

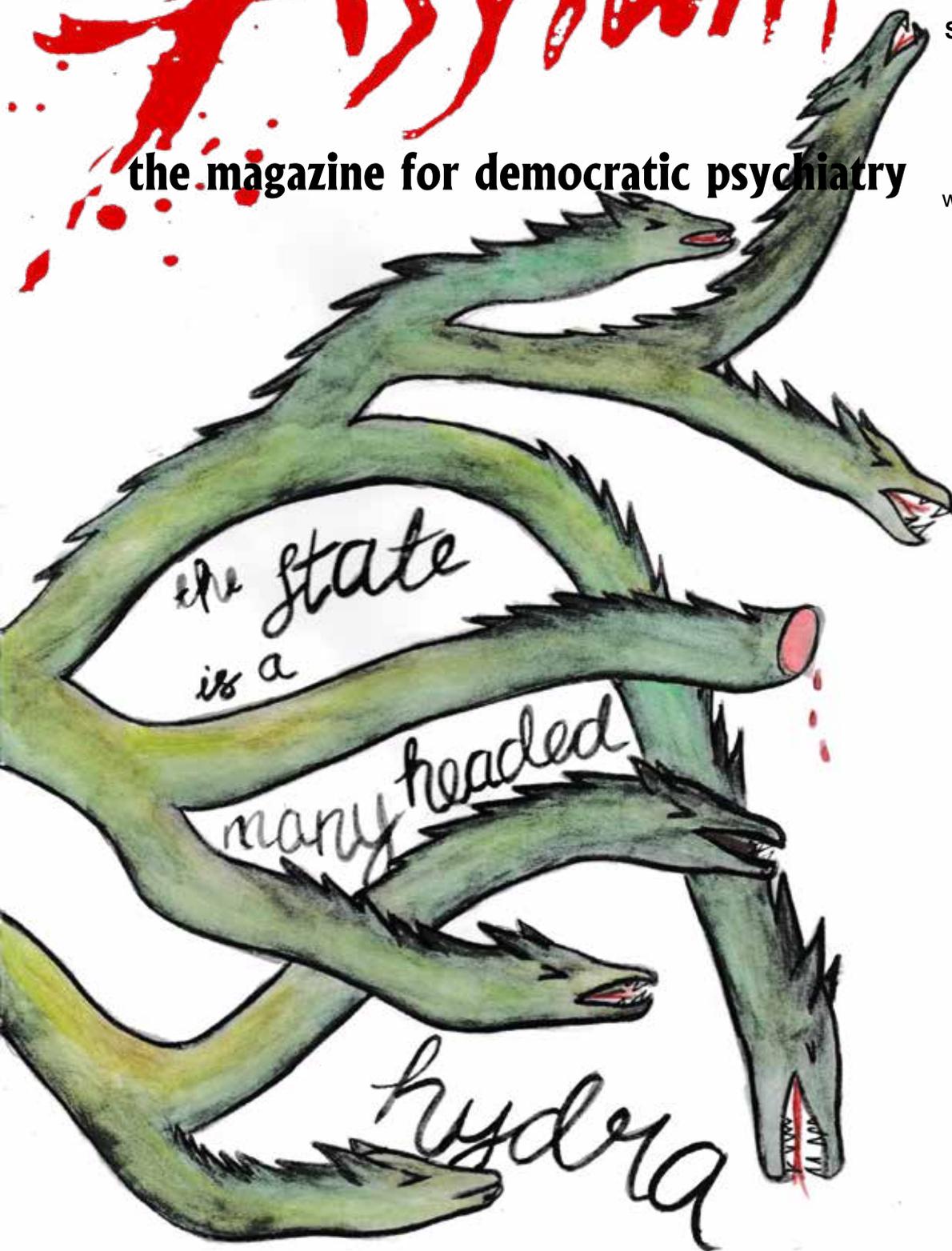
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# Asylum

the magazine for democratic psychiatry



**SPECIAL FEATURE ON WELFARE RIGHTS  
- AUSTERITY FROM ABOVE AND  
RESISTANCE FROM BELOW**

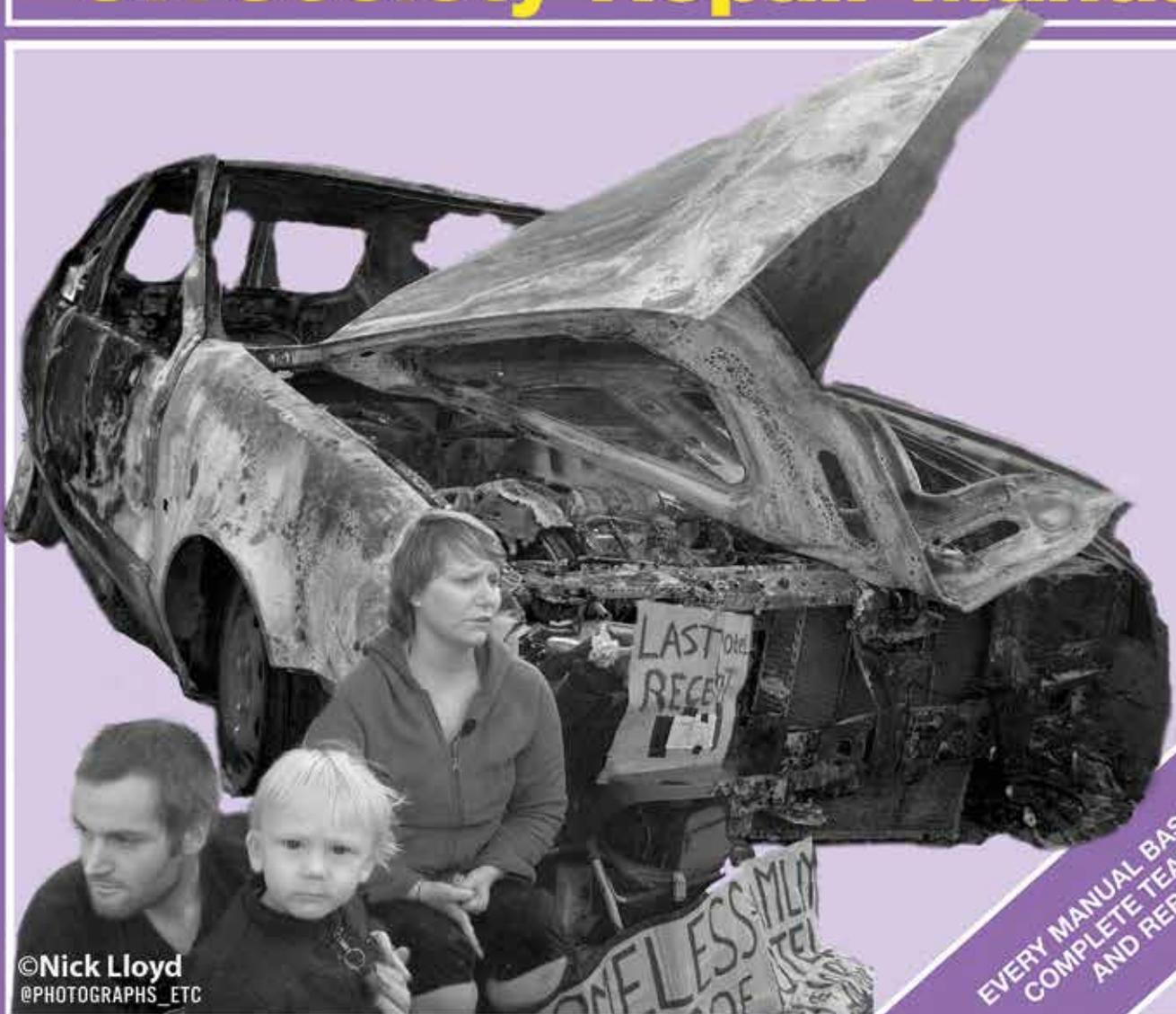
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# UK AUSTERITY TORY GOVT EDITION

2008 thru 2018 (cont.)  
All UK citizens / All ages & genders

## UK Society Repair Manual



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EVERY MANUAL BASED ON A  
COMPLETE TEARDOWN  
AND REBUILD



# The magazine for democratic psychiatry

Volume 25, Number 3, Autumn 2018

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*Asylum* magazine is a forum for free debate, open to anyone with an interest in psychiatry or mental health. We especially welcome contributions from service users or ex-users (or survivors), carers, and frontline psychiatric or mental health workers (anonymously, if you wish). The magazine is not-for-profit and run by a collective of unpaid volunteers. Asylum Collective is open to anyone who wants to help produce and develop the magazine, working in a spirit of equality. Please contact us if you want to help.

The views expressed in the magazine are those of the individual contributors and not necessarily those of the Collective. Articles are accepted in good faith and every effort is made to ensure fairness and veracity.

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# Introduction to Welfare Rights

## Special Feature

DANNY TAGGART



This special Welfare Rights feature was inspired by discussions with people attempting to navigate the welfare system and has been developed by co-editor Ria Dylan and I. It presents a series of articles that reflect the despair, illness and worse that people have suffered as a result of the unprecedented governmental attack upon disabled people in the UK in the previous decade. It also documents examples of how this bureaucratic onslaught has been, and continues to be, resisted by disabled people, their communities and allies.

The state of the welfare system in the UK has deteriorated rapidly since the coalition government in 2010, but any history of welfare reform needs to start much earlier to trace the rot. The Beveridge Report originally called for a “Social Insurance fully implemented (that) may provide income security; it is an attack upon want.” It resisted means testing in most cases and while the ‘abolition of want’ was aimed for, Beveridge recognized the importance, in the relationship between the state and the individual, of leaving “room and encouragement for voluntary action by each individual...”

From the two testimonials in this magazine, little can be inferred from current government policy that would suggest any form of *voluntary participation* on the part of disabled people in the welfare system. As the pieces by Maria Pike, and Miriam Bender on behalf of *Disabled People Against the Cuts* (DPAC) make painfully clear, current UK policy in the provision of social security for disabled people renders us powerless in the face of nonsensical assessment procedures and unpredictable punitive measures that can leave us without the most basic forms of food and shelter.

Maria’s article – “Fear of the Brown envelope” – illuminates what it is like to live in a constant state of fear and highlights the paradoxical impact this has on health, for while the welfare reform agenda is supposed to get people back to work, it actually renders many less capable. Deploying humor through her description of the “Grim Creeper”, as she calls her mobility scooter, Miriam skillfully documents how an apparently minor policy change at a public level, in this case the removal of her entitlement to a social care provided through a wheelchair referral scheme,

can have a profound impact on her daily existence. This includes her ability to participate in forms of social activism: the indirect silencing of people’s voices, by starving them of access to the resources they need in order to speak, could not be starker.

As co-editor of this special feature, Ria Dylan offers a personal insight into the experience of challenging the DWP which has relevance for other people going through a PIP assessment. The piece brings to life one of the thorniest subjects in social science and psychology: how external, macro level policy impacts on individuals and their experience of the world. Psychology has too often assumed the ingredients that drive people to suicidal despair are internal and can be unlocked by focusing on cognition. Ria places her struggles squarely in the social realm with the hostility she felt towards herself an internal extension of how she was being treated by wounding policy reforms. It is instructive for both claimants and their allies to do the best they can to resist the constant, implicit implication in the welfare reform agenda that it must somehow be our fault, and that we are to blame for our destitution.

What strikes me is the parallel with the ‘hostile environment’ towards long-settled Commonwealth migrants that has attracted so much attention in recent months. As the sociologist Will Davies observes of the government’s enactment of this hostile environment policy, there was a form of “weaponised paperwork” that was “intended as a way of destroying (people’s) ability to build normal lives.” The use of the Work Capability Assessment and PIP assessments to systematically confuse claimants, and to conflate their ability to engage in everyday functional activities with a readiness to engage in a precarious labor market, is a form of weaponised assessment that renders the claimant feeling fraudulent. In this I hear echoes of what the Glaswegian political activist Cathy McCormack has named the “War without Bullets”; the sustained structural violence of the state against oppressed communities through the deployment of impoverishing and delegitimizing social and economic policies. The impact on lives described here is heartbreaking and would be more dispiriting were it not for the fact that both pieces have been written by victims of this hostile environment, who have told their stories, despite attempts to silence them.

The Power Threat Meaning Framework (PTMF) is an attempt by a group of British psychologists, with the assistance of a range of stakeholders including service

users, welfare experts and welfare claimants, to develop an alternative approach to the dominant biomedical model of mental health. This is a paradigm shift away from the medicalization of distress that has been one focus of service user activism for decades, and a struggle which has been documented extensively in the pages of this magazine. However, an anonymous service user presents some limitations of the PTMF in the context of austerity and welfare reform. They suggest that any shift away from a diagnostic model risks playing into the DWPs hands by deconstructing the reality of mental illness.

There is already evidence that people with mental health problems are discriminated against in the Work Capability Assessment, and the DWPs version of the biopsychosocial model of illness can be seen as an explicit attempt to delegitimize the embodied experience of extreme distress. This contributor asks challenging questions of those of us working towards what we like to think of as progressive change for people with mental health problems. Not least of these is: how do we end the long-term hegemony of the biomedical model of human distress without jeopardizing the lives of people now?

Writing about a collaborative project with myself and others, Ellen Clifford from Inclusion London offers an alternative model of research practice in the area of welfare reform. Ellen describes the large numbers of research requests her member groups receive to participate in other people's research but how few offer opportunities for a more equal form of engagement. Ellen sees her role on this project as co-supervisor, as offering an opportunity to set the agenda regarding research on welfare reform and to ensure that Disabled people's voices are central to each stage of the research process. This argument is at the heart of survivor led and genuinely co-produced research in the fields of mental health and disability studies more generally.

One pioneer in the area, the survivor academic Peter Beresford, has called for those with 'close by', experiential expertise in research areas to be given parity of participation in a more inclusive form of research. I can say from my vantage point of co-supervisor with Ellen that she was able to detect detail in research transcripts that would have passed me by and to frame the analysis in the wider context of Disabled people's communities that as an outside academic I simply have not got access to. All this added up to making Ellen's involvement not an 'add on' but an essential component of the project's scientific integrity.

