

# How does it feel to be assessed?

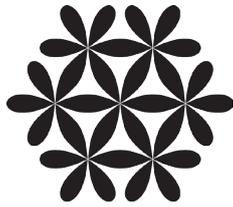
A Paper from the Centre for Welfare Reform

---

Chris Akers

---

NOVEMBER 2016



[www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)

## **Contents**

Summary .....	3
1. Introduction .....	4
2. Method .....	6
3. Analysis.....	8
4. Discussion .....	14
Bibliography.....	17
ABOUT THE AUTHOR.....	18
PUBLISHING INFORMATION .....	19
THE CENTRE FOR WELFARE REFORM .....	19



## Summary

The following small piece of research was carried out by Chris Ackers in March 2015 as a university student studying for a psychology degree with the Open University. The research explores how it feels for people with physical disabilities to be assessed for receipt of benefits.

In particular the research asks how this process affects the sense of self of people with physical disabilities. The paper includes data from semi-structured interviews with two women who have been diagnosed with rheumatoid arthritis.

### **From analysing these interviews, three themes emerged:**

- 1.** The benefit assessment made them consider the independence that the benefits gives them.
- 2.** The lack of understanding about their condition from the assessors.
- 3.** The assessments made them question their capabilities.

# I. Introduction

The self, as Hollway points out, is remarkably difficult to define (2012, p 121). Because of this, though there are a few ideas about what the self is, these are disparate and consequently boil down to a series of binaries. As such this can convolute our understanding of the self.

Yet for the purposes of this research, one such approach to the self is known as the phenomenological self. This approach studies phenomena (the appearance of things) as so to learn about how individuals experience the world. To expand on this idea, it is about ‘investigating the human condition as it manifests in people’s lived experiences’ (Hollway, 2012, p 130). The self in this case is inseparable from their world and constantly, consciously and actively tries to make meaning out of its experience.

One group of people who, it could be argued, attempt to make meaning from their experience are disabled people. Green, Davis, Karshmer, Marsh & Straight (2005) looked at how social processes of felt and enacted stigma impacted on those with disabilities and their families. They suggest that the stigma had negative psychosocial consequences for individuals living with disabilities. They also seems to suggest that people who are stigmatised because of their disability feel worthless.

Following on from this, Underlid (2005) interviewed twenty-five long standing recipients of social security payments and found they felt that most people held low opinions of them. A factor which played a part in this was prevailing views of how the poor are categorised, devaluated and observed within society. How participants perceived their own social situation affected how they thought others felt of them. Underlid’s study produced findings that looked at stigma, albeit in terms of welfare.

This stigma is also found in government policy and media discourse, where people who claim benefits have been labelled as ‘scroungers’, cheating the system and refusing to work. Patrick (2014) highlights the mismatch between government rhetoric of benefits (as a lifestyle choice) and lived experiences. She also found that the majority of claimants engage in hard work such as caring and volunteering.

Stigma is not the only impact that welfare payments have. For people with disabilities four factors in particular are important:

1. the choices they make,
2. their own individuality,
3. autonomy and
4. existence.

Gundersen (2012) looks at how parents of children with disabilities experienced the welfare system and found that applying for benefits may leave parents with a sense of bereavement, after presenting their child as unequal to others.

But how do disabled people themselves feel about the benefit system and how will recipients cope with changes to it? After all, any changes, in terms of payment received and the assessment process itself, could influence how they see themselves.

Benstead (2012) explores Disability Living Allowance (DLA), which helps with the cost of living with a disability. While DLA is the means by which a person can work (for example by paying for public transport), it will be phased out by June 2015 (Benstead, 2012). This change will affect the four factors mentioned earlier.

Harris (2014) attested to this by commenting on Personal Independent Payment (PIP), the benefit replacing DLA. She notes that the vigorous nature of the assessment for PIP could, in the eyes of claimants, imply an abuse of the system on their part. She noted that claimants were angry that the assessors appeared to begin with the premise of a false claim. This can be linked to Patrick's study, in how government rhetoric could have a great influence on how benefit assessments are experienced.

