for online support were less encouraging at just 12%.

Nearly a third (32%) of respondents said that none of these options would have helped them. When asked to elaborate on this, 94% of this category stated that they needed DASCAS to support their application and provide expertise and reassurance.

These findings demonstrate that, whilst there may not be an overwhelming demand for a self-help resource, some members of the disabled community may benefit from a written information guide to help navigate the process by themselves. By providing additional support to those who are better able to help themselves, DASCAS can target their currently stretched resources to those who need it most.

We would, however, emphasise that, in many cases, a self-help resource is not a viable substitute to receiving face-to-face, expert advice. Rather, it may act as a tool for self-empowerment for some members of the disabled community in Wandsworth.

Recommendations

In order to alleviate some of the hardships faced by disabled people in navigating the disability benefit system and make the process a simpler and less stressful experience, the following recommendations are suggested. These have been decided in light of our research findings and following discussions with researchers from the Families, Welfare and Work Team at Citizens Advice.

1) Government/DWP: Simplify the application process and reduce the length of application forms

As our research has shown, 69% of respondents found the application process too complicated to manage without support from DASCAS. There was a general perception among survey respondents and the qualitative interviewees that they would be unable to fill in the form correctly without expert help. The forms were also felt to be repetitive and time-consuming.

Simplifying the application process and reducing the length of the application forms may help to ease the application process for claimants. It would also allow friends, relatives and carers, whom the claimant may be relying on for help, more time to assist claimants with form-filling.

2) Government/DWP: Improve the accuracy of health assessments – get it right first time – and end repeat assessments for the chronically ill

Our research has demonstrated that poor-quality health assessments and negative experiences with health assessments can act as a barrier to gaining full benefit entitlement. Improving the accuracy of health assessments so that claimants are assessed correctly first time will improve the efficiency of the system. Appeals not only mean months of uncertainty, stress and financial loss for claimants, but are also very costly.

3) Government/DWP: Ensure reasonable adjustments are put in place for claimants with mental health issues

As our research has shown, people with mental health issues are particularly vulnerable to the stress and anxiety that comes with engaging with the disability benefit system. In order to make the process a less stressful experience for those suffering from mental health issues, it must be ensured that, wherever

possible, reasonable adjustments are put in place for people with mental health issues.

4) Wandsworth Council: Empower people, organisations and advice services to continue to provide support to those who need it most

Where an individual is prevented from engaging with the application process due to their disability, external support will be required. This could be informal support from friends, relatives, carers and charities, or formal support from specialist advice services such as DASCAS.

We need to ensure that groups who provide support, whether formal or informal, are empowered to do so. This means ensuring funding is secured for advice services like Citizens Advice Wandsworth's DASCAS team and that these organisations have the human resources and expertise needed. It also means ensuring that those who provide informal support to disability benefit claimants, such as friends, relatives, carers and charities feel empowered to do so by ensuring the process is simple to engage with, user friendly and not time consuming.

5) DASCAS: explore the provision of self-help resources that can be made available in hard copy format and on-line to assist people with the disability benefit claims process

Self-help resources may not help all claimants but for some clear and readily available information could be all they need or a good complement to DASCAS Advice. This is an avenue that will be further explored by DASCAS following publication of the report with further input from DASCAS staff and volunteers as well as service users and others who work directly with disabled people in the community.

Conclusion

Our findings have revealed a broken system which many disabled people find complicated, stressful and anxiety inducing, leading a large number to grow disillusioned with it.

We want this research to have maximum impact and to be used as evidence to advocate for better policy making and to help create a more workable and user-friendly system in the future.

The DASCAS team will investigate further the possibility of developing a self-help resource for members of the disabled community who may be able to better help themselves, allowing the team to target their resources to those who need it most. In the meantime, DASCAS will continue to pick up the pieces of this broken system and provide support to disabled people in navigating it.

Volunteer Stories

Below are the stories of the peer volunteers, who talk about why they got involved in the project and their experience with disability benefits, whether direct or indirect.



