

**Garthwaite K, Bambra C, Warren J. 'The unwilling and the unwell'? Exploring stakeholders' perceptions of working with long term sickness benefits recipients. *Disability & Society* 2013, 28(8), 1104-1117.**

**Copyright:**

This is an Accepted Manuscript of an article published by Taylor & Francis in *Disability & Society* on 13/02/2013, available online: <http://dx.doi.org/10.1080/09687599.2012.758032>.

**DOI link to article:**

<http://dx.doi.org/10.1080/09687599.2012.758032>

**Date deposited:**

28/03/2017

**Embargo release date:**

13 August 2014



This work is licensed under a [Creative Commons Attribution-NonCommercial 3.0 Unported License](http://creativecommons.org/licenses/by-nc/3.0/)

# **‘The unwilling and the unwell’? Exploring stakeholders’ perceptions of working with long term sickness benefits recipients**

Kayleigh Garthwaite, Clare Bambra and Jon Warren

Department of Geography, Wolfson Research Institute for Health and Wellbeing,  
Durham University, Stockton on Tees, UK

(Received 27 January 2012; final version received 9 November 2012)

## **Abstract**

This paper draws on qualitative research with Incapacity Benefit (IB) stakeholders in the North East of England, UK. Stakeholders’ experiences of working with long-term sickness benefits recipients reveal multiple barriers that both sick and disabled people, and themselves as practitioners, clearly face. Reflections on what ongoing welfare reform could mean for future practice for both stakeholders and recipients will be explored. The findings suggests that whilst stakeholders recognise the complex barriers faced by those receiving sickness benefits, a wider moral dialogue between ‘deserving’ and ‘undeserving’ is being created and sustained as a result of negative stereotyping of sickness benefits recipients.

**Keywords:** sickness benefits; stakeholders; welfare reform; ‘undeserving’; barriers; stereotype

## **Points of interest**

- Ongoing welfare reform means that people who receive sickness benefits are never far from the public eye.
- This article looks at the experiences of key professional stakeholders who work with long-term sickness benefit recipients on a daily basis.
- Eighteen in-depth interviews were carried out with stakeholders in the North East of England.
- Stakeholders talked about a number of barriers long-term sickness benefit recipients can face in taking the next step towards employment, retraining or improving their health.

- Stakeholders who work with people receiving Incapacity Benefit can negatively stereotype claimants as ‘undeserving’.
- The research recommends that the experiences of people who receive long term sickness benefits should be considered.

## **Introduction**

Sickness benefits receipt is a salient issue in academic literature, the media and wider society. As has been well documented, in the UK there are currently more than 2.5 million people with long-term health conditions or a disability who are claiming Incapacity Benefit (IB) (Beatty and Fothergill 2010). Reducing the number of people claiming sickness benefits has long been a priority of successive governments in the UK, with Brown’s Labour government initiating a new benefit to replace IB, Employment and Support Allowance (ESA), in 2008 (DWP 2008a; 2008b) which attached work-related conditions to the receipt of disability benefit. Importantly, such changes mark a clear transition in the classification of disabled people, given that in the past disabled people were typically viewed as a distinct administrative category with an unquestionable entitlement to welfare assistance (Bambra and Smith 2010). Disability tended to be viewed as ‘deserving’ whilst those who are now classed as ‘sick’ but able to work are at risk of being deemed ‘undeserving’ (Stone 1978; Hyde 2000; Roulstone 2000; Warren 2005; van Orschot 2006; Bambra 2008; Piggott and Grover 2009, Bambra and Smith 2010). The terminology of ‘sick and disabled people’ will be used throughout the paper; when talking about the disabilities of the participants of the study, the term specifically refers to people with physical impairment and manifest/known about mental health problems. People with learning difficulties and social learning

difficulties such as Asperger's or Autism were not represented in the narratives of the participants of the study overall.

Much of the policy and academic literature in the UK centres on moving sickness benefits recipients into paid employment, with government responses to IB receipt, notions of supply and demand, and barriers to employment for IB recipients often discussed (Bambra 2006). For Grover and Piggott (2007:735) this is most visible in the moralising discourse through which the receipt of IB is constructed as being indicative of a 'dependency culture' of sick and disabled people. In particular, welfare-to-work rhetoric has increasingly focused upon addressing people claiming IB as a primary concern or 'problem', embedded within an implication that somehow many of those receiving IB are able to be somewhere else, whether that place is another form of benefit such as Jobseeker's Allowance (JSA), or into the labour market. Indeed, the receipt of IB has become framed by popular concerns that many sick and disabled people are either fraudulently claiming IB or abusing its careless administration (Garthwaite 2011; Piggott and Grover 2009). Whilst many responses to the changing welfare landscape have been presented, what is less often discussed is the reality of long-term sickness benefits receipt.