Experiences that Harris describes are supported by a report produced by Clifton, Noble, Remnant & Reynolds (2013). They found that the current welfare system is unfit for purpose, dehumanising and has a negative effect on health and wellbeing.

For instance, the charity Leonard Cheshire found that of those who had experienced the Work Capability Assessment (which is used to determine whether those in benefits are well enough to work), around three quarters of those questioned stated that the assessment had a negative impact on their physical or mental health and that the face to face appointment had been stressful (Fearn, 2015).

A report by the Work and Pensions Committee bears this out. It states that the claimants they interviewed said that their experience of benefit assessments left them feeling '*dehumanised, ignored or questioned inappropriately*' (2014, p 11).

With this in mind, the research question that has emerged is – how does the experience of participating in benefit assessments affect a person with disabilities sense of self?

## 2. Method

### Participants

Two adults (one in their thirties and one in their sixties) were approached by a series of phone calls and were told about the nature of the research, which they agreed to participate in. They were both promised complete anonymity and as such, are referred to using the pseudonyms 'Adele' and 'Nicola'. Both of them came from the Midlands and are currently unemployed. They have been diagnosed with Rheumatoid Arthritis for at least the last twenty years.

### Data collection

After agreeing to be interviewed, both of the participants arranged by phone an appropriate date and time for the interviews to take place. Due to the complexities of their physical disabilities, they both requested for the interviews to take place at their respective homes.

At the start of the interviews, each participant was told in more detail about both the nature of the research and the consent form before they signed it. Each interview lasted a minimum of 25 minutes and was recorded onto a digital tape recorder.

The aim of this research was to capture the complexity and richness of the participants' own experience of taking part in benefit assessments. Due to this, it was felt that the most appropriate method of data collection would be a semi-structured interview.

**There were three reasons for this:**

- 1.** Conducting an interview that was more restricted in its structure not only would limit the flexibility of what could be asked (as it would not allow for questions about any information obtained in the participants answers), but also reduce the richness to the description been collected
- 2.** The phenomenological approach is about (amongst other things) interpreting someone's experience within their own experience. Both the description of their experience and its interpretation would be very narrow if questions were already pre-planned and given little scope for manoeuvre.

3. This method of collecting data not only allows the participants to speak at their own pace and with as much detailed description as they desire, it gives them to some degree of control of the path of the interview. Though questions were asked at times to get the interview back on topic, this method let the participants play an active role in the interview and not just respond habitually to questions.

Due to the study having an idiographic focus (wanting to understand the world of benefit assessments from the view of the participant), Interpretative Phenomenological Analysis (IPA) was employed in analysing the data and the findings produced through thematic analysis. This is an approach to qualitative research that aims to offer insights into how a given person, in a given context, makes sense of a given phenomenon - the phenomenon in this case being the experience of undertaking the process of benefit assessments. Both interviews were transcribed in full and annotated.

## Ethics

As stated earlier, participants were briefed as to the nature of the interview from first contact. They were also told of their right to withdraw at any time. Only myself, the tutor and the necessary Open University staff (for administration purposes) saw the transcribed interviews. Within these interviews and the analysis section, the participants were only identified by their pseudonyms. Due to the increased vulnerability of people with learning disabilities only disabled people with physical impairments were interviewed.

The participants were also given information about who they could talk to after the interview if need be and were offered the chance to ask questions both before the interview and in the concluding debrief. Information collected was only for the purposed of this research and once the project was concluded, the information was securely deleted or shredded.

### 3. Analysis

The findings after IPA produced three interrelated themes that show how the experience of benefit assessments affects the participants' sense of self. The first theme describes the level of independence that benefits give to the participants and the consequences to that independence if they fail the benefit assessment. It also looks at how much of the benefit assessment they were able to do independently and how much friends and family assisted them.