Psychologist Jay Watts's 'cut out and keep' piece was written with help from *Winvisible* and *Recovery in the Bin* for professionals. It offers a practical guide for advice on how to best support claimants, making particular note of the importance of not privileging emotional over practical support. Given that welfare reform initiatives have relied heavily on psychological theories of behavioral change

drawn from positive psychology and behavioral economics that are designed to 'nudge' claimants towards employment, it is refreshing to hear a contrasting psychological view. These initiatives are forms of what Lynne Friedli has called 'psychocompulsion', attempts to explain social processes such as disability and unemployment through the use of individual psychological mechanisms.

Jay's piece resists this reductionism but still attends to the psychological harm resulting from engagement in the welfare system, advocating for claimants to be helped to manage their shame and fear through relationships based on partnership and practical solidarity, rather than changing how claimants think. For professionals working in mental health settings, and those of us tasked with training them, it offers a stern rebuke for the relative lack of training for professionals in this area and cries out to be pinned to mental health team office boards or introduced into professional training program's curricula.

No *Asylum* magazine would be complete without a Dolly Sen cartoon, which helpfully reminds us that ridicule can often offer the strongest form of resistance. The detail of the 'Piss on Pity' t-shirt nicely subverts the idea that claimants are in need of paternalistic emotions, but need to be respected as equals. This, coupled with Rachel Rowan Olive's cover image, a terrifyingly accurate portrayal of the state as a multi-headed beast, reminds us that arts-based commentaries can offer forms of resistance that can both educate and entertain.

Finally, I want to draw readers' attention to the Tweet below that we were given permission to quote anonymously.



This has been one of the central lessons of compiling this special feature, that in some cases it can be difficult to articulate what it is like to be in the welfare system as the experience itself renders us speechless. This is reminiscent of trauma survivors who 'can't find the words' to relay their experiences. This speechlessness has impacted on the process here with a number of contributors simply being too worn down to put pen to paper. It is lesser for their absence and I would like to dedicate this editorial to my co-editor and the contributing authors; the authors who withdrew; and our fellow citizens who have been rendered speechless by the weaponised assessments of welfare reform. I hope that this edition of *Asylum* can offer some assurances that while they may currently feel silenced, there are many who hear them, and that through speaking together we can be stronger in our resistance. ■

# Dead and Dying:

## The cumulative impact of cuts on disabled people

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**MIRIAM BENDER, DISABLED PEOPLE AGAINST THE CUTS**

On 21<sup>st</sup> April, I checked my Facebook page at 6am and I was confronted by the following post

“... I was due to drop a food parcel to a lady in need today and I asked her friend to go there to give me a hand unloading as she was disabled and as we set off he called me in pieces to inform me the lady was no longer with us! Due to the fact a lack of food caused her to have a fit. After exceeding the food bank uses! ...”

What is really concerning is the fact that this did not chill me to the bone. I've become inured to seeing posts announcing the death of yet another victim of 'Austerity' and its devastating cuts. Cuts to Social Services, cuts to Support Services, cuts in the NHS, the Police, Children Social Care. Cuts to Mental Health services and cuts to emergency services.

The cumulative impact of the cuts is most damaging. Those who are dependant on benefits are subject to cuts to personal income and increasing costs of housing, utilities and food. In addition, lack of compliance can result in sanctions where you will be without income for anything from 3 weeks up to 3 years. And matters are made even worse by the roll out of Universal Credit.

They are being made to pay the ultimate price of Austerity cuts. From the early days of Austerity there were no figures to establish how many deaths occurred after claiming Employment and Support Allowance, Incapacity Benefit or Severe Disablement Allowance. However, following a Freedom of Information (FoI) request, a report was published in August 2015 that determined that 40,680 individuals died within a year of being given a Work Capability Assessment (WCA) decision and that just covers the period between 1 May 2010 to 28 February 2013. That is nearly 90 people a month dying after being declared fit for work. We are not sure about the exact number, however a report published by University College London in November 2017 claimed there was a link between 120,000 deaths and Austerity cuts. Those deaths are not all of disabled people. It must be assumed that a large number of those deaths are due to the rise in Homelessness, Rough Sleeping and the general lack of effective support when people fall on rough times.

Welfare Reform as practised since the onset of the Coalition Government in 2010-2015, and carried on by

the Conservative Government, 2015 to date, has been hard on everyone who has had to rely on the Welfare system. It has fallen harder on the disabled and long term and terminally ill. Studies have shown that the cumulative impact of Austerity cuts falls disproportionately on disabled people with estimates of 9% on the disabled and up to 19% on the severely disabled. The UK signed the UN Convention on the Rights of Persons with Disabilities (CRPD) in March 2007 and ratified the CRPD in June 2009. Yet despite this, the UK was the first country to be put under investigation by the CRPD UN Committee into the impact of Government policies on the rights of disabled people. The report found that the UK was guilty of 'grave and systematic violations of the Convention'.



Photo by Jill Anderson

There are many instances of deaths and suicides. Some are reported on Calum's List (<http://calumslis.org>). Most are gleaned from the occasional newspaper article. People are dying as a direct result of Welfare Reforms, the harshening of the WCA, lack of accountability, and a lack of regard for individual's circumstances. This affects not just the daily bread but the purchase of support to see to those essential, every day activities that impairments mean you cannot do yourself. There are also extra costs for heating a house where there is a disabled person, a long-term ill person or someone undergoing chemotherapy or radiotherapy.

DPAC receives numerous emails from individuals seeking advice and support while they are awaiting the hearing of their appeal; others are received through the DPAC Facebook page. Support workers are essential to the normal everyday lives of some disabled people. The withdrawal of Independent Living Fund in 2015, which was meant to ensure that disabled people with high

support needs would be able to live independent lives, has brought about a reduction in the hours of care and support that people could get.

People requiring rooms to store medical and support equipment are now subject to the Bedroom Tax (under-occupancy tax) as are those who, for whatever reason, cannot share a bedroom with their partner. The money disabled people rely on is having to cover increasing bills. In addition, more and more cuts are made to the financial support that disabled, long term ill and terminally ill patients are receiving.

The elementary basic everyday things you take for granted are not that simple when you are physically, cognitively or mentally unable to perform them. Daily tasks often require immense effort. For example, nipping down to the local shop for a pint of milk, or posting a letter, has to be planned and prepared for; a trip to the local park can leave you exhausted and requiring a recovery period. I use a wheelchair, a power chair. Because of cuts to Social Care, I could no longer get my power chair from the wheelchair referral. I've had to buy my own. The Grim Creeper requires electricity to charge her up daily. It needs maintenance and even then, she can break down unexpectedly. Without it I cannot shop, I cannot attend meetings, I cannot visit my grandchildren or meet up with friends. Yet new tyres cost well over £200, and bearings wear out.

I use my DLA (Disability Living Allowance) mobility allowance for the Grim Creeper. But many disabled people have had their DLA mobility allowance removed when they have been re-assessed. You used to have to prove you could not walk more than 50 meters – this has now been reset to 20 meters. Never mind that walking 20 meters wouldn't get me to the nearest bus stop. As my condition has worsened, fear of letting the powers that be know, fear of losing the income I have, stops me applying for additional support. I struggle with basic household chores, such as laundry, cleaning floors and some days even showering is a step too far.

A few years ago, I got a letter telling me to fill in the enclosed form and return it to the appropriate department or risk losing my benefits. The trouble was, there was no enclosed form. After 5 days trying to reach the department that sent me the letter, out of sheer desperation I contacted the local Job Centre. They agreed to put a hold on the withdrawal of my benefits and send a new form out. As soon as it arrived, I filled it in, took it to the post office and sent it on its way. Two weeks later was a bank holiday and, on the Friday, I was due my ESA (Employment Support Allowance). I also had bills to pay. My bank account was empty.

I was at risk of losing my home as my Housing Benefit was linked to my ESA claim. I prepared for threats of eviction. I packed a bag, but then I fought. I am articulate, educated and, having spent years as a single parent to three daughters and a number of fosterlings, tenacious. It took four months of fighting, and during two of those months, I was also worried about my home. The form I had sent in five months previously was miraculously discovered. I had my ESA claim reinstated. But only because I fought.

Attending a Work Capacity Assessment (WCA) is another, needlessly stressful process with pitfalls aplenty. They are designed, it would seem, with the sole purpose of pushing claimants to the limit. Now all claimants are expected to undergo regular assessments, even those who have a chronic condition with no likelihood of improvement. Not all assessors are actually knowledgeable about what they are assessing, and the assessment itself concentrates on functionality rather than capacity. Does my being able to touch my nose really tell you how I might cope with sitting for four hours at a keyboard? Does my ability to tell my left from my right really say anything about my capacity to deal with calls from irate customers in a call centre? Can the fact that I can make a cup of tea really have any bearing on whether I can be a shop assistant in a bakery or hardware store? Yet those are questions often asked during a WCA.

And all this is happening within a system that is set up to lessen direct accountability on the part of the powers that be, by complicating the process. This hostile environment has created mistrust and despair in interactions between claimants and the DWP, or their appointed operatives. As a result, fear is a near constant in the lives of disabled people today. ■



# The Terror of the Brown Envelope

MARIA PIKE

When I heard it reported in the media that people involved in the Grenfell Tower disaster were having their benefits sanctioned over not doing job search activities I wasn't surprised. No one who has had any dealings with the DWP in recent times would be surprised at the depths of depravity they will stoop. Losing everything you own and your home, and seeing loved ones and friends perish in possibly the worst fire this country has ever seen in recent times, means nothing to them.

Many people are dying each year, directly related to benefit cuts and sanctions. Most of these cases are not picked up on or reported in the media. Coroners courts do not rule that deaths were a direct result of these welfare reforms, even when there is a clear-cut case where someone has been pushed over the edge as the result of an adverse welfare benefits decision. The DWP say there are 'complex reasons' why someone would end their life. Just like there are 'complex reasons' people 'choose' to use foodbanks.

A few years ago, it was Christmas Eve. I always struggle around this time of year, being alone and a care leaver with severe mental illness and autism. I opened the post and time stood still. It was like I was in a suspended state of animation. A cold sweat washed over me as I tried to digest the content of the letter. It was something about a 'Benefit Integrity Centre' interview. All I read in my mind was FRAUD in big red letters as it may have well said that. For anyone unfamiliar with these sorts of letters they are sent at random as a result of (usually) someone making a false allegation, such as disgruntled family member or neighbour, or some issue with someone's claim which could have probably been easily sorted out without resorting to these tactics.



Photo by Jill Anderson

Because of the letter I became seriously unwell and ended up in the A & E department after self-harming. Anyone who says *'If you have done nothing wrong, you have nothing to hide'* do not know what they are talking

about. The letter was telling me to attend an office interview in three weeks' time and told me nothing except that 'an issue has arisen'. I racked my brains over and over, spending sleepless night after sleepless night. I became unwell thinking what the hell could it be? If I had done something wrong I had no clue what it was.

I became very paranoid and felt the DWP were watching me at all times (which is what they want you to think). I felt I could trust no one. Thoughts spiralled out of control, one bizarre scenario after another. I ran through the options of killing myself, going on the run and putting my two cats in a rehoming centre, which broke my heart and led to me sobbing uncontrollably on the floor. As time passed in this torment things got worse and I became more unwell. I had no-one for support and I was losing my grip on life. I struggle on the phone but at one point tried to call but they refused to tell me anything. Prior to the visit I ended up moving in to the small cramped garden shed, frozen and not moving.

At the end of the ordeal it was proved to be nothing but a false report. However, this happened THREE more times and has destroyed me. Each time (I think it is same person) they end up investigating me and each time, even though I tell myself I will NOT let it destroy me, I become very unwell and end up suicidal and self-harming. There seems to be a pattern: these brown envelopes of doom always arrive on a public holiday, birthday or a Saturday. I feel this is a deliberate attempt to cause the most impact and devastation.

Most people in receipt of Employment and Support Allowance (ESA) or Personal Independence Payment (PIP) will understand the **Brown Envelope of Doom**. Except, in a cynical move to get people to open these things, they have started putting letters about medical assessments in a white envelope. People who had been granted a life-time Disability Living Allowance and provided thorough and detailed medical evidence are now having to be completely re-assessed. This entails jumping through hoops of fire to re-prove what you had already proved before. You are forced to answer some questions which, if you have a disability such as a mental health condition or autism, are virtually impossible. If you pass this hurdle, you then have the pleasure of completing a 35-page long form. This is very stressful and many people are turned down for not being able to fill it in correctly as they don't have the support to do so. There are virtually no agencies that provide benefit advice anymore. Citizens Advice rarely do this detailed work because of the specialist and time-consuming nature of the work and they would need detailed knowledge of how

the illness/disability impacted upon the individual's ability to do things. There is no funding to help people with this and people suffer as a result.

After going through this grueling soul-destroying process, I was granted an award for ONE YEAR. This was only a year after being granted a lifetime award. Plus, you have to re-apply a year before the award is due to finish. Forms will be sent automatically one year (at least) before the end date, so my award was over before it had even started! As soon as the new decision is made this cancels out the remainder of the existing award.

Then there is the medical evidence. You must send as much medical evidence as you can, as the DWP will not follow this up. I had 96 pieces of medical evidence including tests, medical reports etc. I have spent much of my life in hospital over the last few years, but it is rare to clinic letters so you have to write and beg for copies. Eventually you get a letter back telling you put in a Data Protection Request which will result in a demand for £50 to get copies of letters you should have been provided with in the first place. Plus, if you have been seen at different hospitals, that means £50 each time. This is unaffordable if you are on benefits.

At the same time I was sent my PIP form I also received the 'double whammy' of the Work Capacity Assessment (WCA). This means two lengthy forms of a similar nature to fill in all at once. This is totally overwhelming and affects your mental and physical wellbeing, creating unimaginable levels of stress and torment. You get four weeks to fill in both - except that the four weeks starts from the date of the letter with the form (which takes over a week to reach you). Plus you have to allow a week to send it back, which gives you a little under two weeks to complete each form.