This paper is based upon research that explores the relationship between long-term IB receipt and stigma in areas of North East England with the highest levels of IB take up. A consideration of the construction of self identity of people claiming IB long-term, amidst wider political, societal and media representations of IB recipients is a key aim of the research. In order to fully explore the qualitative experience of receiving sickness benefits, it is also necessary to discover the perspectives and experiences of key professional stakeholders who engage with long-term sickness benefits recipients on a daily basis. Key

stakeholders such as welfare-to-work providers ultimately decide on whether a claimant is seriously seeking work and consequently have significant, unavoidable discretion (Lipsky 1980). Therefore, exploring the experience of stakeholders is crucial in order to fully understand the complex experience of sickness benefits receipt. Yet despite this, there are relatively few studies that focus upon the experience of stakeholders. Previous research has discussed the barriers perceived by stakeholders in terms of low labour market engagement and a lack of motivation and confidence (Beatty *et al.* 2009). Riddell and Banks (2005) and Thornton (2005) also discuss the barriers faced by disabled people, but from a skills and programme point of view. However, discussions of the barriers stakeholders themselves face, alongside the significance of language surrounding sickness benefits recipients are largely missing from such analyses.

## **Methods**

This article is based on data from in-depth qualitative research with professional stakeholders who are involved with sickness benefits recipients either as welfare-to-work providers, clinicians or advisers. Participants were recruited to the study via Jobcentre Plus (JCP) 'Choices' community outreach events held between September 2009 and June 2010 in areas of North East England that possessed then highest levels of sickness benefits receipt. Jobcentre Plus is a key government agency for working-age people in the UK that seeks to support people in seeking and finding employment. The 'Choices' events aimed to bring together various stakeholders in a community setting, encouraging sickness benefits recipients to attend and discover what options were available for re-entering work, education or training. Following communications at the events, stakeholders were then

approached individually and subsequent interviews were arranged. This initial contact helped to establish good rapport with interviewees, which was demonstrated by the full and frank exchanges that occurred during the interview process.

In total, 18 professional stakeholders were interviewed, including professionals involved with the administration of state benefits and the provision of retraining, rehabilitation and health improvement schemes. For example, participants were professionals from agencies such as Jobcentre Plus, Shaw Trust, Condition Management Programme (CMP), the National Health Service (NHS), and a Primary Care Trust (PCT) various local and national organisations and charities aimed at supporting people who receive long-term sickness benefits. A flexible topic guide prompted interviewees to discuss their role of working alongside people who are receiving benefits due to health conditions or disabilities; their perspectives on the barriers faced by the people they engaged with; their own barriers in working with this group; their perceptions of sickness benefits recipients; and lastly, welfare reform. Interviews were conducted face to face and largely took place in the stakeholders' place of work. Interviews were digitally recorded with prior permission from interviewees and typically lasted between 45 minutes to 60 minutes. Data were then transcribed verbatim and fully anonymised before thematic analysis was undertaken. A thematic framework for analysis was derived partly from the study objectives and partly by identifying themes from ongoing analysis of transcripts. Participants were ensured that all information given would be treated with confidentiality; consequently, all participants' names have been anonymised and it has been ensured that individual participants cannot be identified. All quotations are in participants' own words. Ethical

considerations were respected throughout the research, with the research being approved in advance by Durham University Department of Geography Ethics Committee.

## **Findings**

This section outlines the key themes that occurred following thematic analysis of the data: barriers for sickness benefits recipients and stakeholders; perceptions of recipients; and finally ongoing welfare reform and implications for future practice. The discussion will largely focus on stakeholders' experiences with Incapacity Benefit recipients, as current ongoing welfare reform meant that the majority of stakeholders were working solely with IB recipients whilst the transition to ESA was ongoing.

### ***Barriers for IB recipients***

Stakeholders frequently spoke of the multitude of barriers long-term IB recipients face in taking the next step towards employment, retraining or improving their health. These ranged from supply side barriers that were seen as being part of the individual – for example, oft-cited barriers such as motivation, confidence, culture and a lack of routine (Gardiner 1997), to more structural, demand side barriers including place, discrimination and a lack of jobs. The Disability Discrimination Act (1995; 2005) and The Equality Act (2010) were passed into legislation with the specific aim to protect disabled people and prevent disability discrimination. Such legislation has meant that disabled people have the right to goods, services, facilities and premises. The Equality Act also makes employers also have to make 'reasonable' adjustments to their premises and/or working practices to assist disabled people in their work. Despite their acknowledgement of barriers, some stakeholders suggested that living on benefits had become 'too cosy and comfortable' for some people:

In some cases it can be just their mindset but a lot of these guys are healthy, a lot of them are out with their dogs, they have hobbies, some of them play five-a-side football so they do have stuff they can do so it's become too cosy and comfortable for them so it's maybe about making it uncomfortable.