The second theme centres on the level of understanding, both in terms of the participants explaining their condition to others and the level of expertise of the people assessing them, plus their frustration at both. The final theme looks at the participants describing how the process makes them question their own capabilities. Those themes will now be presented in more detail.

#### Theme 1 - Independence

Both participants draw on the fact that without the benefits that they are awarded, they would be unable to live as fulfilling a life as they currently have. This is because the aids and appliances that their benefits allow them to purchase can make them feel as normal as possible. Without these aids, life for both of them would be very stressful. Going through the benefit assessments made them consider this in some depth.

**Adele underpins this by describing how she was feeling the longer the assessment went on and how she feared her aids may be taken away:**

*'the longer it went on, the more stress I was getting about it and the more worried I was getting because, that's you know, if I'd lost my car, that would have had a massive impact'*

(lines 207-209)

**Nicola also describes this though in more depth. She talks about this in relation to the potential loss of her car:**

*'And I suppose I've got used to it, especially since I've used that money to have a car and that's given me independence, which I wouldn't have without that. And so I think the threat, I suppose it is, because you read about so many*

*people in the papers or through the charity I'm involved in hearing about it...of me losing that, which if I lost that benefit I'd lose my independence. I would be totally reliant on my husband... taking me where I want'*

(lines 25-30)

However, while the benefits allow them to live as independently a life as possible, they still need the support of their family and other professionals to complete the assessment. So they are more dependent during the assessment process.

### **Adele talks about the support she required when she was ill:**

*'...luckily for me, because I was so ill, I had carers coming in, so I had a social worker... so she was able to come and fill the form in for me. Because I couldn't... particularly the first time, because I had my shoulder operated on, I'm right handed...there's no way I could write, ...so she came and did it for me.'*

(lines 168-171)

### **Nicola also describes the support she got in filling in the form:**

*'...I was able to calm down a bit and my husband helped me as well. It [a website] pointed out to me what I couldn't do and that helped me a lot. My friend helped me as well because she filled in the form. So I felt as though I got the right support and was able to fill in the form comprehensively...'*

(lines 155-159)

Without this help, the participants would not be able to complete the form and be able to acquire the aids needed to live as independently a life as possible. It shows how vital the support they get from friends and family, as they act as a conduit in communicating their condition to assessors, who may not have enough expertise about the condition they are describing.

## Theme 2 - Understanding

What is prominent in both interviews is the lack of understanding for the participants' physical disabilities. The participants have to constantly explain their condition to the assessors via supporting evidence.

**Adele explains this in terms of what evidence she has had to produce:**

*'I mean, we'd always taken photocopies of what people had written before, the Ladyhall Trust and the CAB had written before and things like that. So I've got photocopies of every single assessment that I've had to do to refer to.'*

(lines 77-80)

Yet this quote from Adele was from when she was a teenager. Some years later the form has become less specialised and more narrow.

**Nicola conveys this in the data extract below when describing the difference between filling forms for her condition then and now:**

*'Because back then, with it been arthritis if it was active and aggressive polyarthritis, which means it's just very active and affects more than one joint you know, lots of joints through the body, then that was almost like a tick box for you to get through the system and that's what's changing now. That tick box has gone for Rheumatoid arthritis... and that's what's creating problems now.'*

(lines 74-78)

**Adele supports this by explaining how the form has changed over the years:**

*'the form has definitely changed now. There's only one form... and it's on... more weighted now on mental health and learning difficulties, then I think it ever was. Though you may have to do some research into that. So for me there was like 14 or 15 questions that weren't... probably 7 or 8 that were weighted that had nothing to do with me. Which is fine. I think that's a good thing. But yeah. See some of the questions were harder to answer. Cos obviously I'm... well I can cope in that way. I'm physically unwell so...'*

(lines 313-318)

**While Adele says that some of the changes are good, it has led to some confusion amongst people she knows who have the same condition as her:**

*‘Certainly people I know who are disabled, most of them are physically disabled, it’s been quite confusing as to who qualifies for what. Bearing in mind we all have the same illness and we live relatively the same life.’*

