

Deep End Report 21

GP experience of welfare reform in very deprived areas

In March 2012 General Practitioners at the Deep End produced a report “GP experience of the impact of austerity on patients and general practices in very deprived areas”.

This report provides additional information, based on a further 18 month’s experience of welfare reforms.

The report has been compiled by Raymond Orr, David Blane, John Budd, Andrea Williamson, Petra Sambale and Graham Watt, on behalf of the Deep End Steering Group.

October 2013

In March 2012, GPs at the Deep End produced a report on “GP experience of the impact of austerity on patients and general practices in very deprived areas”. Eighteen months on, Deep End practices are seeing increasing problems associated with the welfare reforms. This short report provides a follow-up to last year’s report, and comes at a time when GPs across the UK are receiving criticism for their role in the welfare process.

SUMMARY

- Changes to welfare have both **intended and unintended consequences**, which need to be measured and reflected upon, otherwise they may result in great damage.
- **We remain concerned** that, in its entirety, the welfare reform programme will be detrimental to the lives and well-being of the poorest in society.
- The **Welfare Reform Act (2007)** removed Incapacity Benefit (IB) and the Personal Capability Assessment (PCA) and replaced them with Employment Support Allowance (ESA) and the Work Capability Assessment (WCA).
- **The entire ESA application process is too long and complicated.** Many people, but particularly those with mental health problems, addictions, and cognitive impairment, find the process of form-filling, assessment, rejection, then the appeals process, punctuated by meetings with welfare officers, lawyers and the need for further medical evidence, to be confusing and demanding to navigate and, ultimately, damaging to their health.
- **Requests for medical information and support** fall most heavily on general practices serving very deprived areas, in which the numbers of such requests are concentrated. This places **additional demands on an already overloaded system** and compromises the time available for other aspects of medical care.
- **We all recognise the health benefits of appropriate work.** ESA should be part of a process which enables people to maximise their potential in achieving that benefit. Therefore, the underlying ethos of this process should be that of support, understanding and enablement. ESA, as it stands, fails in that endeavour.
- The **Welfare Reform Act (2012)** has introduced a number of additional changes, including Universal Credit, the Personal Independence Payment (PIP) to replace DLA, and changes to housing benefit, widely referred to as the “Bedroom Tax”.
- **The real costs of the “Bedroom Tax” are unknown**, but there are early indications that, since its introduction in April 2013, there have already been damaging effects on communities, families and support networks for society’s most vulnerable.
- **This report sets out a number of recommendations** to make the welfare system fairer, simpler, and easier to navigate. Central to this is the need for a radical overhaul of the Work Capability Assessment, which is not fit for purpose.

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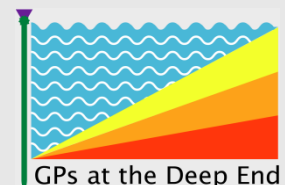
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“General Practitioners at the Deep End” work in 100 general practices, serving the most socio-economically deprived populations in Scotland. The activities of the group are supported by the Scottish Government Health Department, the Royal College of General Practitioners, and General Practice and Primary Care at the University of Glasgow.



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INTRODUCTION

In March 2012, GPs at the Deep End produced a report on “GP experience of the impact of austerity on patients and general practices in very deprived areas”.¹

The report put a human face on the ‘difficult economic conditions’ experienced by the most deprived members of society, and attracted significant attention in policy and media circles.^{2;3}

Eighteen months on, Deep End practices are seeing increasing numbers of problems associated with the welfare reforms.

This short report provides a follow-up to last year’s report, and comes at a time when GPs across the UK are receiving criticism for their role in the welfare process.⁴

Changes have both intended and unintended consequences, which need to be measured and reflected upon, otherwise they may result in great damage. We remain concerned that the welfare reform programme is detrimental to the lives and well-being of patients.