(Alan, case manager, NHS).

Here, Alan seems to make practice decisions based on anecdote, yet fails to recognise that some people who play 'five-a-side' football may indeed have bouts of chronic symptoms which can prevent them from taking part in such activities. Whilst Alan suggests that IB recipients enjoy a 'comfortable' life, other stakeholders disagreed and pointed to the notion that living on benefits can mean constant fear and insecurity. Wider notions of fear were discussed by stakeholders, largely framed by a consideration of sickness benefits as a safety net. Billy worked with disabled people who were engaged in training courses to help them move further towards employment. Billy asks: 'When push comes to shove, why should they move off the permanence of IB into the impermanence of getting a job and possibly being worse off?' Notions of fear and confidence were intertwined throughout the interviews, with stakeholders believing that if sick and disabled people were able to believe in themselves more, they may be able to take steps towards improving their health, entering training or employment. This highlights the distinction between individual 'failings' as seen by stakeholders versus more substantive barriers such as health, place, and employer prejudice.

Although ill health is undoubtedly the key reason why people are receiving sickness benefits, some stakeholders were solely concerned with getting IB recipients into work. Targets and contracts ensure a focus is upon moving people into work, as Rob, a job broker for a local charity, suggests: 'Our only target is to find employment for them, so we haven't

got anything around training or any soft outcomes or anything like that - it's literally engage with them, work with them and get them into work'. Certainly, Dickens *et al.* (2004) report that Jobcentre advisers often regarded targets as a key issue affecting their work. Below, Jenny, who works for a national charity which helps sick and disabled people find employment, clearly outlines the difficulties that can occur when someone makes the transition from sickness benefits to employment when they are not fully ready:

The worst part of this job is meeting somebody who's been on Incapacity Benefit who has pushed themselves into a job and they're coming to me to say they need support because they've got a job and you can guarantee they'll come out of work. They're the hardest to help because then all the ground works, all the levels of support you need to put in place have gone and you've got to start at rock bottom to build that person's confidence up.

(Jenny, personal development advisor, national disability charity).

Place was also cited as an issue. County Durham is a region replete with a coal mining legacy that relates to wider, long-term processes in the economy and regional labour market. Nearly 90 per cent of the coal mining workforce was shed during the first ten years after the miner's strike of 1984-5, and job losses have continued on a smaller scale ever since (Beatty *et al.* 2007: 5). One of the most important features of this job loss following the closure of the pits is that it has been virtually all concentrated in a dozen or so areas across Britain, including Easington and its surrounding areas in County Durham. Following the closure of the pits in the 1980s under Thatcher's reign, many miners were placed onto sickness benefits. IB receipt not only grew, but was arguably used as a smokescreen to hide growing levels of unemployment. For those in their late fifties at the time of closure, this was a fairly unproblematic step; few who have worked in the industry for a couple of decades have not picked up injuries that limit their actions in some way (Strangleman 2002). Yet it is

important to note that at this time, being on sickness benefits was not equated to being 'undeserving'. Indeed for Roulstone (2011) the neo-liberalism of the 1980s and first half of the 1990s did not connect welfare dependency and disability in any meaningful sense. As a result, sick and disabled people were not labelled as 'scroungers', unlike the discourse currently being created via political, media and public opinion alongside ongoing welfare reform (Garthwaite 2011).

The majority of stakeholders spoke about the aftermath of the collapse of the coal industry for the North East and its impact upon sickness benefit take-up. In County Durham, 9.4 percent of the working age population receive sickness benefits, compared to a North East average of 8.4 percent and a national average of 6.5 percent (NOMIS, December 2011). Michael, an occupational therapist for CMP, talks about his experiences of Easington, an area of County Durham that often comes a close second to Merthyr Tydfil in Wales for having the highest percentage of the population receiving IB in the UK:

It's the culture, the culture and the mindset, how people have been growing up having this industry and the belief that it was always gonna be there and in one fell swoop it was gone and it's interesting cos in some of the outlying districts the smaller pits it hasn't affected them the same as say Easington which solely depended upon those pits. I really don't know the answer cos they've pumped millions into Easington, absolute millions and nothing's changed - in fact, it's probably got worse.