(lines 155-158)

**This can lead to frustration for Adele in repeating herself:**

*‘Very frustrated. Very annoyed that people...I don’t think people understand chronic illness such as something like rheumatoid arthritis, because everyone gets arthritis.’*

(lines 115-116)

**And also frustration on the part of Nicola who, while not explicitly saying that the government is wrong in changing the system, thinks they are going about it in the wrong way:**

*‘It definitely needs an overhaul to the system... I think the government is right, but what they’re doing it seems is targeting the wrong section. They’re still some things I believe that you should be able to send a letter in and it has more weight than what it has now.’*

(lines 214-217)

Frustration appears to sum up how people’s lack of understanding of Adele and Nicola’s condition has both made them feel.

## Theme 3 - Capabilities

The nature of the form made the participants question themselves and what they think they are capable of doing.

**Adele emphasises this in two quotes, when asked how repeating her explanations during constant benefit assessment affected how she viewed her disability**

*'I think... I have conversations with my friends all the time about going to work and I should do this and I should do that and they're constantly saying 'Adele you're too ill you know, look at you. You're shattered and what have you done today, nothing'. Or 'you've cooked yourself a meal and you're exhausted, that you can't even eat it', do you know what I mean. It's that sort of thing.'*

(lines 128-133)

**This made Adele think that she should have been assessed even more:**

*'...alright yeah it's stressful, but because I'd never been assessed in all that time maybe I should have been. That's what I was thinking in my head.'*

(lines 175-177)

**For Nicola, it made her face what she couldn't do. This changed her usual positive outlook on her illness:**

*'RA's in the family and everybody just deals with it, you just carry on around and nobody makes a fuss. So that's how I've looked at it. I've always s looked on the positive side, I can't do that, but I can do that. Whereas just filling this form, I just found horrendous. It made me face what I couldn't do.'*

(lines 92-96)

**The language used in the form was more about recording what Nicola could not do and not what she is able to do:**

*'But as I say, it made me, look at what I couldn't do and have to write it down. It was so much. No I can't do this, no I can't do that, well yes I can do that but have to do it this way or I have to alter the way I do it in my house, because my house has everything planned how I need it.'*

(lines 115-118)

**It was also invasive in the way it asked Nicola to describe her condition:**

*'But what...when I came to fill in this new form... I mean it's so invasive...so... really makes you look into what you can do and what you can't do.'*

(lines 110-118)

The repetitive nature of the assessment and the language used during the assessment, made both Adele and Nicola question themselves in relation to their disability in a negative way.

## 4. Discussion

After analysing the interviews with the participants, it was found that the benefit assessment process influenced the participants' sense of self in three ways. This section will look briefly at whether each of these themes fall within the theoretical framework of the introduction to this research

### Independence

Both participants expressed concern over how the potential removal of their benefits will have on their independence. This in part can be inked to the findings of Strandmark (2004), who to reiterate, found that the essence of ill health is powerlessness and also creates a feeling of being trapped in their current situation. This feeling of being trapped could be exacerbated by the removal of benefits which would limit their independence by reducing their autonomy, existence and the choices they make. This could also be linked to Benstead's statement of how the phasing out of Disability Living Allowance will affect independence.

One factor which the literature review did not consider which was discussed in some depth in the interviews, was the assistance and support that each participant received from family members in filling out the requisite forms. Though it could be argued that it has some links to Gundersen's research concerning the experience of parents of disabled children going through the welfare system, the findings of the research would modify Gundersen's work by focusing on the assistance and experience of adults navigating the welfare system for adult disabled significant others.

### Level of understanding

Analysis of the interviews found that the participants became frustrated at the lack of understanding of their condition from both assessors and others. Adele's quote concerning how everyone may think they have arthritis but do not, could be linked tentatively to Green's research in relation to the social stigma of Rheumatoid Arthritis (that it is an old person's disease) adds to the frustration of explaining the condition. Analysis of this theme also showed that this low level of understanding is reflected in both the parochial nature of the forms that need to be completed and the face-to-face assessments.

