

**“It was just nice to be able to talk to somebody”: Long-term Incapacity Benefit recipients’ experiences of a case management intervention**

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## **Abstract**

**Background:** This paper provides important contextual and service implementation data by exploring participant experiences of a pilot case management intervention for long-term Incapacity Benefit recipients.

### **Methods:**

Service experiences were assessed via a postal questionnaire and semi-structured qualitative telephone interviews. Data from 77 service user questionnaires and twenty semi-structured qualitative interviews were obtained. Questionnaire data were analysed using SPSS and telephone interviews were transcribed and analysed thematically coded using NVivo.

**Results:** Respondents were generally positive about their experience of the intervention and particularly the benefit gained from the personal support that case managers provided. However, they also made suggestions about how the service could be delivered more effectively particularly in terms of the duration of the treatments and increasing the level of face to face support.

**Conclusion:** Case management approaches may offer a supportive environment in which the health needs of those in long term receipt of Incapacity Benefit can be addressed.

(151 Words)

**Keywords:** Primary care, case management, service user, welfare to work, sickness absence

## BACKGROUND

In the UK rates of receipt of incapacity-related benefits (Incapacity Benefit [IB] or Employment and Support Allowance [ESA]) increased from 0.5 million recipients in 1975 to 2.4 million in 2012. Around 7% of the UK working age population receive incapacity-related benefits, accounting for 11% of UK social security expenditure, at a cost of around £8 billion per annum and amounting to 1.8% of gross domestic product (GDP) [1]. In recent years, IB and the wider relationship between work, sickness absence and health has become a prominent issue in political, policy and public health circles. This is exemplified by Dame Carol Black's 2008 review of the health of the working age population in the UK [2] which played a key role in initiating a wide debate upon work and public health. It led to the replacement of the "sick note" with a "fit note" and the implementation of a series of "Fit for Work" pilots. It was more recently supplemented by the Black and Frost (2011) review of sickness absence arrangements [3]. In the same time period (2009), the National Institute for Health and Clinical Excellence (NICE) published evidence based guidelines on the management of incapacity, sickness absence and return to work for use by NHS and related 'return to work' professional services [1][4]. These guidelines recommended the use of case management approaches as the most effective interventions in helping people with ill health to return to work. The case management approach has become well established in the area of occupational health and sickness absence, indeed it is expected to be a component of the new "Health and Work Advisory Service" which will be established as part of the UK government's response to Black and Frost (2011) [3]. However, it is worth noting that the new service is still under development and will draw upon the wide range of techniques employed in the "Fit for work Pilot projects" before coming into operation in 2014. The service will provide advice to employers and employees, carry out assessments signpost those with health issues to appropriate services and provide:

*Case management for those employees with complex needs who require ongoing support to enable their return to work*

DWP (2013) [5]

At this point it is important to note that “case management” is a broad approach rather than a prescribed set of procedures. However there is broad agreement that the approach follows some underlying principles. These are that it involves the assessment of need; care planning; implementation; regular review and is client centred, Oynett (1998) [6] Case management is often linked to the biopsychosocial model of medicine , however the two are not mutually dependent. The concept of the biopsychosocial model has in recent years been subject to a critical debate regarding its usefulness e.g. Ghaemi (2009) [7] whereas case management has not. Consequently, the specific shape of case management initiatives can vary considerably.

In line with the NICE guidance, in 2009, County Durham and Darlington Primary Care Trust (PCT) in the North East of England, commissioned a pilot ‘health first’ biopsychosocial case management service for people in long term receipt (> 3 years) of IB. This pilot programme used telephone and face-to-face case management programmes to identify and address individual health needs (including health behaviours) and any other related barriers to employment, such as debt or housing. The scheme was intended to complement mainstream services, with case managers signposting the patients to NHS, Jobcentre Plus and other health and welfare services. They could be referred to these services during their time with the case management service or at exit; case managers coordinated and facilitated access to appropriated services having assessed the service users needs with them. The service provider also referred patients to physiotherapy and counselling services which they provided as part of the case management. Patients were referred on to the programme by NHS services, other community services (such as the Community Alcohol Service), their GPs, or they could self-refer (19.8%). The length of engagement with the service varied according to the needs of each service user (six month average). During their time with the service users health was monitored via the use of validated health tools including EQ5D ,EQ5D VAS, SF-8, Nordic Musculoskeletal questionnaire and HADS. These measures were taken upon entry to the service; at three months; at six months or discharge (whichever was the earlier); and at three months post discharge [8]. Participants were discharged when they were assessed by

their case worker to be ready to enter mainstream services such as Pathways to Work, vocational services, or community health services as a result of improved readiness due to either improved health or the successful implementation of improved support arrangements for individuals with chronic conditions.