Alan (case manager, NHS) suggests that perhaps people do need to look further afield to find work: 'People live in those kinda close knit communities and there's a whole 'I wouldn't dream of moving to Carlisle, moving to Edinburgh or Leeds cos I've always lived here, this is where I've always been' and that box needs to get bigger'. Some commentators have suggested that if an area lacks job opportunities, people should seek work elsewhere. Mead

(2011) suggests that for people claiming IB in an area such as the North East, if there are no opportunities then why don't people who are 'fit but jobless' (2011:281) move to a more prosperous area. Yet such a stark approach does not take into account the wider barriers outlined by the stakeholders in this study, such as confidence, fear of making the next step and also wider issues such as caring responsibilities, housing and transport. This approach has also been favoured by the current Secretary of State for Work and Pensions, Iain Duncan Smith, who suggested that people who are trapped in 'ghettoes of poverty' should be prepared to look further afield for work – reminiscent of Norman Tebbit's famous 'get on your bike' quote in the 1981 aimed towards unemployed people. Although Duncan Smith claims he is not insisting everyone moves to the South of England, even travelling 10 or 15 miles can be problematic for someone who has no access to a car, has to use costly and often unreliable public transport (Lucas *et al.* 2008), whilst also negotiating caring responsibilities, childcare, and of course, complex health problems.

### ***Barriers for stakeholders***

The research also strongly suggests that within the stakeholders' roles, distinct barriers were evident when working with sick and disabled people and also when working with other agencies. The difficulties faced by stakeholders in engaging with long-term IB recipients were frequently discussed within the research. The perception that helping people who are closer to the labour market - for example, the short term unemployed or younger workers - was easier and therefore a more attractive prospect than working with someone with a long-term health condition, loomed large. This perception could be linked to the target driven nature of welfare-to-work services, as Steve (IBPA, JCP) indicates: 'People who are further away and harder to handle, it's easy to push them away cos you know it's gonna be

hard and it is driven by statistics and you have to be looking to get people into work'. Similarly, deciding how much detail to tell people about services available so that they are best informed to make decisions may require careful assessment of individual circumstances and needs. Other research also shows that it can be particularly hard to enable people to understand, in advance, the processes and approaches involved in some services (Corden and Nice 2006). Beatty *et al.* (2009: 65) suggest 'there is a need to carefully target initiatives on those closest to the labour market in order to maximise policy effectiveness and efficiency'. This perception was also believed to be situated within employers' attitudes towards IB recipients, as the following section indicates. Many stakeholders felt that employers do not do enough to give sick and disabled people a chance:

I think there are a lot of good employers but a lot of them don't get it. They see time as money. I think it's that narrow black and white view of the world, it doesn't make a lot of sense cos there will probably be a lot of older workers who will be very good, reliable workers who just need that bit of help and support to get back into work for those first few months until they get on their feet

(Johnny, senior public health specialist, PCT).

Stakeholders reported how they would refrain from telling an employer every detail about their client's disability or health problem in order to give them a better chance of getting a job. A recent House of Commons Work and Pensions Select Committee report (2011) remarked that the government 'will only achieve its objective of getting benefit claimants back into work if employers are willing to employ people who might have been on incapacity benefit and out of work for some time, and who might still have substantial health issues'. The report went on to suggest the government should play a key role in trying to change employer attitudes to former benefit claimants in order to ensure people leaving sickness benefits are not just job ready, but have a job to go to. This was a

fundamental point echoed by the majority of interviewees, who felt that the system was not 'joined up' enough and could lead to diminished confidence for those trying to find a job.

Another key barrier that emerged from the interviews was multi agency working. Working with multiple agencies that were often competing against each other to reach their targets meant that tensions could be found between agencies. Indeed, Barnes and Hudson (2008) report on the 'rivalry' between job brokers and agencies such as CMP. They found that some CMP practitioners believed that the funding base for job brokers meant that they were a little too keen to encourage customers back into work, regardless of whether this was appropriate for them, and were inclined to be wary of them for this reason. Equally, this study found that some stakeholders felt that mainstream services such as Jobcentre Plus did not do enough to encourage disabled people into work:

Within the mainstream services it's a lot of tea and sympathy, there's a lot of poor me, oh dear you're a victim and therefore they deserve help and the bit that gets me is when people say 'It's my entitlement' well no it's not your entitlement, you're not entitled to anything in this life

(Diane, GP).

Furthermore, some stakeholders felt that it was essential other agencies were aware of what they could offer in order to forge a successful working relationship, as Michael (occupational therapist, CMP) states: 'It does depend on which area you work in and which Jobcentre that you cover if they feel that CMP is a good idea or if they have a good understanding of how we can help you tend to get better referrals'. When discussing employers, stakeholders made it clear that employers can be wary about employing someone with a disability. Jim (counsellor, disability training college) feels that the word 'Incapacity' can frighten potential employers off: 'I think a lot of people especially when

we're trying to get them jobs, incapacity frightens people off if they're on IB what are they capable off, they can't do this, they can't do that'. This point articulated by Jim leads onto the following section which discusses stakeholders' perspectives of long-term IB recipients, including a consideration of the language used not only by the stakeholders themselves, but also the wider media, policy and academic discussions surrounding sickness benefit receipt.