Our experience is that patients are suffering greatly from welfare reforms as they are currently unfolding and it is for this reason that we speak out. We hope that by making politicians aware of the problems at an early stage – especially in the case of the changes to Housing Benefit rules – changes could be made to the policy, showing not weakness but strength of character in recognising when unintended consequences outweigh the likely benefits.

We recognise that politicians do not enter politics in order to make the lives of ordinary people worse, and that politicians of all colours, especially those in government, are faced with very difficult decisions. In this context, we attempt to inform the current debate on welfare reform.

This report is informed by the experience of patients and family doctors working in the 100 most deprived general practices in Scotland. We are mindful of the trust that our patients place upon us in sharing their life experiences. We hope that in producing this report we have fulfilled that trust.

THE WELFARE REFORM ACT (2007)

The most controversial part of this act of parliament has been the changes it introduced to the health-related benefit system.

This involved the removal of Incapacity Benefit (IB) and the Personal Capability Assessment (PCA) and their replacement with Employment Support Allowance (ESA) and the Work Capability Assessment (WCA). The primary purpose of the reforms was to reverse the increase in health-related benefits which started in the early 1990s. The growth of these benefits has been seen as an attempt by successive governments to hide an endemic problem of unemployment within government statistics.⁵

The changes have been controversial, as was the government's decision to award the contract to perform the WCA to Atos Healthcare. Previously the PCA was performed by government employees, the regional medical officer and their deputies.

Incapacity Benefit ceased being available to new claimants in 2008. The government undertook a reassessment of all existing claimants of IB, starting in 2010 and due to be completed by 2014.

Parliament placed an obligation on the Secretary of State for the Department of Work and Pensions (DWP) to report annually with an update on the structure and functioning of the ESA and WCA.

Improvements have occurred. Cancer patients have been afforded more consideration. The government says: "we anticipate that each individual will be assessed on a paper basis using a 'light touch' approach with the vast majority being placed in the Support Group".⁶

Such improvements are welcome. The government has listened to a number of well-placed and influential pressure groups. However, many concerns remain and there is evidence that the present government is refusing to follow on from the improvements made in the past.

*"The next stages ...should be focusing on consolidation and monitoring. There is no evidence at this stage for a further period of radical reform"*⁶

This is very disappointing. We believe that improvements can be made to the ESA and WCA and would encourage the government to continue to listen to stakeholders.

EMPLOYMENT SUPPORT ALLOWANCE AND THE WORK CAPABILITY ASSESSMENT

Introduced in October 2008, the Work Capability Assessment is the most demeaning component of all the reforms. Patients find the process of form-filling, assessment, rejection, then the appeals process, punctuated by meetings with welfare officers, lawyers and the need for further medical evidence, to be confusing, and damaging to their health. When the process goes wrong, it is left to the poorest and least able members of society to appeal against the system. To the dispassionate observer, the highly bureaucratic and drawn-out process seems Kafkaesque, and requires urgent reform.

GPs working in the poorest communities are inundated with requests for medical information by organisations including the DWP, Atos and patients' representatives. GPs are keen to ameliorate the damaging effect of welfare reform on their most vulnerable patients but are constrained by lack of time and resource.

The requests for additional information and support fall most heavily on general practices serving very deprived areas, in which the numbers of such requests are concentrated. As a result of the inverse care law these practices already struggle to

address their patients' needs.⁷ The welfare reforms place additional demands on an already overloaded system.

GPs have been blamed for the failure of a system over which they have no control. They find themselves 'reminded' by politicians of their obligations to provide information to the DWP⁸, the implication being that the failure of the overall process is the result of GP failings. This assertion is not supported by the facts. Over half of the decisions which are overturned are done so without recourse to any more information than was available at interview, but rather "by a different conclusion being reached on substantively the same facts" and "differences between the DWP and the Tribunal's approaches".⁹

There is no contractual obligation on GPs to provide information later in the process, e.g. at appeal. The majority of GPs are glad to provide such information when it is requested, but the work is detailed, time-consuming and usually done at the end of a clinical day. When salient information is provided, it can be ignored by those with power to make decisions.