I got into a total panic and was unable to sleep, eat or function. I asked what to do about the evidence as I had only one set for both. Could they pass the evidence on? NO. Could they photocopy it for me? NO. Yet they could see the information on their screens.

Despite all this evidence – and my GP saying I was too unwell to attend and needed to be seen at home – I was still called in for an assessment. They had contacted mental health services, who were not providing me with any help at all, despite my having severe mental illness and autism. It would seem this would go against me. They obviously felt that anyone with mental illness should be in receipt of mental health services, but this is simply not true.

When it came to the assessment report, it seemed the fact I was in and out of hospital so much with my physical health meant that, somehow, I was not disabled enough.

**D** IS FOR  
**DEPARTMENT**  
FOR **WORK AND PENSIONS**

BROWN  
ENVELOPE  
OF  
TERROR

CLAIMS PROCESSING  
OFFICE 37B  
SALMON'S TOWER  
MORDOR

Dear Featureless Claimant,  
We don't believe  
you.

*A is for Awkward* (self-published zine), 2017

"Attack of the Acronyms" / © Rachel Rowan Olive 2018 / @rrowanolive

A benefits advice line confirmed that it could be seen as demonstrating that I was able to get out and about and meet people. I couldn't believe it. I cannot travel on public transport and have to go by ambulance, and my autism and mental health difficulties make interacting with people impossible. I live a life of total isolation and exclusion and have never had any friends. On the other hand, if you have no medical evidence you are also seen as not being disabled. The PIP was a lifeline for me, to manage the extra costs of being disabled.

Living in fear of brown envelopes, feeling paranoid and caught in an endless cycle of assessments makes life unbearable and I am in a constant state of fear and high alert. I can never relax and it is no wonder I have become so detached, as my body has shut down and nothing feels real. I feel like I am dead, my life over, and there is no prospect of ever getting better. I fear that, at any given moment, I could be left destitute. This is my greatest fear, having been homeless for many years and having no friends and/or relatives to rely upon if needed. Even my GP has told me to find another practice as they are sick of having to cope with my 'demands' for medical evidence and supporting letters.

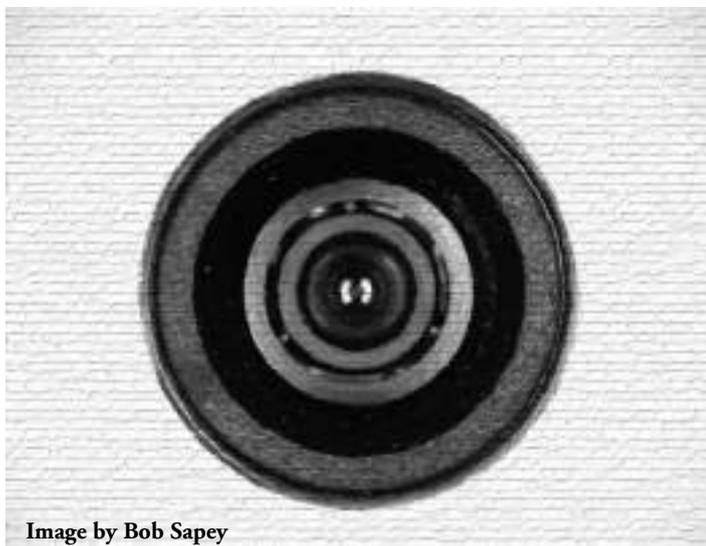
This is the reality for many sick and disabled people. We are creating an underclass of disenfranchised, disempowered people. I feel my life has been stolen from me and I am being blamed for the adverse life events I have endured which have taken their toll on my mental and physical health. How, as a nation, have we become so uncaring about vulnerable people? ■

# *The life and times of a modern day mental*

(Or, reflections on the PIP process)

**RIA DYLAN**

Being on benefits is like being in an abusive relationship with the state. The rules of engagement are complex and ever changing, the penalty for getting it wrong: brutal. The state uses the media to gaslight on a national scale. We cannot escape our abusers, we are financially dependent on them. Our abusers infiltrate every cell of our lives, every moment anxiety filled. It is no longer paranoid to say the government is trying to kill us. Our experiences are invalidated, we are treated as worthless and disposable. We creep around on tiptoes hoping to not alert them to our presence. The double binds render us immobile. With benefit related deaths rising this isn't any old abuser, this is a serial killer whose murders are going under the radar due to the successful propaganda campaign rendering us disposable.



I have had mental health problems my whole life. This has included times where I have been able to hold down employment, and times like now where that is just not possible. Never have I experienced a worse, more fear-filled time to be mental. We talk of brown letter syndrome, the dread so viscerally felt should a brown envelope happen upon our doormat. Letters summoning us to an assessment where we can look forward to being asked 'why are you not dead yet'? Letters telling us we failed. Ding! You are not sufficiently mental. Please move on to an area of our service that will hound you to death.

I wish there was a way of applying for benefits that didn't leave me hating myself. I am more than the sum total of my mental health, but this 40 page bible of me demands to know all the worst aspects of who I am and how I am. The stuff I am really ashamed of, the stuff I hate about myself. Here is a list of all the things I can't do because I am broken. Here are the bones of my despair. It also leaves me with a sense of being fraudulent. My mental health fluctuates. Sometimes I can be sociable, sometimes I cook really great food, and sometimes I want to kill myself and stay in bed for 3 months, to stay still so long it hurts, but even the pain of stillness isn't enough of a motivator to move. Yesterday I laughed, am I committing benefit fraud?

I had the results of my Personal Independent Payment (PIP) application sent to me. I was awarded standard rate daily living and no mobility. The move from Disability Living Allowance (DLA) to PIP cost me £200 a month.

Being poor is like wearing a shirt with a too tight collar. There's no escaping its vice-like grip around your neck. Every moment is coloured by anxiety: can I pay the rent this month? Can I go food shopping this week? Have I enough in my account to cover my direct debits? Or can I expect a fun letter from the bank saying 'Dear poor person, you have no money, we are going to charge you for that. Love from The Bank'.

Politicians have made noises about benefits being a trap. It is a trap now. In the past, benefits gave me the space I needed to gather strength to rejoin the world. I am scared this won't happen now. I am scared I will be trapped on benefits forever. The constant fighting required, the hoops we have to negotiate, the ever-changing dance steps we have to learn, the paranoia induced by the level of scrutiny and media whipped-up public hatred – all this leaves no space for having any kind of life. It is exhausting and all-consuming and I have no energy left to do the things I need to do to be less mental.

I applied for mandatory reconsideration and fell into the 80 percent whose reconsideration turns up the same results. The process made me increasingly suicidal. I was lucky at the time to have a great CPN who saw what it was doing to me and took over and filed the paperwork for an appeal.

*'SuperMental' By Rachel Rowan Olive.  
Dedicated to all those who have had to  
pull their latent super powers out of the  
bag to survive this system.*



My hearing was a full eighteen months after I first applied for this benefit. When I received notification, I had a meltdown. I wondered if death was preferable to having to go to court to plead my craziness. In the two weeks leading up to it I was supermental. The DWP really are the biggest threat to my mental health out of all things in my life. I spent three hours with a friend going through my 80 page appeal bundle, again raking through the bones of my despair and the contempt with which it was received. I got a referral to the Free Representation Unit and was lucky enough to be allocated a pro bono trainee barrister experienced in representing people at appeal. More conversations about my being mental and we drew up two documents to present to the panel. One was a written statement from me – if you go to appeal I strongly recommend you do this. They will tell you it's informal and not supposed to be intimidating, but it's still in court with airport security and people making judgements as you tell them all the ways you don't work. Having it written down and presenting it to them made it easier, if I forgot details or was too scared to speak it was written down

anyway. My representative also prepared a submission stating the facts of my case, the places where we felt I hadn't got enough points, and some legal points around how PIP is supposed to be administered.

DWP sent a Presenting Officer to my appeal in a last ditch attempt to ensure I did not receive this benefit. I won my appeal in a big way. I went from 11 daily living points to 13 – taking me from standard to enhanced rate. My mobility score went from 4 to 12 points, taking me from no mobility to enhanced. I am obviously delighted to have won. I am proud to be part of the tribe proving over and over that these assessments are not fit for purpose. I am looking forward to a year or so of not having to worry about money. Winning, however, does not make up for the 15 months of being on far less money than I needed, the stress of having to apply for it in three different ways, and the constant fear of not being able to pay my rent. That's 15 months of my life made considerably more stressful by assessors who wilfully misinterpreted what I said to them.

This misery-go-round never ends. 5 months after winning my appeal I was sent a review form and I am awaiting the outcome now. Who knows what they will make of my wild claims this time and whether or not I will have the energy to fight them if they take it off me again. I'm also not sure what I can even do with myself. PIP is supposed to enable us to have some semblance of a life, but if we start having one we stop being eligible. How can I hope for a different life if any steps towards that life will have me kicked off benefits before I am ready to be self-sufficient?

When asked to write this piece I was asked to focus on resistance, on what we can do as a community to survive. Indeed as co-editor of this edition I don't want to produce a misery verse of doom. I want to say 'hey, this is really tough but there are ways through'. I do believe this, and there is more to my life than repeat batterings from the system. What I found overwhelming in trying to write about this is how bruising, how energy zapping and how isolating the process can be.

In the absence of any wisdom and in the scarcity of hope here are some words from Dumbledore: 'while you may only have delayed his return to power, it will merely take someone else who is prepared to fight what seems a losing battle next time – and if he is delayed again, and again why, he may never return at all'.

Dumbledore is telling Harry that he counts, that his efforts count, that every pocket of resistance throughout the land has meaning and value, and may one day add up to something new and better. These are dark days. Every appeal won, every court case overturning legislation are small victories to celebrate. Know that there will always be people who will fight alongside you, and for those days when you cannot fight, know that there will always be people fighting for you. ■

# Case studies no longer

## Disabled people researching welfare reform

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ELLEN CLIFFORD, INCLUSION LONDON

'Nothing about us without us' was a principle first developed within the Disabled People's Rights Movement in response to the exclusion of disabled people's voices from decisions affecting our lives. This experience operates at both an individual level, with Disabled people routinely denied choice and control within our everyday lives, and at a broader level where systems and policies directly affecting Disabled people are designed without our involvement. Now, at a time when Disabled people's rights are under direct attack by government, it seems more important than ever that our voices are heard. Therefore, the opportunity for *Inclusion London*, an organisation run and controlled by Deaf and Disabled people, to be meaningfully involved in research with the University of Essex was one we were keen to take.

News coverage of disability routinely use Disabled people as "case studies" to highlight a problem but then speak to non-disabled people working for charities for the analysis. When challenged, journalists will admit that for issues affecting other oppressed groups, it would be unthinkable to go for comment to anyone but members of oppressed communities themselves, but confess to never having considered disability in the same way. Too often disability simply isn't viewed as an equalities issue but rather seen through the prism of a pity model, continuously reinforced by media and cultural reference points that portray disability as tragedy.

At the heart of Disabled people's exclusion are judgments made by non-Disabled people about our abilities and, fundamentally, our worth as human beings. The most extreme manifestation of such attitudes occurred under the Nazi regime where disabled people were labelled as "Lebensunwertes Leben" (life unworthy of life) and "Nutzlose Esser" (useless eaters) and mass murdered by the State. A survey carried out by Ewald Meltzer, the director of an asylum for young people, found these views shared by the parents of the Disabled children in his care, with 73% in favour of the "curtailment" of the life of their own child. The atrocities carried out under the Nazi's Aktion T4 programme may seem a far cry from conditions in Britain today, and certainly there has been enormous progress

here towards inclusion since the days of forced mass incarceration in abusive institutions, however Disabled people have remained essentially marginalised with negative attitudes towards disability highly prevalent. The "Hidden in Plain Sight" report published by the Equality and Human Rights Commission in 2011 found that, for many Disabled people, harassment is part of everyday life. Conditions such as these have made it easier for the UK Government to deliberately and systematically implement policies adversely affecting Disabled people from 2010 onwards.

What we have experienced since then is a dramatic regression of our rights, as a direct consequence of austerity measures targeted at Disabled people. In November 2016 the United Nations disability committee published the report of their special investigation into the UK, concluding that the threshold of evidence had been met for grave and systematic violations of Disabled people's rights due to welfare reform. Cuts to social security payments and support services that Disabled people rely on is a deeply pernicious attempt to redefine and deny disability in order to remove state responsibility. Systems have been designed to relocate the burden of survival onto individuals regardless of impairment, illness or disabling barriers. The American insurance company UnumProvident, brought into the UK under New Labour to advise on welfare reform, had been previously fined millions of dollars following a successful class action law suit that charged them with running "disability denial factories".

Since 2010, with welfare reform accelerated under the Tories, Disabled people have experienced a deliberate invalidation of our lived experience. The benefit scrounger narrative, constructed by right wing politicians and media, encourages the view that Disabled people are not to be believed if we say we are too ill or face too many barriers to work. Benefit assessments are designed to ignore Disabled people's evidence of eligibility while the role of the DWP Behavioural Insights team (or "Nudge Unit") is to create a system that forces people to change, operating on the basis that Disabled people have mistaken beliefs about what is good for us. Similar things are happening in social care as local authorities find ways to justify

Photo by Jill Anderson



the rationing of support. Throughout, Disabled people are suffering not only through the removal of essential income and support, but through assaults on our integrity and our very sense of self.

It is within this wider context that the opportunity for *Inclusion London* to work with the University of Essex came about. On a day-to-day basis we are inundated with far more requests to participate in student interviews than we can accommodate. However, here the offer extended beyond this to contributing to research, co-supervising a research dissertation and, from that, co-authoring an article for publication. With this level of involvement, the research would be carried out and written from a social model of disability perspective, would examine a subject relevant to key issues facing Disabled people in the current climate, and had potential to contribute to positive social change. In spite of the overwhelming strains on capacity that are part and parcel of the systemic change that has occurred since 2010, the opportunity was too important for *Inclusion London* to miss.