### ***Perceptions of IB recipients – 'the unwilling and the unwell'***

The following section explores the distinctions of 'deserving' and 'undeserving' presented by the stakeholders before thinking critically about the language used when discussing long-term IB recipients. An overarching finding that arose from the research is that many of the stakeholders' views fell in line with negative stereotypes of benefit recipients. As Steve (IBPA, JCP) comments:

It can be that life is too comfortable on benefits they've got their council tax, they've got their rent paid, they're maybe doing a bit of work on the side, they've got kids so they're on that whole Daily Mail thing y'know getting everything provided for them and their family y'know where most of their needs are met, yeah they're limited needs but they get used to living in that sort of lifestyle.

This indicates a clear moral hierarchy by the stakeholders who subscribe to an 'us' and 'them' dichotomy, with IB recipients being described as the 'Other', as this extract from Alan's interview details: 'The unwilling are different from the unwell and I think that what needs to happen is we need to identify the unwell and the unwilling and separate them out and work in two different ways'. Such moral judgements are by no means UK centric. Research on benefit administrators in the USA found similar negative views of claimants,

including recipients being labelled as dishonest and lazy, with a clear theme of 'deserving' and 'undeserving' running throughout the narratives of the professionals (Kingfisher, 1998).

Not all stakeholders in the study adhered to the 'scrounger' viewpoint. For Johnny (senior public health specialist, PCT), only a very small number of IB recipients are actually not genuine, as with any other benefit: 'There's the media perception that's just boozy scroungers people should be going out to work and I don't subscribe to that, I think you'll always get a percentage of people who try any system on and you'll get that on IB but it's a very small number'. Albeit less frequently, other stakeholders pointed to the belief of many long-term IB recipients that work would in fact improve their health, as shown by Jenny's comment: 'We do get an awful lot of people through who say 'I'll be alright if I get a job''. This statement contradicts much rhetoric that assumes people receiving sickness benefits do not want to work. Indeed, other research (Garthwaite, 2012) strongly indicates that chronically ill and disabled people have a deep-seated desire to work, and believe that work could improve their lives for the better. Patrick (2011b: 314) also reports that disabled people do, in fact, possess aspirations to work; however, such aspirations are undermined by both disabling barriers and the impact of their own impairment. The following section examines how language can be of importance when considering long-term IB recipients.

Stakeholders' use of language when discussing long-term IB recipients was also laden with moral overtones. Some stakeholders spoke of the creation of a 'diseased personality', whereby disabled people have 'an investment to staying sick and living out that sickness so it becomes part of who you are' (Alan, case manager, NHS). For Diane (GP), IB recipients create a 'disabled lifestyle' that they wished to remain part of. Often, this belief was underlined by the idea that people on long-term sickness benefits had been told they were

unfit for work, and had grasped onto that idea and refused to let go, despite possibly being fit for work. Certainly, Beatty *et al.* (2009) found that the stakeholders they interviewed strongly indicated that they believed a culture of dependency does indeed exist. The idea that people on IB fashioned a 'sick' identity or adopted a 'disabled lifestyle' may be implicitly legitimised by the ready-made distinctions created by ESA between those who are viewed as genuinely sick and 'deserving', alongside others who are simply unemployed with minor health conditions who are considered fit for work. Such an approach fails to take into account the effects of the inflexible and disabling benefits system that long-term sickness benefits recipients must contend with.

The language used to describe IB recipients was highlighted as a barrier in a recent report by the House of Commons Work and Pensions Select Committee (2011). According to the report, 'the language currently used to describe the outcome of the WCA is a barrier to the government's objectives for the reassessment being properly communicated'. The report points out there are sections of the media that routinely use pejorative language, such as 'work-shy' or 'scrounger', when referring to IB claimants. It continues: 'Portraying the reassessment of incapacity benefit claimants as some sort of scheme to 'weed out benefit cheats' shows a fundamental misunderstanding of the government's objectives'. Whilst the report, and indeed the government will have limited power to change the coverage, the situation could be improved if the government were to ensure its own commentary on the statistics and the context that is provided is wholly accurate. This signals the need for research that considers the views of IB recipients themselves with regards to benefit receipt, stigma and dependency (Garthwaite, 2012).