## Capabilities

Through both interviews, both participants describe how the nature of the benefit assessments made them question their own physical capabilities. Adele stated that the process made her think that she was able to go to work and that receiving the result made her sick, due to the stress it had put her under. This concurs with the Clifton et al's research, stating that the current welfare system is dehumanising and has a negative effect on health and wellbeing. This also coincides with the study by Leonard Cheshire.

Nicola spoke of the nature of the form being invasive and this supports the finding of the Work & Pensions Committee, which found that the experience of benefit assessments left claimants feeling 'dehumanised, ignored or questioned inappropriately'.

## Conclusions

As for my own feelings, I have been in receipt of benefits and have participated in activism concerning changes to the welfare system. This could have greatly influenced my analysis of the interview transcripts, due to the empathy I have towards benefit claimants & the disabled and understanding what it is like to live a life dependent on the welfare system. It must be said that a level of trust had already been obtained due to having been a friend of one of the participants for a number of years. This means that she may have been more open with me than another researcher.

When conducting the interviews, the only specific problem encountered was that one of the interviews is more tangential and shorter than the other. This would not only have greatly affected the analysis, but also the depth of the relevant information.

Using the phenomenological method enabled a great of richness of information to be recorded and analysed. This was further supported by the open ended nature of the questions asked. It should be mentioned however that the two interviews were people with a chronic illness for at least twenty years. This alone could have influenced their own sense of self.

Though the participants described how the benefit assessment process made them feel, they did not describe why they felt like they did. A replication of this study could include how people with learning

disabilities feel about the benefit process. Yet due to ethical concerns, this would be extremely difficult to conduct. The length of time they acquired their disability and also the way their disability was acquired could be areas to be researched. Perhaps a more longitudinal approach to the study to reflect changes to the welfare state and societal attitudes to disability could be beneficial.

Finally, it is important that those who are disabled are given the assistance and guidance they require to flourish in society. This research could be used in the future to adapt the benefit process to make it fair, humane and considerate to the needs of those who need it. A true understanding of how those on benefits really face life can be supported by this research and not just clichéd rhetoric such as scroungers to describe those in need who are asking for help.

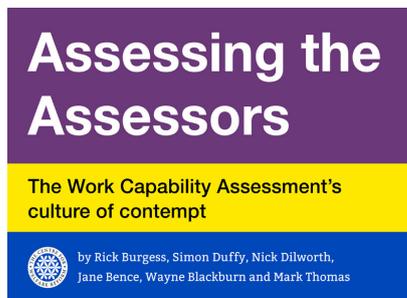
## BIBLIOGRAPHY

- Benstead S (2012) *Why We're Not Benefit Scroungers: Life with chronic illness or disability in Modern Britain*. Woodstock, Oxfordshire, Aleksia Publishing.
- Clifton A, Noble J, Remnant, J & Reynolds, J (2013) *A consultation examining the impact of welfare reforms on people in the North East of England*. Retrieved from <http://www.centreforwelfarereform.org/library/by-az/the-impact-of-welfare-reforms.html>
- Fearn H (2015) *Government fitness for work test is making disabled people sicker, report claims*. The Independent. Retrieved from <http://www.independent.co.uk/news/uk/politics/government-fitness-for-work-test-is-making-disabled-people-sicker-report-claims-10082452.html?origin=internalSearch>
- Green S, Davis C, Karshmer E, Marsh P & Straight B (2005) *Living Stigma: The Impact of Labeling, Stereotyping, Separation, Status Loss and Discrimination in the Lives of Individuals with Disabilities and Their Families*. *Sociological Inquiry*, 75(2), 197-215.
- Gundersen T (2012) *Human dignity at stake – how parents of disabled experience the welfare system*. *Scandinavian Journal of Disability Research*, 14(4), 375-390.
- Harris N (2014) *Welfare Reform and the Shifting Threshold of Support for Disabled People*. *Modern Law Review*, 77(6), 888-927.
- Hollway W (2012) *Self*. In Hollway W, Lucey H, Phoenix A & Lewis G (Eds) *Social Psychology Matters* (2nd Ed. pp. 119-144). Milton Keynes, The Open University.
- House of Commons Work and Pensions Committee (2014) *Employment and Support Allowance and Work Capability Assessment: First report of 2014-15 (House Paper No. 302)*. London, The Stationery Office Limited.
- Patrick, R (2014) *Working on Welfare: Findings from a Qualitative Longitudinal Study Into the Lived Experiences of Welfare Reform in the UK*. *Journal of Social Policy*, 43(4), 705-725.
- Strandmark M (2004) *Ill health is powerlessness: a phenomenological study about worthlessness, limitations and suffering*. *Scandinavian Journal of Caring Sciences*, 18(2), 135-144.
- Underlid K (2005) *Poverty and experiences of social devaluation: A qualitative interview study of 25 long-standing recipients of social security payments*. *Scandinavian Journal of Psychology*, 46(3), 273-283.