"Being in a cattle market" ...

and *"humiliating"...*

"like begging for money"

For society's most vulnerable people, the WCA is neither sophisticated nor sensitive. It fails to identify or quantify their disabilities and its reductive quality has a dehumanising effect, failing to recognise that the real nature of disability is in how the illness interacts with everyday life.

The failure rate of the WCA, as assessed by successful appeals, is also an issue. Official figures stated that 39% of ESA appeals that were dealt with at a tribunal hearing were successful, increasing to 42% in the first quarter of 2012/2013.

Some patient groups appear particularly failed by the process, including those who:

- have poor literacy skills
- have suffered childhood sexual abuse
- have or continue to suffer domestic violence and abuse
- are homeless
- have complex mental health problems
- have borderline and other personality disorders
- have complex drug and alcohol problems

"They put me on the scrap heap when I was young and forgot about me for years. Now that I am old, they kick me like an old car thinking that this will get me to work again"

THE WELFARE REFORM ACT (2012)

Enacted by Parliament in 2012, the most recent welfare reform act introduces several changes. The following is a list of the most significant changes either already in force or coming into force shortly:¹⁰

- The introduction of new rules for the size of accommodation that Housing Benefit will cover for tenants renting in the social sector. This has become widely referred to as the “Bedroom Tax”.
- The introduction of Universal Credit.
- A new benefit, the Personal Independence Payment (PIP) to replace DLA.
- The introduction of a benefits cap.

THE “BEDROOM TAX”

Changes to housing benefit rules introduced from 1 April 2013 mean that working-age adults, renting in the social sector and in receipt of housing benefit, will lose a percentage of their benefit if their home is ‘under-occupied’. Widely referred to as the “Bedroom Tax”, these changes have already generated stress for many patients and caregivers.

The government refers to this change in the housing benefit rules as the “removal of the spare room subsidy”. Many are confused by this. Who was aware that such a subsidy existed? Its “removal” appears punitive and directed against those in receipt of housing benefit. Government advice is that patients can:

“Choose whether they want to pay the difference to their rent... or ... move to more appropriately sized accommodation”¹

Patients argue that they never chose a house or flat that was too big. They accepted whatever was offered by the council or housing association many years earlier. They feel let down. Their families may have grown and left home. They may have had changes in their lives requiring the support of Housing Benefit. The decision to live in an under-occupied home is not really a choice.

There is not enough social housing stock available for patients to move easily between homes without disruption to social ties. The government’s own impact assessment states:

“Surplus of three bedroom properties.... lack of one bedroom accommodation in the social sector...insufficient properties ... of an appropriate size ... In these circumstances individuals may have to...look further afield for appropriately sized accommodation”²

The government claims that the changes will save £500 million per year in Housing Benefit. We see little evidence that disruption to communities has been considered as part of the equation. The true cost of these changes and the damage to support networks are impossible to monetise.

We are concerned that the burden of debt placed on the poorest in our communities will have a devastating effect, particularly on mental health, and note that:

“statistics reveal the scale of debt created by the government’s under-occupancy charge, as one council house tenant in three has been pushed into rent arrears since it was introduced in April”³

THE EFFECT OF GOVERNMENT POLICY ON FAMILIES AND CHILDREN

Government's ability to change society for the better is undoubted. Between 1998 and 2012, 1.1 million children were lifted out of poverty.¹⁴

It was not only increasing benefits which resulted in the reduction in child poverty. The increase in lone parent working and the rising tide of economic growth which 'lifted many boats' also contributed to improved living conditions and life chances.

The trend is now backwards. Six hundred thousand more children living in poverty in the UK are predicted by 2016¹⁵

*"Tax and benefit reforms introduced since April 2010 can account for almost all of the increase in child poverty projected over the next few years using the absolute low income measure... using the relative low income measure, child poverty would actually have fallen in the absence of reforms"*¹⁶

As a direct result of the "Bedroom Tax" we see the potential for family ties to be broken. Much of the informal support which young families, the elderly and those with special needs rely upon will be lost. The cost of replacing this support, via social work and health care, is not known.