## ***Perspectives on welfare reform***

The majority of stakeholders agreed that welfare reform was important and it was largely viewed in a positive light. For example, Michael (occupational therapist, CMP) quite simply stated: 'I agree with it cos surely getting people into productive work is the point - I mean sitting on IB for 20 years until you die, what's the point in that?' However, criticism was aimed at the way in which changes should be implemented, with the belief that 'at the moment they're just kicking everybody off it' (Jackie, JCP) and instead the changes should be gradually introduced. Indeed, recent reports suggest that the Work Capability Assessments are falling short of what recipients can rightly expect, leading to fear and mistrust surrounding the whole process. This fear was replicated in the stakeholders' own perspectives:

They're saying they'll make it more simple as in the one size fits all i.e. we don't fit anybody properly at all – it doesn't work because it's oversimplified. But I can see where the government is coming from because simplified it would be easier to understand

(Billy, advisor, disability training college).

Stakeholders felt that increased conditionality and sanctions for sick and disabled people will result in widespread fear and anxiety. Amongst others, Cheryl (local partnership manager, JCP) talked about the fear people had about losing benefits, which in turn can have a negative impact on people's mental health: 'There's a lot of fear in people, people are afraid they're not gonna cope - they get afraid that it won't work for them, they get anxious it won't last and say to me will they have enough money, will I lose my benefits?' Concerns over the implementation of the Work Programme and what that will mean for

stakeholders as providers were rife. For example, Jeff believed that their approach would have to become 'a lot more cut throat':

I think it'll affect the duty of care I don't think it'll be as...when it gets down to the grass roots I don't think it'll be as much of the care side anymore because obviously now we work with people like drug users, offenders, people with long-term health issues and you've got to put a lot of support in and I think the support'll go when the Work Programme comes in cos it's all targets, target related so we'll end up more...well providers will end up more like recruitment agencies because it'll be more business orientated.

(Jeff, job broker, regional charity).

Others outlined the potential for error within the new system, with people being classified as fit for work when they genuinely are not:

I've got one lad who's going blind erm because he had a bleed on the brain and he's lost his sight and he's in the WRAG group when actually his sight is deteriorating so rapidly that he really should be in the support group to deal with the health issues that he's got, so there's a little bit of injustice there as far as the medicals concerned.

(Jenny, personal development advisor, disability charity).

This point was reinforced by Jackie, who stated: 'I've got one lady with breast cancer and she's actually still undergoing treatment but she was found fit for work so the medicals are coming back quite harsh cos of the way they are - they're rigid'. These narratives echo findings from an independent government review of the assessment process carried out by Professor Malcolm Harrington (2010:8) that 'the system can be impersonal and mechanistic, that the process lacks transparency and that a lack of communication between the various parties involved contributes to poor decision making and a high rate of appeals'. Funding cuts and the termination of services was also a topic of concern for stakeholders, who pointed to the fact that 'one minute a service is here and the next minute they're not' (Helen, occupational therapist, CMP). Fundamentally, welfare reform will result in changes

not only for recipients themselves, but also for stakeholders who must negotiate an ever-changing welfare landscape.

Perhaps what is needed in addition to discussions of the welfare reform process is a reconsideration of what work actually is and what it means – does it have to mean paid work, 5 days a week totalling 40 hours? Indeed, the very idea of this is targeted towards the able-bodied worker without impairment. Barnes and Roulstone (2005: 315) note how previous literature suggests an alternative approach should include both the reconfiguration of the meaning of work, alongside the de-stigmatisation of welfare provision. Such a reconfiguration of work should include everyday tasks that non-disabled people carry out daily without a second thought. It may be helpful to acknowledge the concept of a meaningful occupation, such as voluntary work, as being a socio-economic contribution which is not necessarily paid work but an act which refutes notions of 'idleness'. Additionally, questions need to be asked about the type and quality of jobs available to people leaving long-term IB – after all, research shows that poor work - low-quality, insecure employment that fails to provide labour market security or progress - can indeed be bad for health (Butterworth *et al.* 2011; Marmot 2010). Poor work and economic marginality – rather than either regular employment or permanent unemployment – is said to have become more common in recent decades for larger numbers of workers at the bottom of the labour market (Byrne, 2005; McKnight, 2002). This point is stressed below by Johnny (senior public health specialist, PCT):

I wonder if these people do end up in employment what sort of work they'll end up in, will it be a good job, will they be able to sustain that work or will they end up looping back into the system or not and I wonder what will happen to them in the long-term.

These notions are reinforced by Patrick's (2011a) research which suggests that the government's conditionality prescription for raising the employment rate of disabled people is likely to fail. Sanctions and increased conditionality are unlikely to provide a remedy, particularly when the problem is with the disabling structures and practices of society, rather than any individual deficits with sick and disabled people themselves. What is interesting to note here is the change in discourse surrounding sickness benefits receipt. In the 1980s under the Thatcherite regime, placing someone on sickness benefits was seen as preferable to unemployment benefits; however, now the opposite is the case. Overnight, individuals classed as 'sick' are being told they are now fit for work. For Grover and Piggott (2010), ESA is effectively a form of 'social sorting', separating people who are sick and/or who have impairments into subgroups of claimants dependent upon medicalised perceptions of their sickness and/or impairment, thus reviving old discussions of 'deserving' and 'undeserving'.