The effectiveness and cost-effectiveness of this 'health first' case management intervention has been described in detail elsewhere [8]. Baseline data found that the majority of participants had ill health levels well above the general population norm and that the majority experienced complicated co-morbidities [8]. Evaluation of the intervention found that over a six month period, it positively impacted on mental (HADS) and general health outcomes (EQ5D) (although not on musculoskeletal pain [Nordic] or physical health [SF-8]). Tentative estimates also found it to be cost-effective. Qualitative comparative analysis has also been used to examine pathways to health improvement and who was most likely to benefit from the programme (younger participants, men aged over 50 and those with an occupational history of skilled manual work or higher) [9]. This paper supplements these by providing useful implementation data which can aid service commissioners in understanding the mechanisms underpinning effective interventions and how they can be translated into other contexts. It is important to take into account the views of service users as experiential data of this type is often collected but all too often it is not published and remains hidden – as 'grey' - literature.

## **METHODS**

In the first two years of the pilot case management service (Sept 2009 to August 2011) there were 235 users. A quantitative postal survey was sent anonymously to all 235 participants on a rolling basis within three months of discharge. The questionnaire was designed jointly by the research team, the service providers and the commissioning body. It contained a mixture of closed and open questions which asked about participants' motivations, expectations and experience of the case management service. Of the 235 participants, 77 (33%) returned a completed questionnaire and a signed consent form. The survey data was supplemented by semi-structured qualitative telephone interviews (conducted in February and May 2012) with 20 of the service users who consented to speak to the research team in more detail about

their experience of the service. Data were collected on their expectations of the service, its impact on their lives, and what they considered to be the most important elements of the service.

Univariate (proportions) analysis of the service user questionnaire was conducted using SPSS software. Qualitative telephone interviews were transcribed and thematically coding and analysed using NVivo software.

## **RESULTS**

### **Survey results**

The socio-demographic characteristics of the survey respondents are shown in Table 1. There were more women than men (n=42, 55%), the majority (n=39, 51%) were aged 41-55 years, and described their ethnic background as White (n=72, 94%) whilst almost a third (27%) had been in receipt of IB for over 10 years. Table 2 shows the results of the closed questions and Table 3 provides example answers to the open questions. The majority of service users were motivated to participate in the service in order to improve their health (64%); and a similar proportion (60%) expected the service to improve their health. However, only a third expected engagement with the service to improve their chances of getting a job (34%). In terms of service experience, the vast majority rated the service as good or better (93%; 34% excellent; 33% very good; 26% as good). Only a minority rated the service as merely adequate (7%) and no one rated it as poor. There was a similarly positive opinion of the service staff (indeed in the open questions, having the opportunity to talk to professionals who listened to their problems and concerns and who treated them with respect was ranked as one of the best things about the intervention); the treatments received; and the frequency of contact. However the open question responses revealed some concerns about the limited duration of counselling and physiotherapy treatments (only six sessions per individual) and the intensity of the service. There were also a number of comments about the reliance on remote telephone based case management, with some respondents feeling that more face-to-face encounters would have provided better support. Service users were also asked if they thought the service had improved their health and the majority agreed that it had with 30% saying that

the service had improved their health a lot and a further 34% that it had improved their health a little. Finally, service users were asked whether they thought the service had improved their prospects of getting a job: whilst 35% said it had, the majority (53%) said there had been no change in their employment opportunities.

### **Qualitative interviews**

In general, those who agreed to take part in the qualitative interviews about their involvement with the service were positive about their experience. Their views echo and elaborate on the survey findings outlined above. Participants' names have been anonymised.

#### Expectations and impact of the service

The impact of the service upon the health and wider lives of participants varied greatly. For example, the service had a dramatic effect on Kevin who returned to full time work as a bus driver after 10 years. The back and neck problems which had stopped him from working were brought under control by a series of physiotherapy sessions, resulting in him stopping taking the high dose painkillers that that led to him losing his licence. This surpassed his expectations of the service which had been to reduce his painkiller intake:

*"I'm mobile, I go out on my pushbike, I walk the dogs, I do my allotment I go to work so something gone right! All I can say is that it worked for me. I know it won't work for everyone but it worked for me. I think anyone going on this program with the right attitude and realistic goals can get somewhere. I got more than I ever expected you know".*

Colin had long-term ongoing health problems having suffered from encephalitis and also undergone a double lung transplant. The service made very little impact upon his health problems but managed to put him in touch with an organisation which he did voluntary work with. His illness had meant that he had become socially isolated after leaving work and his marriage had also broken up; therefore, the ability to move in a wider social circle again was highly beneficial:

*"I'm so fortunate to sort of be like involved with the print shop. Put it this way like, when Wednesday comes along, I don't come here on Wednesday right and the day's horrible".*

Anne had struggled with mental health issues for 25 years which had begun with the loss of a child. She had tried the service out of desperation, and although the counselling she had undergone did not resolve her problems, she felt she had made progress as she now had a diagnosis of post traumatic stress disorder (PTSD) and was able to seek further support services: *"It put me on the right road, to think that I just can't keep living with this and that there now might be a way out"*.