"If my mother is forced to move, who will pick up the children from school when I am at work?"

SUMMARY

- We recognise the health benefits of appropriate work.
- Employment and Support Allowance should aim to enable people to maximise their potential. The underlying ethos of this process should be support, understanding and enablement. The current system is failing in these respects.
- The processing of the Employment and Support Allowance is too long and taken in its entirety, especially including repeated Work Capability Assessments, has a detrimental impact on patients' health and well-being.
- The Work Capability Assessment continues to fail significant numbers of disadvantaged people.
- The Work Capability Assessment is demeaning and in need of radical reform.
- The Welfare Reform Act 2012 will directly result in six hundred thousand more children living in poverty.
- The real costs of the "Bedroom Tax" are unknown.
- The "Bedroom Tax" will damage communities, families and support networks for society's most vulnerable.

- There needs to be provision made for timely and sufficient benefits being made available to people going through the appeals process to prevent exacerbating health problems.
- Many people have difficulty navigating the benefits system. We believe more support should be offered to people to 'navigate' the system, in particular access to face to face support, as many people struggle with phones and computers.
- The additional burden placed on the health professionals serving the poorest populations is huge and compromises the time available for medical care.

RECOMMENDATIONS

- The government should re-focus its efforts to make appropriate work available to as many as possible.
- Financial and practical support should be given to those with disablements to enable their entry into the workforce where this would be to their benefit.
- The government should improve the system of allocating this support in order that those in need of support are not unfairly discriminated against.
- The system of sanctions inherent in the current ESA is punitive, damaging to vulnerable people's health and in need of significant change.
- Central to this policy failure is a Work Capability Assessment which is not fit for purpose. This needs radical overhaul.
- The Welfare Reform Act 2012 will directly harm many of society's most vulnerable, especially children. The government must act now to avert a potential social disaster.
- The recent changes to Housing Benefit rules will damage poor communities and should be re-thought as a matter of urgency.
- The welfare system must be simplified and action taken to prevent disenfranchising those with limited skills in navigating a complex system.

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ANNEX: TÉMOIGNAGE

NOTE “Témoignage” comes from the French verb “témoigner”, meaning “to witness”. “Témoignage” means “willing to speak out about what we see happening in front of us”.

The testimonies that follow bear witness to the ongoing daily suffering caused by the current welfare system.

Patient details, including names, ages, locations and medical conditions, have been changed to ensure anonymity.

The Reid family

Both parents have complex mental health problems. There are three children in the home, all of primary school age. Teachers informed social work that one of the children was going to school smelling of urine. The family home was visited by social workers and was found to be in a neglected state. Rather than take the children into formal care they were taken to live with the extended family while work was done to improve the home and improve parental behaviour. The children were able to live just a few hundred metres from the home with the mother’s aunt. They could continue going to the local school and see their parents regularly.

GP’s comment

This case underlines a very important unintended consequence of the changes to housing benefit rules. These children were only able to stay within the local community because they had extended family close by.

My concern is that by changing the housing benefit rules we are encouraging older members of the extended family to move home into smaller homes further afield rather than stay within the community. I feel this is a significant loss to the community.

Older members of an extended family often have a protective effect on especially vulnerable children, and in this example an older aunt was able to take the children in rather than the children going into a formal care setting. I have lost count over the years how many times I have heard “my parents were alcoholics and I stayed round the corner with my...”.

I have seen over the last few years a big increase in the number of children taken outside the family home at the request – almost always justified and reasonable – of the social work department. My impression is that many of these children do not become formally “looked after” by the local authorities, rather, that informal arrangements are made for kinship care of the children within the extended family. Again I think this is good.

I am concerned, however, that encouraging older family members to move to smaller houses that are further away, would likely result in them losing contact with extended family and a loss of social capital.