The research is about the impact of conditionality and sanctions on Disabled people in the Employment and

Allowance Work Related Activity group. This is one of the areas of welfare reform where Disabled people have felt our voices have been most ignored, with some of the worst consequences including deaths, suicides/ suicide attempts and serious mental health impacts. For many years Disabled campaigners have raised concerns about the lack of an evidence base supporting the use of conditionality for achieving employment outcomes and the discriminatory application of sanctions on Disabled benefit claimants. In 2015, the DWP admitted that 10 of the 49 benefit claimants whose deaths were subject to secret reviews had had their payments sanctioned. In spite of widespread concern and mounting evidence of harm, the government has not only continued with, but extended conditionality, to cover new groups of

people. The research took as its starting point the voices of Disabled people who had themselves experienced conditionality.

The research provides a valuable contribution to the debate around conditionality and sanctions. It supports recently published research from both Demos and the University of York, that conditionality is counter-productive. Thematic analysis of the interviews with participants confirm adverse effects, but also present a deeper and more complex picture of psychological impacts. Participants had both positive and negative experiences of relationships with work coaches. Some made statements distancing themselves, as “genuinely” Disabled people, from “scroungers”, indicating an acceptance of narratives that demonise claimants. What emerges clearly is the individual disempowerment inflicted by a system that ostensibly aims to develop claimants’ employable attributes. By contrast, it is through a rejection of that system, whether attitudinally or through active involvement in resistance, that participants appeared to regain confidence and a sense of self. ■

# Will the ‘Power Threat Meaning Framework’ help survivors on welfare?

## A SERVICE USER’S PERSPECTIVE

The Power Threat Meaning Framework (PTMF) released earlier this year has been celebrated as a much-needed “paradigm shift” in mental health. Although published by the British Psychological Society (BPS) Division of Clinical Psychology (DCP), its authors clarify that it “is not an official DCP or BPS position or model.” It is some ideas to explore and discuss. However, given the intensive nationwide promotion of the framework and BPS branding, it might as well be an official position. The authors clearly do wish to encourage people to implement the ideas and this article discusses some of the problems with the framework.

Its biggest failing is in the welfare section which clearly had limited input from current claimants, or advisors, charities, organisations and groups doing welfare support. Policy and practice are very different, so although welfare policies may not state that assessors look for particular diagnoses, in reality they do.

PTMF descriptions, such as “Experiencing temporary and enduring or regularly occurring severe mental distress” (PTMF p.298) just wouldn’t cut it in the “Health condition or disability” list on Personal Independent Payment (PIP) forms. The mental health PIP example given by Citizens Advice lists “Agoraphobia” – another medical diagnosis. Both ESA and PIP require a medical report (DS1500). The guidance for completing this includes a brief section on “Conditions affecting mental function” (p. 20). The first line of this specifies “diagnosis”, asking whether “mental illness or cognitive impairments, for example autistic spectrum disorders” are present and their severity. Equivocal and diluted PTMF descriptions would not be good enough, especially when compared with authoritative medical descriptions (mental and physical) in others’ reports.

This is not about a psychological dependence on diagnosis, it’s about trying to materially stay alive, ensuring mental health professionals provide information in an effective way but more importantly, what the culture of the department demands. The Department of Work and Pensions (DWP) have callously put historical abuse and rape victims attending court for their case through a review, just as they’ve sent forms and demanded face to face interviews and assessments of people in hospital, on mental health wards, even on section.

It’s assumed that the DWP will somehow make allowances for victims of trauma. Yet the DWP so cruelly let disabled people become homeless and terminally ill people face Job Centre harassment to look for work and some die with no income in their final weeks. On this



topic the framework not only doesn't reflect current reality, some of the suggestions might have adverse outcomes. People are more likely to get the support they need, if professionals helping them speak the same language as the decision makers.

The other assumption appears to be that the framework can be inserted into existing neoliberal recovery oriented services and punitive DWP processes, that it will somehow have a ripple out effect, and the DWP will accept vaguer descriptions and 'strengths-based' descriptions. This has no basis within the experience of claimants and those who work with them.

The framework seems especially orientated towards survivors of specific early trauma such as child sexual abuse (CSA). For that patient group it has some merit. It utilises existing materials on the topic so, in that respect, it's not an entirely 'new' proposal but it arranges those materials in a format to offer patterns. Its appeal to survivors with experience of early trauma with an existing diagnosis of personality disorder (PD), or at risk from receiving that diagnosis, is understandable.

For service users without experience of early trauma, especially CSA, I'm uncertain whether the framework will translate to all and any experience of mental distress, or even to other adult experiences of trauma and powerlessness. I'm unconvinced that all service users will identify a life defining trauma or be able to answer the proposed question, "What happened to you?" methodically.

The suggestion of 'formulation' instead of diagnosis raises other issues. For example, in some areas team formulation seems to be compulsory if service users do not complete an individual formulation 1:1 with a service provider. Is the construction of a formulation, without the service user present, any better than a diagnosis? Service users have seen formulations every bit as stigmatising as a set of notes with a PD diagnosis, just without using the diagnosis. I don't see the PTMF as an alternative to all diagnosis for all people and fear that more trauma would get described in a PD-like way if all experience is viewed through the lens of trauma.

People with long-term mental health conditions are being denied proper social care. They are forced off welfare benefits, directed to work coaching, and welfare sanctions are imposed as treatment. Rather than debate the intricacies of diagnosis, I prefer to focus my energies on assisting people to stay alive until the political landscape changes and we have more room to manoeuvre. ■

# Supporting Claimants: a practical guide

JAY WATTS

Dear Fellow Health and Social Care Professionals,

I have been asked to write something about being a useful ally to benefits claimants. I don't think that there is anything we can do that is more important at this point in history, when attempted suicide rates for people on ESA have demonstrably doubled between 2007 and 2014 as a result of welfare changes. As I write, I have friends and claimants going through this process, subject to 'compliance officer' reviews and endless re-assessment. As many say, this is often **more devastating, more life threatening** than decades of psychiatric oppression and traumatic experiences such as abuse. If we do not call out the devastating effects of these policies on our friends and claimants, we are, as far as I am concerned, complicit. So, some tips.

First, er, **ignore anything fellow professionals tell you!** The knowledge on what is happening is held by disabled activists so connect with and offer yourself as an ally to national groups, such as Disabled People Against Cuts, Mental Health Resistance Network, Black Triangle, Recovery in the Bin and WinVisible. Sign up to newsletters, respond to government consultations, lobby your professional organizations, amplify tweets, go to local actions and connect with the people who KNOW.

Make sure you know which benefits do what, so that you can ensure claimants have access to the benefits they are entitled to, and ensure you understand the processes surrounding application, reassessment, appeal and so on. Find out about **PIP and ESA**, of course, including the difference between being in the support-group and work-related activity group, but also things like bus passes, carer support and prescription exemptions. Make sure you know when **Universal Credit** will be introduced in your area, if it hasn't been already, and what that will mean for claimants. It is exhausting and frightening for claimants repeatedly to have to explain to professionals what is needed when.

It beggars belief that health teams have no training on benefits, given the demonstrable connection between being a claimant, poor mental (and physical) health and reduced life expectancy. Be the change we need to see by **organizing team training** with a real practical focus. Then write about it in your professional magazines to encourage others. Consider setting up support or information groups for claimants e.g. how to survive an ATOS assessment, what will happen when Universal Credit is introduced. Ensure that you and others in your team **don't farm claimants off to local organizations** such as Citizens Advice Bureau. Yes, this can be super useful, and they will probably know more than you, BUT approaching new people can be impossibly

anxiety-provoking when one is in agony. You are known, and of course many people will nod along to recommendations to go somewhere else, because it can feel shameful to admit this is difficult. I know I have done this many times in the past.

Think about how you can send out **counter-narratives to the government propaganda** that many people identify with and internalize (e.g. that people on benefits are 'scroungers', that benefits are a 'lifestyle choice' and that claimants only have 'rights' if they perform certain acts to fulfil their 'responsibilities'). Explicitly and frequently **acknowledge the brutality of the welfare system**, and your disagreement with how claimants are treated. Ensure you do not 'gaslight' claimants by presuming that certain things are a symptom of illness rather than a reflection of reality. For example, claimants often ARE being recorded when they walk from the car park to the DWP assessors office, they ARE sometimes being monitored on Facebook. If claimants would find this useful, explicitly link internal distress with the sociopolitical DWP context in things like CPAs, psychological formulations and so on.

Think with claimants about how to respond to the **triggering effects of benefits related things**. How might they seek help? It is useful to put it down on a risk assessment, or even as a red alert on electronic notes, so workers from other teams, such as the Home Treatment Team, or Psychiatric Liaison, realize their gravity as triggers. Staff can be quite cut off, as we know, and sometimes need these kind of prompts to **react with sufficient compassion and gravitas**.

Think how can you as a professional, and your service, keep particular claimants' trajectories re benefits in mind. For example, you might ensure that **claimants receive a text when letters are sent out** to ensure the sound of the postbox doesn't trigger DWP anxiety. Or you might make a note in your **calendar of key dates**, like the date of an assessment meeting, so you can send a text in support in the morning if you cannot attend and check-in afterwards. These small acts of recognition matter. **Beware of assuming that claimants are well-supported**, and have someone to attend benefits meetings with them. The shame associated with benefits can make people, even prominent DWP activists, find it difficult to ask for assistance. Try to do this in a way that **maintains the dignity of claimants** as needing help can be a devastating blow to pride (we all, of course, need help at times).

With individual claimants, your **overwhelming priority** is to help with filling in forms, provide letters of support and work to ensure claimants are 'awarded' benefits and are exempt from face-to-face assessments. If time dictates that you need to choose between helping a claimant fill in a form



and writing a letter of support, go for the latter. Without a good letter of support, a claimant has little chance of success – however severe their disability, however well filled out their form. Appealing later down the line can take up to 18 months.

**Offer to be present when claimants fill in forms** and allow at least 90 minutes in your diary so you can have 15 minutes before and after the form-filling to breathe out. **Bring tea** to form-filling sessions, and perhaps even biscuits, if the claimant does not have eating difficulties. Do anything that you can to acknowledge the stressful nature of dealing with the DWP. Claimants will likely be in a state of high alert, so it can also be useful to put a sign on your office door saying ‘do not disturb’. You might wish to offer to post the form for the claimant so that they can leave the office with it done.

It is incredibly important to **have the descriptors for each question to hand, with the scoring points for each question**. You can find these for ESA at the bottom of this letter. The descriptors are written in a way that is biased towards physical health problems, so you and the claimant need to think together **beyond your first impressions** to apply them to mental health. For example, dissociation and social anxiety may make it difficult to travel on public transport. Cognitive problems **INCLUDE** things like cognitive biases – e.g. all-or-nothing thinking – though the context of the form doesn’t imply that (this was made clear during RF’s case against the DWP in 2017). Ensure claimants approach thinking about each question from the vantage point of their worst days but acknowledge fluctuation.

Claimants need to provide evidence for any activity they cannot do, to use the government’s own words, “**reliably, repeatedly and safely**”. This, in my experience, includes a lot more things than claimants initially think. If the claimant does voluntary work, ensure they explicitly write how this differs from paid work. For example, “because I am not paid, and I know they don’t rely on me, I can take time off, and don’t have to concentrate when my voices are bad, and I don’t feel crippling guilt. When I used to work, one of my voices

attacked me for letting people down and this caused me to have a breakdown”.

Help claimants to **acquire as many letters of support and supporting documents as possible**. Include prescription forms from the GP if medications are not explicitly mentioned in consultant letters. Some GPs charge for letters of support. Costs like this can mean the difference between being able to eat and not for many claimants, in which case use your professional power to pressurise the GP to do it for free. In my experience, this normally works.

Filling in forms in the way the DWP requires, and providing useful letters of support, often means focusing on what is difficult and writing in a far more **pathologising, medical model manner than you might normally**. It must be deficits based, with diagnosis used as shorthand. If you are critically minded, speak with claimants first about the need to adopt what Recovery in the Bin Administrators calls ‘**double speak**’, i.e. writing in a way that you disagree with because that is the best way to serve the interests of the claimant. Ask permission to do so. I have always found claimants understand, are relieved, and say yes to this.

Start your letter of support by stating your qualifications and your relationship to the claimant, then mention if the claimant is not able to attend a face-to-face assessment (in which case note the **severity and type of risk** behind this – the DWP considers this to be ANY deterioration in mental health), then the diagnosis, symptoms, and descriptors. End the letter by stating you support the claim, and provide your contact details for any further questions. Be sure to add page numbers and put the claimants name and NI number on each page after the first one (which has their address and DoB).

Be careful not to mark your letter of support as ‘**confidential**’. The DWP takes this to mean it should not be directed to assessors, even if the letter is addressed to them! Yes, really. If your letter of support only covers mental health and the claimant also has **physical disabilities**, state this explicitly – acknowledging the other diagnoses if possible, and stating you will not be covering this in your letter.

Write your letter of support with the descriptors to hand, trying to get as high a score on each one as possible, and putting in bold words that tally with these criteria. Assessors do not care about your psychological formulation, the claimant’s history or the developmental and/or socio-political causes of their distress. Indeed, feedback suggests that **empathic, long letters can be counterproductive as assessors do not read them**, so frame your letter around the descriptors. It is not enough to say ‘x cannot learn to do y’. You need to explain and give examples. For example, ‘x’s ability to adapt to new situations is severely compromised by the intrusive nature of the voices she hears, which are considered to be a symptom of y’; or ‘y’s obsessive compulsive symptoms are so severe that ritualized behaviours take up the overwhelming majority of her day,



meaning she is unable to cope with change'. You can find a super useful link on writing letters of support at the bottom of this letter.

As aforementioned, getting a paper assessment is crucial. This is because assessors are wont to ask questions like 'So why haven't you killed yourself yet,' and **assessments are nearly always traumatic** with weeks/months of anxiety beforehand. Because this is so important, write a separate three or four-line letter stating how a face-to-face assessment would damage the claimant's mental health (e.g. by increasing suicide risk). This is a life saver. Don't justify your request by saying the claimant finds it difficult to leave home or they will offer the claimant a home visit!