## **Conclusion**

This article has examined professional stakeholder's perspectives of long-term IB recipients. Whilst all stakeholders recognised the diverse barriers faced not only by long-term IB recipients but also the barriers they themselves contend with, underlying tensions are apparent when discussing stakeholders' perspectives of recipients. Stakeholders repeatedly expressed stereotypical views that lend credence to a notion of a 'culture of dependency', with notions of 'deserving' and 'undeserving' recurrently creeping into their accounts. Critical reflections upon the use of language by stakeholders reveals that on the one hand, some used language that negatively portrays long-term IB recipients, whilst on the other

hand, the word 'incapacity' itself had negative connotations for others who felt the term was disabling rather than enabling. Largely, the stakeholders in this study welcome welfare reform but worry about how it might be implemented, with fears of people being wrongly classified as fit for work under a 'one size fits all' approach. The findings suggests that whilst stakeholders recognise and continually negotiate the complex barriers faced by IB recipients, a wider dialogue of 'deserving' and 'undeserving' is being created and embedded through negative stereotyping of sick and disabled people. Whilst such findings may not be wholly surprising, they should not be underestimated or dismissed. As growing negative publicity surrounds sick and disabled people facing welfare reforms, stereotypical views can and do have a real impact upon the lives of sick and disabled people. Government rhetoric, media portrayals and public opinion of sickness benefits recipients may all play a role in shaping the stakeholders' perspectives, further exacerbating notions of 'deserving' and 'undeserving' amongst sick and disabled people.

Finally, in order to fully understand the lived reality of receiving sickness benefits, research must question how stigma can affect long-term IB recipients. Such debates should be undertaken alongside a wider consideration of how to overcome structural, supply side barriers such as discrimination and the accessibility of the labour market. All of these factors must be considered in relation to long-term IB recipients' perspectives on welfare reform and how this can impact upon their experiences. What's more, it is likely that the dichotomy between 'deserving' and 'undeserving' will be exacerbated further by ongoing welfare reform and increased conditionality that will further marginalise sick and disabled people.

## **References**

Bambra, C. and K.E. Smith. 2010 No longer deserving? Sickness benefit reform and the politics of (ill) health. *Critical Public Health* 20, no. 1: 71-83.

Bambra, C. 2008. In sickness or in health? Incapacity Benefit reform and the politics of ill health. *British Medical Journal*, 337: 1452–1453.

Barnes, H., and Hudson, M. 2008. *Pathways to Work: Qualitative research on the Condition Management Programme*. Department for Work and Pensions Research Report No 346. Leeds: Corporate Document Services.

Barnes, C., and Roulstone, A. 2005. 'Work' is a four-letter word: disability, work and welfare. In: A. Roulstone and C. Barnes (Eds.) *Working futures: Disabled people, policy and social inclusion*, pp. 315-327. Bristol: The Policy Press.

Beatty, C. and Fothergill, S. 2010. *Incapacity Benefits in the UK: an issue of health or jobs?* University of Sheffield: Centre for Regional and Economic Social Research. Available at [www.social-policy.org.uk/lincoln/Beatty.pdf](http://www.social-policy.org.uk/lincoln/Beatty.pdf).

Beatty, C., S. Fothergill, D. Houston, R. Powell. and P. Sissons. 2009. *Women on Incapacity Benefits*. Centre for Regional Economic and Social Research: Sheffield Hallam University.

Beatty, C., Fothergill, S. and Powell, R. 2007. Twenty years on: has the economy of the UK coalfields recovered? *Environment and Planning A*, 39: 1654-75.

Butterworth, P., L.S. Leach, L. Strazdins, S.C. Olesen, B. Rodgers, and D.H. Broom. 2011. The psychosocial quality of work determines whether employment has benefits for mental health: results from a longitudinal national household panel survey. *Occupational and Environmental Medicine*, Online First, March 2011.

Byrne, D. 2005. *Social Exclusion, Second Edition*. Maidenhead: Open University Press.

Corden, A. and Nice, K. (2006) *Incapacity Benefit Reforms Pilot: Findings from the second cohort in a longitudinal panel of clients*. DWP Research Report No 345, Corporate Document Services, Leeds.

Dickens, S., A. Mowlam, and K. Woodfield. 2004. *Incapacity Benefit Reforms - the Personal Adviser Role & Practices*. Department for Work and Pensions (DWP).