#### What made the difference?

The process of case management, in particular its one-to-one nature and the dialogue participants had with staff were seen as key aspects of the service. Being listened to and taken seriously was something that several participants like Julia mentioned. Julia had long-term back problems and had accessed physiotherapy and acupuncture via the service:

*"I actually really did find the service excellent, they were people you could actually talk to. They were genuinely, genuinely interested in what your problems were and finding a solution"*.

For Andrea, a recovering alcoholic, being treated as an individual was important and a key part of being able to move on:

*"I was basically treated as a person not just a number. Without being pushy or saying, you have to do this or you have to do that, they gave me the motivation to actually do something for myself"*.



Ella had ongoing issues with depression which had led to her having to leave the labour market. Following her engagement with the service, she felt able to return to work again. This reinforces the key point that being taken seriously and treated as an individual was central to successful engagement with the service: *“It was the fact that someone did care that made a difference, they weren’t just looking for numbers to put on some screen”*.

#### Could things have been better?

Participants who had had both positive and negative experiences of the service had suggestions for how it could be improved. Neil, who had been out of the labour market for over ten years as a result of depression felt that he needed to be motivated to try new things. For Neil, face-to-face interaction with his case manager rather than telephone contact would have helped him:

*“I would have been happier meeting somebody face to face I think. More helpful, rather than speak to somebody at the end of a phone which I didn’t think could do an awful lot you know. I was wanting more help and ongoing support really”*.

Equally, for Andrew who had long-term issues with depression, the service was not successful as he felt that he wanted both more support but less telephone interaction:

*“In the end they were just phoning me up and I didn’t think it helped much. I just felt pressurised. They were asking what I was doing to find work, you know and I thought that it was really what they should have been doing”*.

The duration of the service was also an issue for some. For example, Sarah felt that the counselling she received was very good but that more sessions over a longer time scale would have been more beneficial:

*“The counselling was extremely good. The thing I was concerned about was the fact that it stopped. I felt it was too soon. It’s a shame they didn’t do like well we’ll see you in a couple of months then four months then six months you know?”.*

### Summing up the experience

Participants talked about the service in different ways when they were asked to sum up their overall experiences. Some reflected upon how the process had worked, whilst others spoke about the effect it had on them and their situation. Susan used the analogy of a jigsaw to describe her situation:

*“I felt like somebody had took my life that was a jigsaw puzzle and sort of threw all the bits up in the air and I was scrambling around trying to gather them all back together. Now I’m sort of more in a situation where I’ve got them all on the table and the corners is all in place and everything’s getting put back in, and yes there’s a few pieces that I haven’t quite placed yet but now the control’s back with me now to be able to do that”.*

Her experience had been one which allowed her to move on after multiple physical and mental health problems. Sam had been very physically active at work and outside of work until he had had a stroke at the age of 40; for Sam, the interaction with his case manager and his counsellor was very helpful and different to what he had initially expected:

*“I was pleasantly surprised as it wasn’t a case of you will do this, you will do that. It was a case of right, you know, let’s try and work this out and see where we can help you. You know this is our long term goal and this is what we want to achieve and this is one way that we are going to try to sort it out”.*

Jerry had felt frustrated and abandoned after engaging with numerous initiatives aimed at returning him to the workplace but which were unable to deal with his underlying health problems of Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS).

Unfortunately, the health services he had engaged with were also ineffective and he felt abandoned:

*“It was just nice to be able talk to someone actually. I felt that I had got so far with the health services I had been with before and then they just seemed to have left us. This got me started again”.*

His experiences of the service allowed him to re-engage with primary care and begin to access the help he needed.

## **DISCUSSION**

### *Main findings of this study*

Participating in the case management intervention was a positive experience for the majority of service users and it generally exceeded their expectations. The study does highlight some important areas for consideration in future service design though including whether telephone case management is sufficiently personalised and the duration of the treatments required to aid specific long term conditions.

### *What is already known on this subject?*

It is known that case management can be beneficial for those with long-term health conditions particularly in terms of mental health [8]. Likewise, an evaluation of a case management programme to improve the health of chronically ill, homeless people [10] also found that participants highly valued the interpersonal relationship of case management and considered this to be a key driver in their health improvements. Another evaluation of a case management service for chronically ill service users in Northern England found that the most important factor that appeared to influence the scope and quality of the service was the pattern of interaction between the case managers and their co-workers [11].