Consider writing an additional three or four line letter if the claimant finds phone calls or emails difficult. The method by which the **DWP contacts claimants** can be seen as a 'reasonable adjustment' under the 'Equalities Act'. This can ever so slightly decrease claimants' sense that they can be intruded on at any minute.

If a benefits form has already been sent in, and the claimant receives an appointment letter, it is perfectly possible to get this paused and then stopped with a phone call and by faxing an '**exceptional circumstances – further medical evidence**' form. Any health professional can make this request. For further details of how to do this, read WinVisible's superb guide – a link is at the bottom of this letter.

After filling out forms, or sharing your letter of support with claimants, I suggest setting up another session as soon as possible to co-write a document celebrating what is unique and worth celebrating in the claimant – a '**counter narrative**' to what the DWP has just made you both do. Try to make sure both the **form-filling and counter-narrative sessions are supernumerary** i.e. are not taken away from the number of sessions claimants are entitled to.

If the claimant ends up having a face-to-face assessment, ensure they **know their rights** which include the right to reasonable adjustments such as having an assessor of the same gender, being in a large room with a window if one gets claustrophobia and so on. It may be easier for you to call as this needs to be arranged **in advance** and calling the DWP is a zillion times more stressful if you are the claimant.

It is really important to get assessments recorded as **the presence of the tape recorder** means DWP assessors are more likely to be fair and polite (or it may come back at them). Claimants have the right to record assessments but only if they are double recorded i.e. if the assessors get a copy too. It is best to request this in advance, as some assessors have been known to refuse when put on the spot. Offer to attend too if you can.

If a decision is made about benefits which the claimant, or you, disagrees with it is important to **request a mandatory reconsideration** within a month. The claimant may be so drained by the whole process, or feel so unworthy, that they are reluctant to go through this again even if it means financial destitution. As a professional, it is important to be present enough, and supportive enough, to help people continue to get the benefits they need.

If claimants are being harassed by the DWP, for example being called when they are in hospital, a phone call can stop this. **Whenever you call the DWP, have the claimant's name, address and NI number to hand.** Speak in an authoritative voice, mentioning your profession, and state the claimant is with you or, if not, why. If you are calling a named DWP assessor, and reach an answer machine, leave a message saying that you have another appointment in x amount of time but this is super important and could they call back urgently. This tends to work.

Claimants who get the benefits they need, or win appeals, are often subject to the whole process again within the year, or receive a call from the 'compliance officer' to check the legitimacy of their claim. **It can feel never ending.** Don't underestimate the significance of giving time and space for the despair, anxiety and rage this process provokes. But, to bore you silly with my main point, NEVER PUT EMOTIONAL SUPPORT ABOVE PRACTICAL SUPPORT WHERE BENEFITS ARE CONCERNED.

When claimants are being **discharged from your team**, prepare a letter of support, ready to go when needed in future. Otherwise, you are effectively punishing claimants for doing better/being victim to NHS funding cuts. I know that is time consuming but even if you just do a couple of paragraphs, it can make all the difference. And, trust me, the more benefits support letters you do, the quicker it gets.

Showing solidarity matters. So, **get active**, respond to public consultations, attend protests, organize conferences, demand professional courses have relevant training, write newspaper articles or comment on the 'workless equals worthless' bollocks so prevalent in the media. Use any skill that you have to chip away at government and media propaganda that dehumanizes claimants, from your research skills, to your creative skills, to your professional skills – anything and everything.

We have such power, such privilege as professionals, whatever the personal circumstances of our lives. Let's use this, in solidarity with claimants, to make things better.

In solidarity,  
Jay x ■

*Huge thank you to WinVisible not only for their brilliant medical exemption guide – link below – but their advice on recording. Thanks to Rita Binns of Recovery in the Bin for making so many helpful comments on the draft and generally being amazing. And to the very lovely 'RF' for reminding me that, in David and Goliath fights, sometimes David DOES win.*

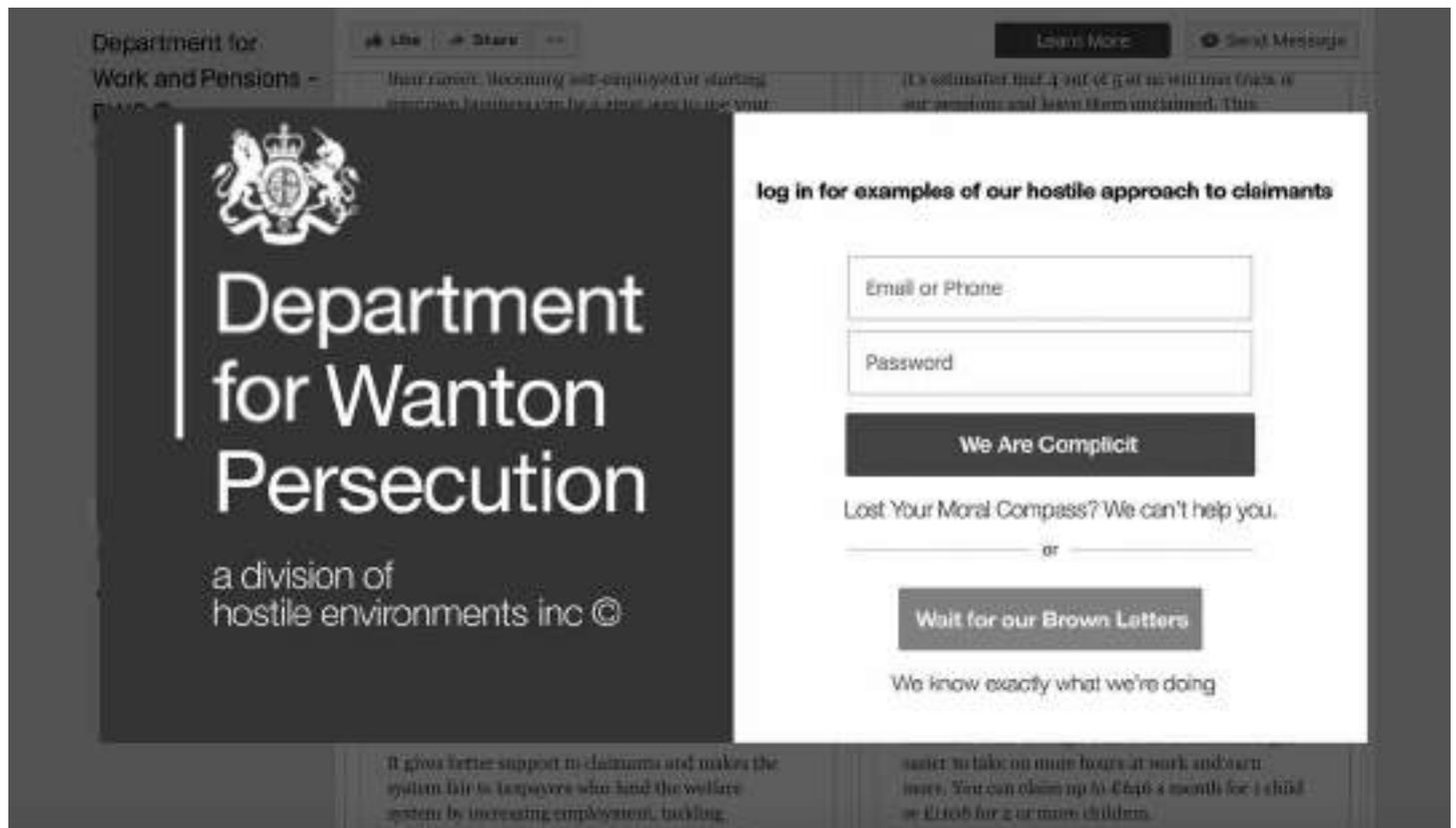
### Links

ESA descriptors: <https://www.sense.org.uk/get-support/information-and-advice/welfare-benefits/esa/esa-descriptors/>

How to get a medical exemption: <https://winvisibleblog.files.wordpress.com/2017/12/benefit-assessments-exemptions-briefing-for-professionals-v2.pdf>

More advice on professionals' letters of support: [https://citizensadviceteignbridge.org.uk/wp-content/uploads/Med\\_Evidence\\_WCP\\_Guidance\\_final\\_14dec.pdf](https://citizensadviceteignbridge.org.uk/wp-content/uploads/Med_Evidence_WCP_Guidance_final_14dec.pdf)

How to win a PIP appeal <https://www.advicenow.org.uk/guides/how-win-pip-appeal>



# Pursuing choice, not truth: debates around diagnosis in mental health

AKIKO HART

The debates around diagnosis and medication are fraught and passionate. They easily become polarised, especially on reductive platforms like Twitter, and positions can quickly become entrenched. It's because the debates matter: they are about us and the people we love, they are about how we support one another, and what kind of world we want to live in. They are also about expertise and power: who has the right to talk and whose views matter more.

But my fear is that in the anger and passion, in the quest for truth and wins, we are perhaps forgetting people. The recent online scuffles around pill shaming and diagnosis have highlighted for me the widening gulf between theory and practice in the debate around diagnosis, and how individual meaning making may be lost in the search for ideological purity. When I see the anger, the in-fighting and people turning on each other in the gladiatorial pit of Twitter, I think – who is winning here? The truth – and if so, at what cost?

I find, and I am pained to say this, that there are at times more similarities than differences between those who believe vehemently in the biomedical model, and those who argue passionately against it. Most people don't live in either of these camps, and have nuanced views about the validity of different diagnoses, or on the different impact they can have on our lives.

Most of us are familiar with the entrenched arguments of those who argue that mental health difficulties are psychiatric illnesses which require in the first and sometimes only instance a medical response. But for me, in a way more insidious and just as powerful, is the subtle judgment emanating from some people who strongly disagree with the biomedical model. There can be an evangelical fervour about those who argue that distress is not a symptom of a mental illness, but a natural response to trauma and adversity – and that medication therefore cannot be the answer to a problem which does not in fact exist. At conferences, in groups, on forums, I've seen people who identify as ill being shut down, or, perhaps worse, subtly patronised. There can be a sense that on this supposed journey we're all on, understanding yourself as mentally ill is an intermediate step towards a more enlightened state of being – and that one day we'll all understand that our distress is in fact a meaningful response to what has happened to us.

Is it possible to say that that the biomedical view is 'a lie', without saying that the people who believe in it have

been tricked or believe lies? Often, the question is fudged, with the vast majority of people saying they respect the choice of individuals to define themselves as ill if they choose. But it can be, in my view, a fudge, a sleight of hand – and the fudge is what people are responding to when they say they feel invalidated. Moreover, there is, for me, something deeply uncomfortable in witnessing a small group of people with power debating someone's experiences with another small group of people with power – and telling them that what they've believed until now is in fact a lie. This is very difficult to write, but it feels invalidating to me – in fact, it feels almost oppressive. Most of those who argue passionately against diagnosis have themselves experienced trauma and adversity. They have felt silenced. They believe that they are fighting for all those who have been oppressed in similar ways. And yet for me, as soon as we start to talk in absolutes and speak for others, we risk silencing people.

## How we talk about medication and diagnosis

I believe that in this polarised debate, both sides can be equally guilty of not respecting or not seeking to represent all the views out there. It can sometimes feel like we are so concerned with talking about the System, or the Evidence Base, or Big Pharma, or Discourses, that we talk in absolutes, and forget the nuance.



For example, it's quite clear to me that we can't talk about pills being bad or good for everyone. I think some people can find medication life-saving, others life-ending, many more something in-between. It depends on the meds. Talking about anti-depressants is different to talking about anti-psychotics. Talking about a depot is different to talking about a Prozac script from a GP. For some, it's literally life or death, salvation or abuse. For others, meds worked for a while, and then stopped working. For yet others, meds are forced upon them in a violation of their human rights. It's complicated and fraught.

For me, it feels unacceptable to write about psychiatric medication without referring to the deep suffering and anguish it has caused many – in the experience in itself, in the side effects, in the withdrawal and in the iatrogenic trauma. It is equally unacceptable, in my view, to write about diagnosis without honouring the myriad survivor stories there are out there of people feeling shamed, stigmatised, hopeless and stuck because of their diagnosis, and of people who describe the harm, distress and abuse they have suffered as a direct consequence of the medical model.

But for me, it's equally unacceptable to write about meds without acknowledging that for so many, they have proved to be helpful and lifesaving; that, weighing up the pros and cons, many decide to stay on them. Some people find diagnosis a necessary evil, a gateway to the support that they need. Many people find it validating, as it gives a name to the suffering and path towards recovery.

Diagnosis and medication, like any issue in mental health, take place in an emotional and political space. If you are accessing services or need a diagnosis to be eligible for benefits, diagnosis is not an interesting debate: it's about survival. Equally, there are also those who have found that it's only by challenging their diagnosis and politicising their madness that they have found a way to survive. The political context of diagnosis is that most people simply do not have a choice. The biomedical model is the dominant one, and the only one which many of us will come across when seeking help. Additionally, very few of us will be prescribed medication with full informed consent. The many side effects of medication, some of them life-altering, the addictive nature of some and the difficulties we may have in withdrawing from them; the lack of evidence around the efficacy of many drugs, the deep and complex ties between pharmaceutical companies and the medical profession which skewer objectivity – these are not issues most lay people are aware of. However, anyone who is writing about the mental health world will know that these are live, contentious issues, and not referring to them, even if we disagree with them, can only paint a partial picture of medication.

### **The single story and epistemic injustice**

Therefore the debate is often unfortunately framed in binary terms (for or against the medical model) and

both sides can be guilty of ignoring the evidence and testimonies which do not buttress their arguments. But for me, the challenge is actually deeper.

As a direct consequence of the debate being framed in binary terms, we're witnessing the emergence of the alternative single story. In the same way that the biomedical story has been the single story around mental health, so it can seem to many that the trauma model is attempting to usurp this position.