## ABOUT THE AUTHOR

**Chris Akers** graduated in 2016 with a 2.1 psychology degree from the Open University and is hoping to do a Masters in either psychology or sociology in the future. Chris's job involves supporting adults with physical and learning difficulties. He has a general interest in how the benefit system and any changes to it affect people with both physical and mental disabilities, as well as those who are in poverty. Chris is an honorary member of the Disability Enabling and Empowerment Project (DEAEP).

Email Chris: [cwa21@outlook.com](mailto:cwa21@outlook.com)



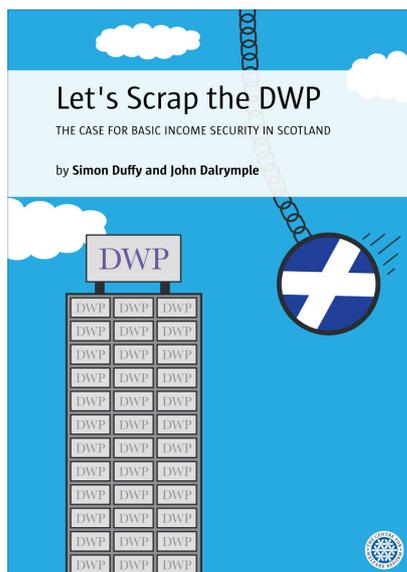
You may also be interested in:

### [Assessing the Assessors](#)

The Work Capability Assessment's culture of contempt

The report is available to read at:

<http://bit.ly/assessWCA>



### [Let's Scrap the DWP](#)

The Case for Basic Income Security in Scotland

The report is available to read at:

<http://bit.ly/IncomeBasic>

## PUBLISHING INFORMATION

How does it feel to be assessed? © Chris Akers 2016

Designed by Henry Iles

All rights reserved.

First published November 2016

ISBN download: 978-1-907790-85-0

22 pp.

No part of this paper may be reproduced in any form without permission from the publisher, except for the quotation of brief passages in reviews.

*How does it feel to be assessed?* is published by the Centre for Welfare Reform.

The publication is free to download from: [www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)

## THE CENTRE FOR WELFARE REFORM

The Centre for Welfare Reform is an independent research and development network. Its aim is to transform the current welfare state so that it supports citizenship, family and community. It works by developing and sharing social innovations and influencing government and society to achieve necessary reforms.

To find out more visit: [www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)

Subscribe to our monthly email newsletter: [bit.ly/CfWR-subscribe](http://bit.ly/CfWR-subscribe)

Follow us on twitter: [@CforWR](https://twitter.com/CforWR)

Find us on Facebook: [centreforwelfarereform](https://www.facebook.com/centreforwelfarereform)



Published by the Centre for Welfare Reform

[www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)

design: henry iles & associates / [design@henryiles.com](mailto:design@henryiles.com)