Amina aged 30

When she was a child, Amina was moved from her home in Wales to Scotland along with parents and two sisters. Her father died when she was 18 years old. Amina overcame this bereavement through working and studying, until she was tricked into visiting an elderly relative abroad. While there, she was held captive and assaulted with intent to accepting a forced marriage. She managed to escape and return to Scotland, where she sought support in a women's refuge. She still experiences intimidation from members of her extended family, who tell her that she is a disgrace and has brought shame upon the family name. She suffers a skin condition and heavy periods, but more significant are her persistent anxiety and chronic depression, exacerbated by abuse and domestic violence she experienced within her family. Amina lives alone and rarely leaves her home for fear of intimidation. She has little contact with other people. Her anxiety and depression have restricted her social functioning and she experiences panic attacks, causing chest pains and palpitations, when she has to leave the house. She has poor sleeping patterns and decreased concentration. Amina was refused Employment and Support Allowance by the Department for Work and Pensions but won on appeal.

GP's comment

I wonder if the assessment was culturally sensitive to this young woman's problems. It may have been possible to assess this difficult and complex case more adequately, if she had been given more time and space to explain her impairments.

Karen aged 50

Karen had what she described as a "nervous breakdown" a few years ago. The precipitant of this was that her teenage daughter left home with an older man, not speaking to her family for months. She has since been reunited with her daughter, who moved home after the relationship ended, but Karen has not fully recovered from this most recent trauma. Karen herself has had a difficult upbringing. She suffered sexual abuse when she was a child and attended "special" primary and secondary schools. She is unsure of the reason why she received special schooling, and there is nothing in the medical notes regarding this. Even today, she is unable to read and write, and this is despite having objectively normal intelligence. She left home early and was married for 10 years. She had three children, but suffered domestic violence and mental abuse at the hands of her husband, who had alcohol problems. Her son was also physically abused. After her mental breakdown, Karen stopped working as a cleaner. She was on Jobseekers' Allowance for the first three months before applying for Employment and Support Allowance. Her income at that stage was £71 a week. She applied for ESA, was refused and appealed this decision, which was upheld. Her income therefore increased from £71 per week to £98 per week. She found the entire application process very stressful. She described the Atos offices as like "being in a cattle market" and "it was humiliating ...like begging for money". This is despite the fact that she worked for the best part of two decades and became workless only after a "mental breakdown". In contrast, she described the Appeals Tribunal as being very kind and considerate. She has been awarded ESA for only one year, and is due to go through the whole process again in February. She is also concerned about the effects of the so-called "Bedroom Tax", given that there is limited availability of social housing close to where she lives with her extended family.

GP's comment

The main problem was that the application, assessment and appeals process was damaging to her health. It caused a great deal of stress and further affected her self-esteem. It appeared obvious in correspondence from the GP that the patient should have been awarded ESA from the outset instead of having to engage in a long process which appeared to worsen her mental health.

The McMillan family

This family live in an entirely bespoke home owned by the local housing association. There are two children – a boy aged 18 with cerebral palsy and a 19 year old girl. The mother has syringomyelia and both the son and mother are wheelchair users. The father spends his time caring for the family. The daughter has now left to go to university in London. The family now live in an “under occupied” home, which has been radically altered to suit two wheelchairs.

GP's comment

I assume that the cost of redeveloping their new home would be huge and met by the local government. I am concerned by the disruption that this will cause to family life. In my view, the interests of the family would be best served by allowing them to stay where they are without an extra cost being applied.