Once we opt for a single story around mental health, whether that's the story of illness, or the story of trauma, then we by definition exclude others. Arguing that all distress stems from trauma and adversity might not speak to those who experience their distress as spiritual renewal; those who see it as neurodiversity, as part of who they are and how they are in the world; those who understand it as a psychosocial disability; and of course those who see madness as an illness, a sickness of the brain. Many of us will probably see ourselves in some or all of these stories, a patchwork of identities. Some of us won't make sense of our distress. That's OK too. There are in fact as many stories as there are people. The single story, whether that of illness or that of trauma, doesn't honour this multiplicity and this complexity.

However, my main concern is how we're framing the debate around diagnosis in scientific terms. I deeply respect all of those who have put forward cogent and compelling arguments as to the scientific invalidity of diagnosis. But I'm worried that the logical consequence of this might be that we find ourselves only advancing alternative models to understanding distress and madness which are evidence based. But if we argue that we can only understand distress through a scientific model, albeit a more rigorous one than diagnosis, what does this mean for those who don't make sense of their experiences in this way? What happens to those who find spiritual meaning in madness? How can we hear and hold the stories of those who have radically different beliefs to ours, which defy current scientific thinking? I worry that stories about aliens, conspiracies and persecution might get re-worded and reframed, just like they have been by psychiatry.

The issue for me is not which story is true – because in a way they can all be true for us individually, and none of them are true for everyone. It feels urgent and important for me to rethink how we argue about diagnosis, to be aware of the consequences of framing the conversation in scientific terms, to explore what we mean by truth and to reflect on how epistemic injustice can be perpetuated.

### **Choice, not truth**

But these arguments do not (just) take place in lecture theatres. They are about people's lives. What really matters to me is practice.

On a practical level, it feels like so many are pushing for deep reform along specific lines, where, for example,

we drop the language of disorder entirely. I don't disagree that mental health services in the UK need deep reform, but I'm also interested in what is possible. On a personal level, there are few things I like more than the beauty of a clean and elegant argument. But I'm suggesting that it's entirely plausible to imagine an imperfect system which is utterly theoretically illogical and yet which offers choice: which offers medication, and trauma informed therapy, and CBT and mindfulness, and peer support and social prescribing. A system where the language of illness might sit side by side with the language of trauma, where we talk about the biological causes of mental illness as well

as the social causes of distress. It's utterly illogical and it's probably deeply undesirable for both biomedical and trauma purists.

But, here's the thing. I think we're very good at creating muddled and illogical systems. Why not this one? For me, this is about challenging the hegemony of the biomedical model rather than its truth. Let's try and chip away at the power of the diagnostic mode I – position it as one story amongst many – rather than try and see it swept away in a trauma informed revolution. Let's move the argument away from lecture halls, conferences and Twitter – and into people's lives. Let's fight for choice, not truth. ■

# Is the NHS a Cash Cow?

LIAM KIRK

*The NHS is increasingly reliant on the dedication and skills of low paid workers, whilst handing over enormous sums of money to private agencies. Is this ethical, asks Liam Kirk?*

There's no money in mental health services – that's the mantra. For one caring and dedicated nursing assistant at the Gordon Hospital, London SW1 the mantra holds true, because he is prepared to be exploited financially. Willing to work long hours at weekends, and unlike many who toil on an acute psychiatric ward, he mixes with the patients in an open and comfortable manner.

One Saturday evening (in 2012), he passed around two items sent by his nursing agency: the invoice for his services, sent to the hospital, and his payslip, sent directly to him. . What they revealed was the largest grab of pay, percentagewise, by any employment agency that I have ever known.

In 1992, my flatmate worked at Barings Bank (at the time a highly respected merchant bank). Then, without warning, he was fired under acrimonious circumstances. In the recriminations he complained about his low pay, only to learn that the employment agency that represented him was charging top dollar, keeping 90% of what they charged Barings Bank for themselves and passing on a paltry 10% to him. Natural justice demanded that it should have been the other way around. This was the largest pay-grab of any agency I had come across until the nursing assistant showed me his paper statements.

These statements revealed the nursing agency charged his labour to the NHS to the tune of £125 per hour. By contrast, his hourly rate of pay was a puny £8.95 (before tax). They failed to pay him the London Living Wage. Each 12 hour night shift he worked cost the NHS £1500, making a total sum of £3000 for the weekend,



Photo by Jill Anderson

while his gross pay for the weekend came to £224.80: an agency pay-grab of over 90 per cent.

The nursing assistant was not bitter or even downhearted by this knowledge, rather he was just glad to be working. There are not many who would work the antisocial hours he does for so little. I was left to ponder: how long can the NHS afford to be so profligate?

The more I learn about psychiatry the more I realise that the NHS is being used by employment agencies as a cash cow. ■

# LETTERS

## A service user's experience of the RADAR study

Dear Asylum,

In the previous issue of *Asylum* ('On the RADAR' 25.2: 16) I wrote about my involvement with the RADAR study into antipsychotic discontinuation and reduction. It is a Dr Joanna Moncrieff initiative, where the intention is the patient and the physician work together to create a plan of a gradual reduction of the patient's antipsychotics until the patient becomes drug free. This ground-breaking study has profound implications for the future treatment of those who experience a psychotic episode.

I expected an unhurried reduction in medication with a tapering off with specially prepared micro-doses of olanzapine, that is, the size of the dosage of the drug is smaller than the smallest commercially available tablet. Psychiatrists who as a matter of routine wean their patients off major tranquilizers, antipsychotics, and antidepressants use this methodology.

Sadly, however, in my review of my gradual withdrawal I was told by my consultant 'you will go straight from being prescribed 5 milligrams of olanzapine to zero'. His position on the wholesale withdrawal is

not co-ordinated with RADAR or any other psychiatrist with a history of weaning patients off medication. Aside from fretting how unsupportive my family are, I fret about developing a withdrawal-induced psychosis. But my psychiatrist is a withdrawal syndrome denier. According to him, if an individual loses lucidity months after stopping an antipsychotic, or even a cocktail of psychiatric medication, the individual is unwell from an underlying psychiatric condition, not as a result of the drugs leaching from the body thereby holding in abeyance a withdrawal-induced psychosis that comes to the fore once the individual's system is free of psychoactive substances.

In my view, suddenly withdrawing all medication is an irresponsible approach to what is intended to be a gradual reduction in medication. If this approach is being applied to me, then it is also being applied to others involved in the RADAR research study. This potentially compromises successful outcomes, and inflicts damage on the lives of individuals taking part in the study.

*Liam Kirk*

## Let's talk about fear of the System

Dear Asylum magazine,

I strongly agree with Liam Kirk that fear of the system would be worth covering in a future issue ('Is fear the missing link?' *Asylum* 25.2: 28). This has been a big part of my experience of having used mental health services over the last eighteen years. I can think of (at least) three reasons why it needs talking about.

First, there is the general fear among people that if you act strangely or differently, you'll 'end up in the loony bin'. When I was at school in the eighties two of the worst things another kid could say were to make a sound that meant you were gay, and to say 'Fulbourn' in a 'stupid' voice, which meant you were mad. Fulbourn was the mental hospital near Cambridge where I went to school. I believe that the overall effect of the fear and stigma around mental illness, and around the mental health system, is to increase social conformity and the fear of difference, which is not a good thing.

Second, a psychiatric admission is traumatising for many people, as it was for me, and once it has happened to you once, the fear of it happening again can hang over you for a very long time. Although I have had a less difficult relationship with the psychiatric services than some people whose stories I have heard, it is only in the

last year or so that I have begun to get over this fear, seventeen years after I was last sectioned, and I still have episodes where I find myself in fear that it will happen again. The long-term effects of this on someone's life aren't recognised in the standard debates about 'harm versus benefit' as to whether coercion should be allowed in mental health care.

Third, it is a strange thing to be in a therapeutic relationship with someone who has the power to remove your freedom. However well-intentioned they may be as individuals, I don't think people in the mental health professions fully recognise how the fear of being sectioned can hang over these relationships and distort them against their intended purpose. People suffering from mental and emotional distress are encouraged to talk to someone in the psychiatric services, but then it is hard to open up to someone when you know that if you say the wrong thing, that could result in you being locked up or forced to take medication.

For these reasons and more, I strongly support the idea that this is something that would be worth covering in future.

Yours Sincerely,  
*Andrew Baxter*

# Creative Writing

## Look But Don't Touch

*Joanna Marsh*

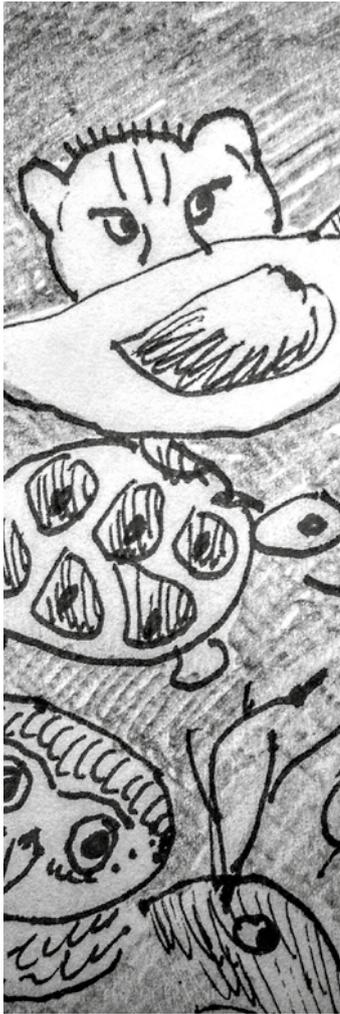
I want to get close  
 Spend time with you  
 In a positive mind  
 I can see this happening  
 However  
 In the cold light of nightfall  
 I know the truth  
 How can I show you all I have  
 So you won't run away  
 Because, really I am a monster  
 Covered in scars and hair  
 With a disfigurement to put off every man  
 This burning desire has to fade  
 Leave me in peace  
 So I can focus on just me.



## Breakdown

*Roy Hayde*

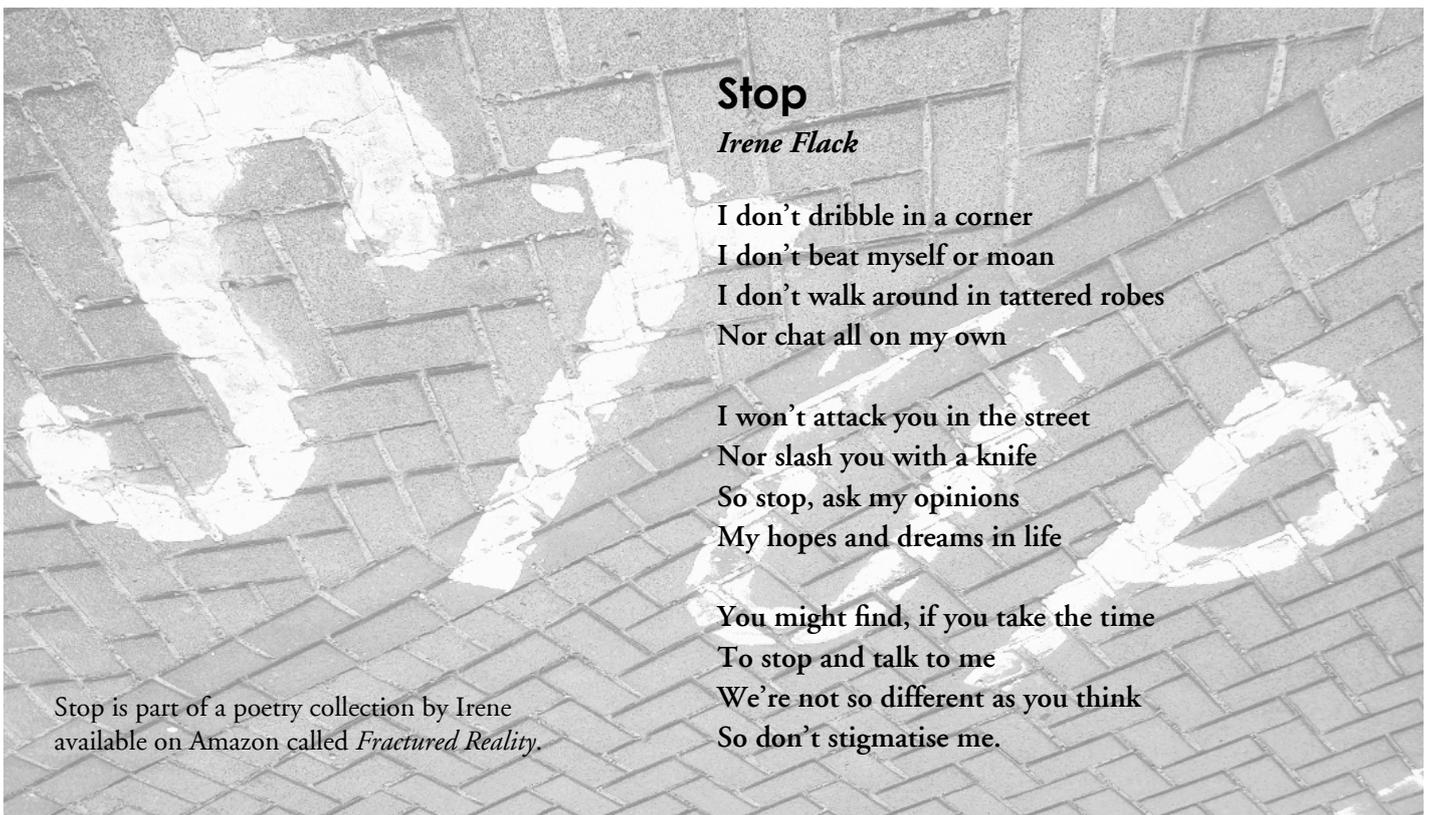
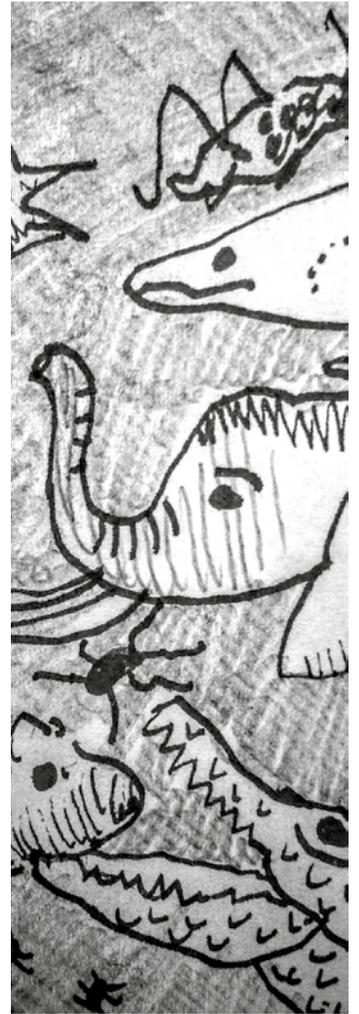
Weekends come and weekends go.  
 Different kinda life to the one I used to know.  
 Since all the madness things have changed,  
 I really don't know if they will ever be the same,  
 Used to be active used to have fun.  
 Used to sit around and bun, bun, bun.  
 I don't smoke no more cause it intoxicate the brain  
 something that could quite literally send me insane,  
 Friends stick around glad that they care.  
 Don't know what I would do if they were not there.  
 On medication one tablet a night,  
 put on so much weight it cause quite a fright.  
 Deep in my thoughts have to keep strong  
 sometimes I wonder where it all went wrong,  
 Was it stress like the doctor said  
 or was it a depressed state deep in my head.  
 I guess some things you'll never ever know  
 It's just so funny how life can go.  
 Prada, stone island clothes I used to wear,  
 when I was on benefit they seem pretty dear  
 renegade Eminem sending me crazy  
 why did I become so bloody lazy.  
 Was it the meds that got me in this state  
 or was it pure and simple that I put on this weight.  
 People say rocker pull yourself together  
 but sometimes I fill like I'm rougher than leather.  
 Going insane, insane is a crazy thing  
 whole heap of problems it can bring  
 Thank God for family thank God for friends  
 All the things that help you mend.  
 Stopping my mind from a Uri Geller bend.  
 Time on my hands to work out the end.