Liping Liu

I am a volunteer for the DASCAS research project and also work as a carer to support elderly and disabled people in Wandsworth.

During my care work, I found that many of my clients would need help, not only by way of physical and emotional support, but also with practical things, such as filling in forms, making appointments and checking their mail. It is often really difficult for them to write and read themselves, and dealing with these things often makes them stressed.

One of my clients (who is an ex-DASCAS service user) recommended that I volunteer for DASCAS, so that I can learn how the system works, what the policies are and how support for disabled people in accessing disability benefits can be improved. Once I got involved in the research project, I learnt so much from doing surveys and working with DASCAS staff, and gained knowledge about the support that Citizens Advice offers.

It was a very rewarding experience and I have enjoyed working with the project team, doing the surveys and receiving very positive feedback from the service users about DASCAS and their efforts.

Habiba Sheikh

My husband and I are both recipients of ESA and PIP. I suffer from rheumatoid arthritis and my husband has osteoarthritis.

Our experience with the disability benefit system has been extremely stressful. My husband has had his ESA under continual review since he started to receive it in 2012, and having to travel to assessments as well as hospital appointments has created a lot of stress for us both. We have also had the experience of going to a tribunal after my husband had his ESA stopped. I believe the stress of the experience caused flare-ups in my arthritis.

When I applied for PIP we got help from DASCAS. Even as an educated person, I found the forms very long and complicated. DASCAS were of great help to myself and my husband, and when I heard about the opportunity to volunteer for their research project, I immediately leapt at the opportunity to give something back. DASCAS do immensely valuable work for disabled people in the community and I don't know where we would be without them.

Appendix

Copy of questionnaire from Survey Monkey:

1. Why did you contact DASCAS?
 - a. For help applying for a specific benefit.
 - b. For help with a mandatory reconsideration or appeal.
 - c. To see if eligible for disability benefits.
 - d. For help changing from DLA to PIP.
 - e. Other (please specify)
2. Why did you feel you could not deal with this issue yourself?
 - a. I found the process too complicated to manage without advice.
 - b. I did not understand the mandatory reconsideration or appeal process.
 - c. The application process made me feel anxious or stressed.
 - d. I have had a previous negative experience of claiming disability benefits.
 - e. Other (please specify)
3. Would any of the following have helped you to manage your disability benefit issue without the help of DASCAS?
 - a. Having a written information pack or advice guide.
 - b. Having a telephone advice service.
 - c. Online support.
 - d. Help from a friend or relative.
 - e. Help from an interpreter.
 - f. Being able to travel to appointments.
 - g. Having easier access to medical evidence to support my application or appeal.
 - h. None of the above.
 - i. Other (please specify)
4. If you are making a claim and you are unsuccessful, do you think you will appeal?
 - a. Yes.
 - b. No.
 - c. Not sure.
 - d. Not applicable.
5. Would you feel confident making an appeal without external advice or support?
 - a. Yes.
 - b. No.
6. If you don't think you will appeal, why not?
7. Has receiving help from DASCAS made you feel less anxious or stressed?
 - a. Yes.
 - b. No.

8. Do you struggle with reading or writing?
 - a. Yes.
 - b. No.
9. Do you need help to understand English?
 - a. Yes.
 - b. No.
10. Do you suffer from depression?
 - a. Yes.
 - b. No.
11. Do you experience stress or anxiety?
 - a. Yes.
 - b. No.

Sample of qualitative interview questions¹¹:

1. Please give an overview of your experience with the disability benefit system.
2. Please describe any difficulties you faced when making your application.
3. Did you try to access any other help before turning to CAW/DASCAS?
4. Has the process impacted upon your mental health?
5. How would you improve the disability benefit application process in order to make it easier for claimants to access benefits?
6. Why did you disengage from the application process?
7. Why did you decide to not go through with your mandatory reconsideration/appeal?
8. Do you feel receiving advice has empowered you to deal with disability benefit issues in the future?

¹¹ These are sample questions. The questions asked varied for each respondent depending on their individual circumstances.

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