### *What this study adds*

Exploring service users' experiences provides evidence that the health benefits of this case management service [8] were strongly linked to the holistic and personalised delivery of the service rather than any particular content or treatment. This type of experiential data is often collected but not published and remains hidden – or 'grey' - literature. It provides useful implementation data which can aid service commissioners in understanding the mechanisms underpinning effective interventions and how they can be translated into other contexts. Many participants highlighted the fact that they were listened to and made to feel valued, treated as individuals and their problems were taken seriously by the service as the things which had the most impact upon their health and well being. These skills are by no means exclusive to a case management approach. Nor is a biopsychosocial approach a pre requisite for this type of approach. For those with long-term health conditions, it would seem relatively easy to transfer this skill set to other primary care initiatives aimed at this group and at minimal cost. This increased sense of wellbeing may also be an important precursor for health improvement in the longer term for this group.

#### *Limitations of the study*

This study is limited by the fact that the respondents were a self selecting group, i.e. those who were motivated enough by their experience of the service (either positive or negative) to reply to the postal questionnaire. Qualitative interview participants were also drawn from the same group after expressing an interest in participating in further research. The response rate to the survey was only 33%, although this is in keeping with the majority of other postal surveys.

#### **Conclusion**

The data suggest that the personalised dynamics and process of the case management service was a positive experience. Case management approaches may therefore offer a supportive environment in which the health needs of those in long term receipt of IB can be addressed.



## Research Ethics

This study received NHS National Research Ethics Service ethical approval from the County Durham and Tees Valley 2 Research Ethics Committee (REC reference 09/H0908/84).

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## Author Contribution Statement

Principal investigator CB designed and oversaw all stages of the study with support from JW. Data collection was conducted by JW and data analysis was conducted by JW with input from KG. JW drafted the article with input from KG and CB.

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**Table 1: Socio-Demographic Characteristics of Service User Questionnaire Respondents**

	<b>N=77 (%)</b>
<b>Gender</b>	
Male	31 (40.3)
Female	42 (54.5)
<b>Age Group</b>	
16-25	5 (6.5)
26-40	16 (20.8)
41-55	39 (50.6)
56-70	12 (15.6)
<b>Ethnicity</b>	
White	72 (93.5)
Asian Indian	1 (1.3)
<b>Time on IB/ESA</b>	
3-5 years	24 (31.2)
6-9 years	12 (15.6)
10 plus years	21 (27.3)

**Table 2: Respondents views of the Case management service**

	<b>N=77 (%)</b>
<b>Why did you decide to try the service?</b>	
Staff	4 (5.2)
Heard good things about the service	4 (5.2)
To improve my Health	49 (63.6)
Recommended by a friend/family member	1 (1.3)
Other	17 (22.1)
<b>Did you expect your health to improve when you joined the service?</b>	
Yes	46 (59.7)
No	27 (35.1)
<b>Did you expect your chances of getting a job to improve when you joined the service?</b>	
Yes	26 (33.8)
No	48 (62.3)
<b>Was the service what you expected?</b>	
Yes	53 (68.8)
No	20 (26.0)
<b>How would you rate the staff who worked with you?</b>	
Excellent	38 (49.4)
Very Good	24 (31.2)
Good	11 (14.3)
Adequate	2 (2.6)
<b>How would you rate the treatment recommended for you?</b>	
Excellent	23 (29.9)
Very Good	25 (32.5)
Good	17 (22.1)
Adequate	9 (11.7)
Poor	0 (0)
Very Poor	1 (1.3)
<b>Did the service contact you:</b>	
Too often	2 (2.6)
About the right amount	69 (89.9)
Too little	5 (6.5)
<b>Do you think the service improved your health?</b>	
Yes, a lot	23 (29.9)
Yes, a little	26 (33.8)
No change	20 (26.0)
No, it's worse	4 (5.2)
<b>Do you think the service has improved your chances of getting a job?</b>	
Yes, a lot	10 (13.0)
Yes, a little	17 (22.1)
No change	41 (53.2)
No, they are worse	2 (2.6)



### **Table 3: Responses to open Questions – Examples**

#### **Please tell us how any of the treatments you had received could be improved?**

“All the treatments I had were just right”

“Both the counselling and dietary help could have been longer”

“Increased number of sessions”

“I felt frustrated that I only had 6 sessions of counselling”

“I had 6 physiotherapy sessions which were excellent but I would preferred to have had more”

#### **What were the best things about the service?**

“The staff put me at ease, explained everything about what was expected and always phoned back when they said they would”

“They listened to me”

“I was made to feel like an individual”

“The staff were friendly and understanding”

“Just to talk and someone to listen”

#### **What were the worst things about the service?**

“It didn't go on long enough”

“Not meeting face to face”

“Not enough practical help”

“Not based locally”

“Not enough sessions”