## ACROSTIC ECT

*Oliver Swingler*

Elephants don't arrange to have memories wiped out  
Larks don't sing tunes that awaken chronic doubt  
Electric eels don't give shocks to others of their kind  
Cheetahs don't advise speedy cures that damage the mind  
Tortoises don't punish those who are a bit slower  
Reindeer don't stigmatise whatever they see as lower  
Owls don't manufacture darkness for hunting their prey  
Crocodiles don't submerge animals in terror for pay  
Oysters don't clam up if treatment is put to the test  
Nightingales don't wilfully disturb other creatures' rest  
Voles don't produce the dependence on hibernation  
Unicorns don't pretend what's real is an invention  
Locusts don't strip bare while announcing that it's healing  
Spiders don't weave to confuse other spiders' feeling  
Iguana don't make ugly innocent hope and belief  
Vultures don't pick at the bones of those suffering grief  
Earthworms don't aim to undermine the vulnerable naïve  
Tigers don't lurk behind caring postures that deceive  
Hornets don't sting to sell results in published research  
Eagles don't use old, weak ones to establish their perch  
Rattlesnakes don't have hidden agendas that cause fear  
Ants don't build nests that alienate every ant near  
Psychiatrists and their drugs often do – they've done it to me  
Yours may be the next mind to be raped by ECT



## Stop

*Irene Flack*

I don't dribble in a corner  
I don't beat myself or moan  
I don't walk around in tattered robes  
Nor chat all on my own

I won't attack you in the street  
Nor slash you with a knife  
So stop, ask my opinions  
My hopes and dreams in life

You might find, if you take the time  
To stop and talk to me  
We're not so different as you think  
So don't stigmatise me.

Stop is part of a poetry collection by Irene  
available on Amazon called *Fractured Reality*.

# WORKING TOGETHER FOR CHANGE

Patrick Wood reflects on the history and current state of the independent mental health service user/survivor movement

There's nothing new about user controlled mental health groups and survivor activism. *Survivors Speak Out* was formed in 1986 and it's more than 30 years since the group's national conference met in Edale to unanimously agree its 15 point charter of needs and demands. It's interesting to reflect on the extent to which these demands have been met. You could argue that considerable progress has been made in certain areas, such as recognising and using people's firsthand experience of emotional distress for the good of others and user representation on statutory bodies. But there has been little movement with regard to the more radical idea of the provision of refuge, planned and under the control of survivors of psychiatry, and the provision of choice of services – including self-help alternatives – remains severely limited for most people who come into contact with the mental health system.

There were mental health groups that focused on the views and experiences of service users before *Survivors Speak Out* but the period following its formation marked the high point of independent user group activism at both national and local levels. Despite being formally part of Mind, the user group *Mindlink* (which developed around the same time as *Survivors Speak Out*) enjoyed a great deal of autonomy and did much to support the growth of local groups throughout the country as a result of its ability to host regional gatherings of service users. The National Advocacy Network Steering Group, which emerged from the same grassroots movement as *Survivors Speak Out*, became the Sheffield based *UK Advocacy Network* (UKAN) in 1993, which was instrumental in enabling hundreds of local advocacy projects, patients' councils, service user forums and mutual support groups to flourish. Despite not winning the argument that peer advocacy represents the most empowering and therefore effective form of advocacy (because professional decision makers were not prepared to listen), UKAN's landmark 'Advocacy – A Code of Practice' established core principles that form the bedrock of mental health advocacy to this day. *Survivors Speak Out*, *Mindlink* and UKAN were joined by high profile direct action networks like *Reclaim Bedlam* and *Mad Pride* in the mid to late 1990s.

These groups were characterised by their diversity and the wide range of their interests. The main thing they shared in common (with the possible exception of

*Mindlink*) was their independence, which gave them the freedom to decide for themselves and the liberty to criticise those elements of the mental health system that were commonly experienced as oppressive. Although they featured high profile and charismatic individuals, they were committed to collective endeavour and valued everyone's contribution. They provided invaluable opportunities for users and survivors to learn from each other and performed a kind of consciousness raising function that has yet to be properly recognised.

The factors that led to the diminishment of national groups have also had a local impact. I live in Sheffield, where a number of independent user controlled initiatives have operated since that late 1980s, including the user run day centre, *McMurphys*; MHAGS (which started out as an organisation run by a carer, with the aim of securing concessionary bus passes for service users, but which developed into a group providing social opportunities for the hundreds of members on its books); SODIT; SUST (Sheffield User Survivor Trainers); Sheffield SHIP, which supported the development of a dozen mental health self-



help groups in its 18 month history; and *Your Voice*, the mental health magazine that celebrated 20 productive years before being forced to close through lack of funding. Sheffield was also the birth place of the *Hearing Voices Network* and witnessed the launch of *Asylum* in 1986.

Sadly, the future of the independent locality based groups that still exist is precarious. Recent research by the *National Survivor User Network* found that more than a quarter of its member groups had been forced to close since January 2015, often losing out to larger organisations that are not user led, but which have successfully co-opted the language of peer support, advocacy, involvement and recovery.

Once they're gone, these organisations will be impossible to replace; their values, ethos and commitment to securing the human rights of mental health service users will be lost to history, and people with lived experience of mental health problems will have to negotiate a diminished network of support. Now is the time for people to come together to stand up for the unique contribution that independent user controlled mental health groups can make and to work together to do all they can to secure the future existence of these threatened resources. ■



Photo by Patrick Wood

*Patrick Wood has been actively involved in mental health survivor groups at local, regional and national levels since 1989. He was Training and Development Worker for UKAN from 1995 - 2007 and is a founding member and co-ordinator of SUST (Sheffield User Survivor Trainers), which was formed in 2007.*

**In the next issue of *ASYLUM* the veteran survivor activist Peter Campbell will reflect on the early years of the user/survivor movement...**

## ***Celebrating 25 years of PCCS Books Conference: The Future of Counselling? November 1st, 2018 – Manchester***



### **Morning session – Chair: Stephen Joseph**

**What makes counselling worthwhile? – Pete Sanders**  
Pete will critically examine the place, meaning and purpose of counselling in 21st century Anglo-American society.

**Power, counselling and class – Gillian Proctor**  
Gillian will explore the dynamics of power in the therapy relationship, with particular reference to class.

**Critical mental health nursing: politics and compassion – Stephen Williams**  
Stephen will look at how mental health nurses can transform their practice to become critical, reflexive providers of care for people in emotional distress.

**Therapy as a human-rights intervention – Col Bashir & Prossy Kakooza**  
Col and Prossy will talk about the importance of a human-rights framework when offering therapy to people who have fled persecution and torture to seek safety in the UK.

### **Afternoon session – Chair: Gillian Proctor**

**Neoliberalism and why it matters – Philip Thomas**  
Philip will explore how neoliberalism, and the resulting 'malignant individualism', is infecting mental health policy and provision, and society more widely.

**McMindfulness and the work cure – Steven Stanley**  
Steven will critique the current 'turn to mindfulness' in the context of consumer capitalism, therapeutic culture and religion.

**Drop the disorder – Jo Watson**  
Jo will explore how the language of diagnosis and disorder has infiltrated counselling and psychotherapy, and why we need to challenge the labels.

**VENUE: KINGS HOUSE CONFERENCE CENTRE, MANCHESTER, M1 7HB**

**Ticket and booking information can be found at [www.pccs-books.co.uk/conference](http://www.pccs-books.co.uk/conference)**

# CAMPAIGN TO END MECHANICAL RESTRAINT IN SPAIN

**#0Contenciones (zero restraints)** is a campaign to end the practice of mechanical restraint in Spanish psychiatric facilities. Locomún, an active mental health collective, initiated this campaign. Their objective is to mobilise people and provide information and campaign materials.

Here is what they say:

Mechanical restraint consists in tying a person to a bed with straps across the waist, on the wrists and ankles, to impede moving freely. The person may be tied up for hours or even days, depending on the decisions of hospital staff. It causes suffering, trauma and even death. Mechanical restraint in Spain is unregulated and often covered up. It is not possible to access files explaining who is restrained, by whom, why and for how long, and least of all – how. This means instances of serious injuries and fatalities go unpunished.

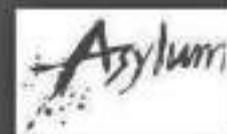
In theory, we are strapped down as an extreme measure to prevent us from hurting ourselves and / or others. In reality, we are strapped down when staff are frightened and do not know how to deal with us, when they do not understand what we are asking for, or when they cannot tolerate our level of distress. Or it may be to punish us if we break a hospital rule. These decisions are based on power, control and fear. They have nothing to do with therapy. Restraint saves having to face the other person as a human being and be moved by the connection. It

is often argued that it is used due to “lack of resources”. Yet restraint costs money, that could be used to develop more humane alternatives.

Physical restraint can cause bruises, fractures, muscle atrophy, coma, asphyxia by aspiration, skin and respiratory problems, hypercatabolic states that weaken the respiratory muscles, dehydration, incontinence, self-injury and death. Despite attempts to cover up deaths inflicted by this practice in the State’s psychiatric units, in 2017 two deaths caused by physical restraint were reported in the media.

On a psychological and human level, being strapped down wounds our dignity in a way that is often incurable. It damages our emotions, our disposition towards ourselves and towards others. Not only is it not therapeutic (and the thought that it could be is, without a doubt, the greatest madness), but it also undermines any previous therapy that we have done and destroys any trust we may have had in the mental health system. It adds to our suffering and trauma, and takes us even longer, if ever, to recover.

The United Nations has stated that immobilizing people “with psychosocial disabilities”, even for a short period of time, can amount to torture and mistreatment. They have said physical restraint is the result of systemic failure to protect the rights of individuals. The World Health

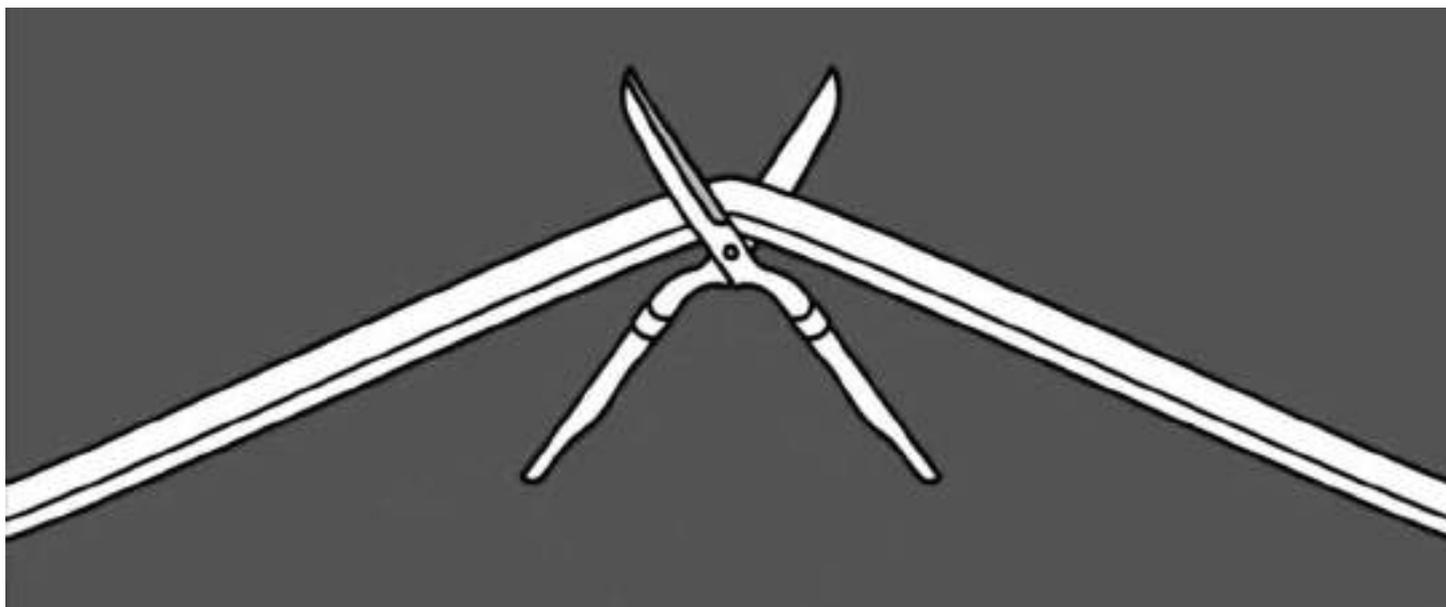


[asylummagazine.org/](http://asylummagazine.org/)

*Defenders of coercion typically argue that it is a necessary evil, because patients do not know what is in their best interests. This argument, of course, assumes that patients are irrational in rejecting psychiatric care, that psychiatric treatments such as antipsychotic medication are always beneficial, and that patients compelled to receive treatment do better in the long-run".*



#0CONTENCIONES



Organization affirms that these practices are never justified, even in extreme circumstances.