DWP. 2008a. *Raising Expectations and Increasing Support: Reforming Welfare for the Future*, London: TSO.

DWP. 2008b. *Transformation of the Personal Capability Assessment*, London: DWP, <http://www.dwp.gov.uk/welfarereform/pca.asp> (updated 12/07).

Gardiner, K. 1997. *Bridges from benefit to work*. York: Joseph Rowntree Foundation.

- Garthwaite, K. 2012, forthcoming. *Incapacitated? The health and illness narratives of long-term Incapacity Benefit recipients*. PhD thesis, Durham University.
- Garthwaite, K. 2011. The language of shirkers and scroungers?' Talking about illness, disability and coalition welfare reform. *Disability and Society* 26, no. 3: 369-372.
- Grover, C. and L. Piggott. 2010. From Incapacity Benefit to Employment and Support Allowance: social sorting, sickness and impairment, and social security. *Policy Studies* 31, no. 2: 265 -282.
- Grover, C., and L. Piggott. 2007. Social security, employment and Incapacity Benefit: Critical reflections on 'a new deal for welfare'. *Disability & Society* 22, no. 7: 733–46.
- Harrington, M. 2010. *An independent review of the work capability assessment*. London: TSO.
- House of Commons Work and Pensions Select Committee. 2011. *6th Report - The Role of Incapacity Benefit Reassessment in Helping Claimants into Employment - Volume I*. London: TSO.
- Hudson, M., J. Phillips, K. Ray, S. Vegeris, and R. Davidson. 2010. *The influence of outcome-based contracting on Provider-led Pathways to Work*. DWP Research Report No 638, London: TSO.
- Hyde, M. 2000. From welfare-to-work? Social policy for disabled people of working age in the United Kingdom in the 1990s. *Disability & Society*, 1, no. 2: 327–41.
- Kingfisher, C.P. 1998. How Providers Make Policy: an analysis of everyday conversation in a welfare office. *Journal of Community and Applied Psychology*, 8: 119-136.
- Lipsky, M. 1980. *Street Level Bureaucracy: dilemmas of the individual in public services*. New York: Russell Sage Foundation.
- Lucas, K., Tyler, S. and Christodoulou, G. 2008. *The benefits of providing new public transport in deprived areas*. York: JRF.
- Marmot, M. 2010. *Fair society, healthy lives*. The Marmot review Executive Summary. London: The Marmot Review.
- McKnight, A. 2002. 'Low-Paid Work: Drip-Feeding the Poor' in Hills, J., Le Grand, J., and Piachaud, D. (eds.) *Understanding Social Exclusion*. Oxford: Oxford University Press.
- Mead, L. 2011. Debate: the wrong prescription. *Policy & Politics* 39, no. 2: 275-291.
- Patrick, R. 2011a. The wrong prescription: disabled people and welfare conditionality. *Policy & Politics* 39, no. 2:275-291.

Patrick, R. 2011b. Disabling or enabling: the extension of work related conditionality to disabled people. *Social Policy and Society* 10, no. 3: 309-320.

Piggott, L. and L. Grover. 2009. Retrenching Incapacity Benefit: Employment Support Allowance and Paid Work. *Social Policy and Society* 8: 159-170.

Riddell, S. and Banks, P. 2005. 'Disabled people, employment and the Work Preparation programme'. In: A. Roulstone and C. Barnes (eds.) *Working futures: Disabled people, policy and social inclusion*. Bristol: Policy Press.

Roulstone, A. 2011. *Coalition Disability Policy - A Consolidation of Neo-Liberalism or Benign Pragmatism? Paper presented at the Annual Social Policy Association conference*. Lincoln University, 4th- 6th July 2011.

Roulstone, A. 2000. Disability, Dependency and the New Deal for Disabled People. *Disability & Society* 15: 427-444.

Stone, D.A. 1978. The deserving sick: income-maintenance policy towards the ill and disabled. *Policy Sciences* 10, no. 2/3: 133-55.

Strangleman, T. 2002. Networks, Place and Identities in Post-Industrial Mining Communities. *International Journal of Urban and Regional Research* 25, no. 2: 253-267.

Thornton, P. 2005. 'Jobcentre Plus: can specialised personal advisers be justified?' In: A. Roulstone and C. Barnes (eds.) *Working futures: Disabled people, policy and social inclusion*. Bristol: Policy Press.

van Orschot, W. 2006. Making the difference in social Europe: deservingness perceptions among citizens of European welfare states. *Journal of European Social Policy* 16: 23-42.

Warren, J. 2005. Disabled people, the state and employment: Historical lessons and welfare policy. In: A. Roulstone and C. Barnes (eds.) *Working futures: Disabled people, policy and social inclusion*. Bristol: Policy Press.