Alison aged 45

Alison was refused Disability Living Allowance (DLA) after assessment by Atos and a decision by the “decision maker” at the DWP. She lives with her husband and four children, and applied for DLA in order to supplement her part-time work and help manage her additional mobility and care needs more. She has osteoarthritis in the lumbar spine, fibromyalgia, COPD, and a history of gynaecological surgery resulting in chronic pelvic pain. She is on a number of medications for chronic pain. Despite living with severe pain, she continues to work part-time in a factory. This lady has been in continuous employment for 15 years except for a period of a few months when she was unemployed. She has only ever worked in a factory and receives just above minimum wage. She has suffered back and leg pain for 15 years, which causes her to sometimes use sticks when walking. The pain is in her hips and low back and radiates into both legs, occasionally causing numbness in her legs when walking. Her musculoskeletal problems affect her daily activities. She takes around 10 minutes to climb two flights of stairs, and is only able to walk up to 150 yards very slowly before experiencing pain. She sometimes struggles to get out of the bath but she is usually able to dress and wash herself without problem. The pain radiating in her lower back and lumbar spine is limiting to the extent that she sleeps in a chair to alleviate this. She is able to drive to a supermarket to do her weekly shop. She was awarded DLA only after appeal.

GP's comment

The problem here relates to the Work Capability Assessment's inability to assess patients with fluctuating medical conditions. It appears that having a “good day” at the time of the Work Capability Assessment fails to recognise that patients also have many “bad days”.

Bernadette aged 45

This lady was diagnosed with cancer in 2008, but she is thankfully in remission. Her most significant health problems are back pain and an anxiety disorder secondary to a history of sexual abuse. When she was between around five and 10 years old, Bernadette was sexually abused. This abuse has led to significant ongoing problems, including an inability to trust people. These problems were exacerbated further when she was raped aged 18 by someone she viewed as a friend. She has received intensive counselling for these incidents but still experiences anxiety especially in the company of men she does not know. She enjoyed working in a bakery but unfortunately had to give up this job after falling at work and sustaining a back injury. She applied for Employment and Support Allowance which was refused. Only after appeal was she awarded ESA.

GP's comment

Much of the information regarding this lady was not accessible in her medical records. Much of the care she received was outside the formal NHS setting and correspondence was not sent to her GP. It would be wrong to assume that GP medical records contain all relevant information.

It is too much to ask for the Atos (WCA) assessment to be able to identify these issues. The question is, how can the DWP best access information that would only really come from a therapeutic relationship and may not be available routinely from the general practitioner?

It may be better for the patient to be allowed to nominate someone to provide this sensitive information instead of seeking information from the GP.

Charlie aged 55

Charlie was brought up in a deprived area. During her childhood and early adolescence, she suffered from nocturnal enuresis (bed-wetting). This led to her smelling of urine and being bullied by her classmates. She developed low self-esteem. Charlie developed more serious mental health problems when she moved up to secondary school, but even when she showed serious symptoms of anxiety no action was taken to address this. She left school and started working, but her mental health problems were complicated further by a significant alcohol problem. During this period of ill-health, she was in trouble with the police. She was then referred to psychiatry. At this time, she was treated with antipsychotic medication and spent time in a hostel. After a few years, she moved away and stopped taking the antipsychotic medication, suffering unusual withdrawal symptoms. She has not worked since the early 1980s. Charlie's main mental health problems are Obsessive Compulsive Disorder and Persistent Delusional Disorder of Persecution. She is obsessed with personal hygiene. About four years ago, Charlie was seen by a psychiatrist who considered "sectioning" her under the Mental Health Act. Since then, she has refused to engage with either Mental Health Services or her GP, and this contributes to her complicated health problems. She was refused ESA but the appeal was upheld.

GP's comment

This lady was disengaged from medical services. She required an accurate assessment of her problems, and was served poorly by the Work Capability Assessment, with its 'tick box' approach encouraged by Atos.

An astute clinician would have picked up on her problems but not if bogged down completing a range of questions on physical capability completely unrelated to her mental health problems – she was, after all, in perfectly good physical health.

The refusal of ESA is particularly disappointing because an award of ESA would have resulted in her being included in the Work-Related Activity Group. She would then have received skills, training and a likely improvement in her employability and self-esteem. This may have been genuinely therapeutic.