There are always alternatives to tying up another human being and places which have eliminated the practice clearly demonstrate this: Iceland, United Kingdom, Mendrisio (Switzerland) or Trieste and Modena (Italy). Alternatives like listening to us, giving us a hug if we need it, reassuring us with words or gestures, stay nearby or let us calm down alone in a quiet environment where we feel safe. Accompany us in our crisis until it passes. In extreme cases physical restraint can be done with the body (provided it is done in a respectful way) – never with straps, and always for the shortest possible time.

We also want to draw attention to the practice of so-called “chemical restraint” where straps are replaced with high doses of sedative drugs that paralyze our bodies and our

minds, putting our health and our lives at serious risk. The use of a medication that is not part of the person’s usual treatment, to limit their movement or control their behaviour, is not a reasonable alternative.

We want responsible parties in psychiatric facilities to refuse to restrain patients. But we also demand regulations prohibiting the use of all forms of restraint. We demand an end to impunity in the cases where injury of any kind was been caused by physical restraint. We want this practice abolished and sent to the garbage dump of history.

We call on readers and supporters of Asylum magazine to support our campaign ---

E-mail: [colectivolocomun@gmail.com](mailto:colectivolocomun@gmail.com)

Website: [0Contenciones.org](http://0Contenciones.org)



# NEWS & REPORTS

## RESTRAINT: RECORD NUMBER OF INJURIES

Restraint at mental health units injured 3,652 patients in the year to March 2017, according to the Crisis Prevention Institute (CPI) drawing on data from 48 of England's 56 mental health trusts. Overall, restraint was used 97,000 times, with 2,600 staff also injured. This is far more than previous studies suggest, and raises serious questions about the effectiveness of the government's drive to reduce the use of techniques which can be traumatic for patients and even endanger their lives. Worryingly, 13% of Trusts do not have a policy on restraint, despite it being a requirement since 2014.

Liberal Democrat MP Norman Lamb commented that – whilst the dramatic increase can be explained, in part, by improved reporting – the 'scale of injuries is horrifying'. The increase in the use of restraint can be seen as one result of the strain that Trusts are under, with bed occupancy rates high and the use of agency staff. It amounts, Lamb said, to 'a serious and unacceptable breach of people's human rights' – particularly, in view of the fact, that some of those against whom restraint is used have suffered prior trauma and 'for them, restraint amounts to an assault' and undermining any possibility of trust.

Campbell, D (2018) Figures reveal 'alarming' rise in injuries at mental health units. *The Observer* 10 Jun.

## RESTRAINT: SENI'S LAW

'Seni's law' was inspired by 23-year-old Olaseni Lewis who died of a heart attack in 2010, after being restrained by eleven police officers in Bethlem Royal Hospital, Beckenham. The officers were judged to have used 'excessive force' and yet none have been prosecuted. Seni's law would ensure better monitoring of the use of force against patients in mental health units. In July, Marcia Rigg, the sister of Sean Rigg who died after being restrained in 2008, was in the public gallery along with Seni's parents, Aji and Conrad Lewis, to see this new law – The Mental Health Units (Use of Force) Bill – receive an unopposed third reading in the Commons. It should become law after going to the Lords.

This legislation was brought forward as a Private Member's Bill by Labour MP Steve Reed, who praised Mr Lewis' parents for their seven year campaign. As a result of this, police officers will be required to wear body cameras when carrying out restraint, unless there are legitimate operational reasons for doing otherwise. And,

whereas previously there was no statutory requirement for an inquest following a death in a mental hospital, now any non-natural death in any mental health unit will automatically trigger an independent investigation.

Seni's law: Commons approve mental health unit reforms (2018) *BBC News* 6 July. Sabbagh, D (2018) MPs pass mental health restraint bill after filibuster fears. *The Guardian* 6 Jul.

## RISE IN DEATHS OF HOMELESS PEOPLE WITH MENTAL HEALTH NEEDS

Research by the homelessness charity St Mungo's found that 80% of rough sleepers who died in London in 2017 had mental health needs, compared with 29% in 2010. There is concern that specialist services are not reaching those who need them. 70% of outreach workers surveyed said access to mental health support for people sleeping rough had deteriorated over the last five years. One commented on the absence of on-street mental health services, the lack of bed spaces, and how homeless people with mental health needs are falling between the gaps in services.

Earlier this year *The Guardian* and the Bureau of Investigative Journalists revealed that 340 homeless people have died on the streets or in temporary accommodation in the last six years, surging from 32 in 2013 to 78 in 2017. A further 59 deaths have been recorded so far this year, already more than for the whole of 2016. In London, the only area where a local authority actively records homeless deaths, 158 people died between 2010 and 2017, an average of one death a fortnight. These figures come amid concern about the growing number of deaths amongst homeless people and that, out of the hundreds of such deaths in recent years, only eight resulted in a review.

Marsh, S & Greenfield, P (2018) Deaths of mentally ill rough sleepers in London rise sharply. *The Guardian* 19 Jun.

## IMPROVING THE MOVE FROM CHILD TO ADULT SERVICES

Every year, 25,000 young people with mental health problems make the transition from child to adult services. An inquiry by the Healthcare Safety Investigation Branch (HSIB) reveals that care often breaks down at this point, at a time when young people are most vulnerable.

HSIB is a new body set up to carry out 'no-blame' investigations, so as to help the NHS to learn from its mistakes. Its report recommends a more flexible approach to this move into adult services: replacing the sudden cut-

off point at 18 (or even 16 or 17 in some areas) with a wider window, so that transition can take place gradually up to the age of 25.

Triggle, N (2018) Mental health: Children failed at vulnerable point. *BBC News* 10 July.

## POST-CODE LOTTERY FOR TALKING THERAPY

Improving Access to Psychological Therapies (IAPT) was introduced in 2008 to improve treatment for anxiety and depression, usually cognitive behavioural therapy or self-guided therapy. Research by the House of Commons library now finds that in some places people face delays of up to four months before starting 'talking therapy'. Last year, patients in Leicester waited an average of 135 days after referral for their first appointment; this contrasted with just five days at Stoke-on-Trent, the shortest waiting time.

Mental health charities are uneasy about the delays. "IAPT was introduced to cut waiting times and expand access, so it is worrying to see people waiting up to four months for therapy," said Brian Dow, director of external affairs at Rethink Mental Illness. "In four months your mental health can get a lot worse, and people should be able to get the treatment they need when they need it." Mind said the findings should prompt NHS England to introduce a maximum four-week waiting time for IAPT.

Campbell, D (2018) Patients seeking mental health treatment face delays of up to four months *The Guardian* 26 Apr

## EUROPE'S MH FACILITIES MOSTLY SUBSTANDARD

Teams of trained assessors were recently sent to 75 mental institutions across 25 European countries to see whether they met the standards set out by the UN Convention on the Rights of Persons with Disabilities (CRPD). Nowhere fully met the care standards set by the World Health Organisation (WHO). While some trained staff to deal with crises, create individual recovery plans and provide access to legal support, others failed, even partially, to meet such standards.

There was widespread failure to safeguard residents' human rights, with many institutions described as "shocking": broken windows, bedbug infestations, patients sleeping on floors, lack of toilet paper, and many facilities not even having toilet doors, shower screens or curtains. At most sites patients were not free to roam, and most placed restrictions on patients' communications with people outside, while only a few respected their right to privacy. In general, staff were found to treat patients well,

but neglect, isolation and even sexual abuse of female patients, was found in some institutions.

Few institutions offered patients opportunities for learning or occupational training skills. Moreover, few offered help to rehabilitate patients back into the community. Staff often saw admission as a permanent step, due in part to lack of supported housing.

The UK did not take part in this particular study, but Liberal Democrat MP, and former health minister, Norman Lamb commented that many of the report's "dreadful findings" reflected situations found in parts of the UK. He concluded that "the treatment of people with mental health problems as second-class citizens is a global scandal which demands a global response."

Davis, N (2018) Europe's mental health institutions uniformly substandard, says WHO. *The Guardian* 5 Jun.

## PERINATAL MENTAL HEALTH SERVICES FOR ALL?

In the last issue of *Asylum* there was a News item about there still being no help at all for one-quarter of women in need of perinatal mental health services. Now, at a cost of £23m, NHS England is putting into effect a second wave of community perinatal services. The aim is to ensure that new and expectant mothers will be able access such services in every part of England by April 2019. This is part of a wider package of measures aimed at providing care to 30,000 more women by 2021.

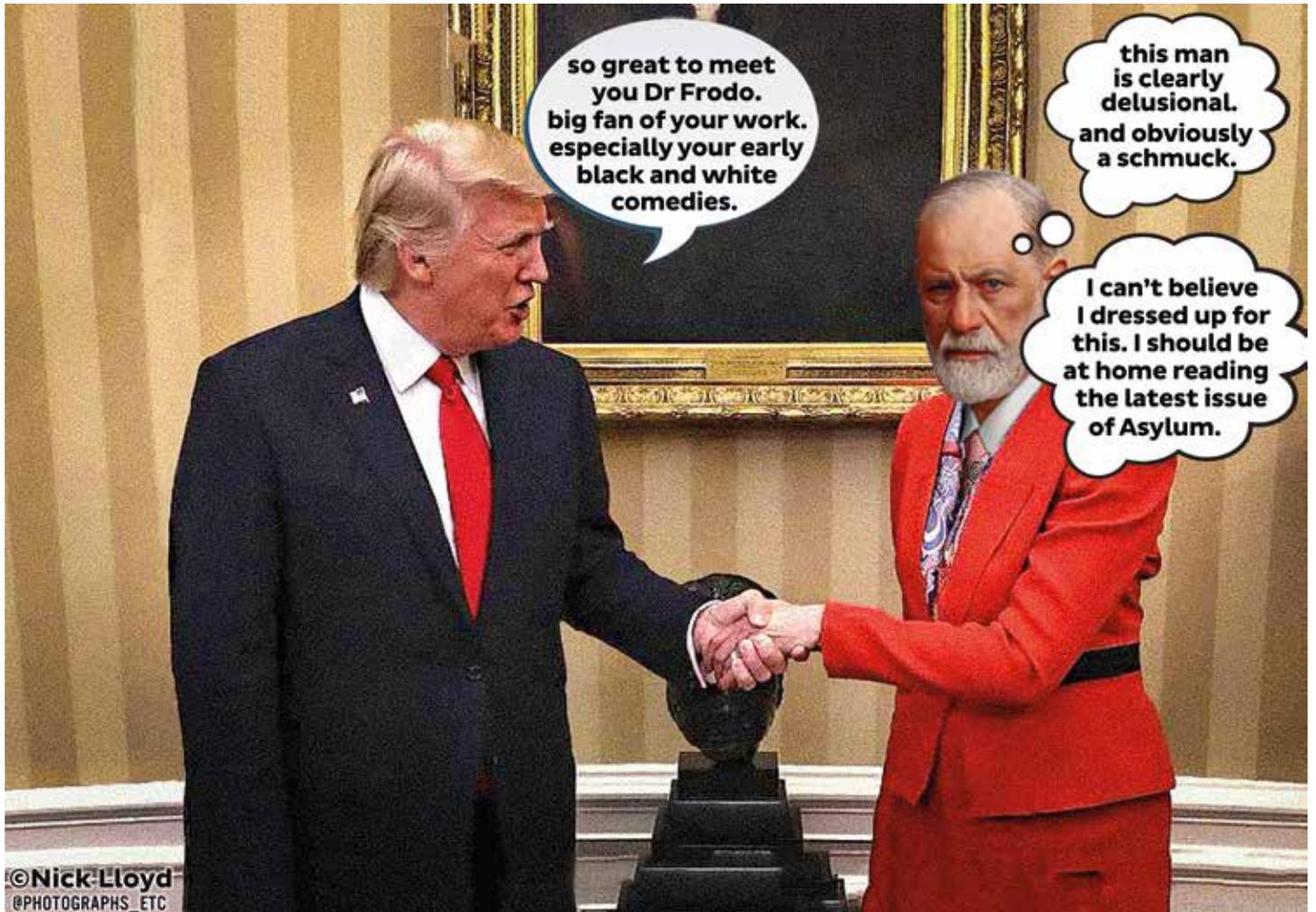
Rawlinson, K (2018) NHS to make perinatal mental health available across England. *The Guardian* 8 May.

## LAUNCH OF MAD IN ASIA



An e-zine with the aim of contributing to changing the narrative about madness and mental distress in the Asia region has been launched. *Mad in Asia* is led by persons with psychosocial disabilities from Asian countries. It hopes to showcase narratives that are contextually relevant to the Asia region, with a focus on the human rights of persons with psychosocial disabilities. It is a development of TCI Asia, in partnership with *Mad in America*, with financial support from the *International Disability Alliance*.

<https://madinasia.org>



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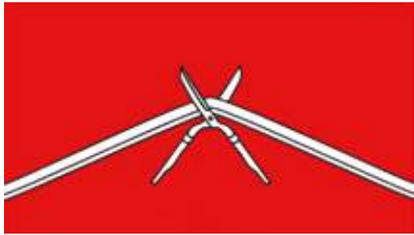
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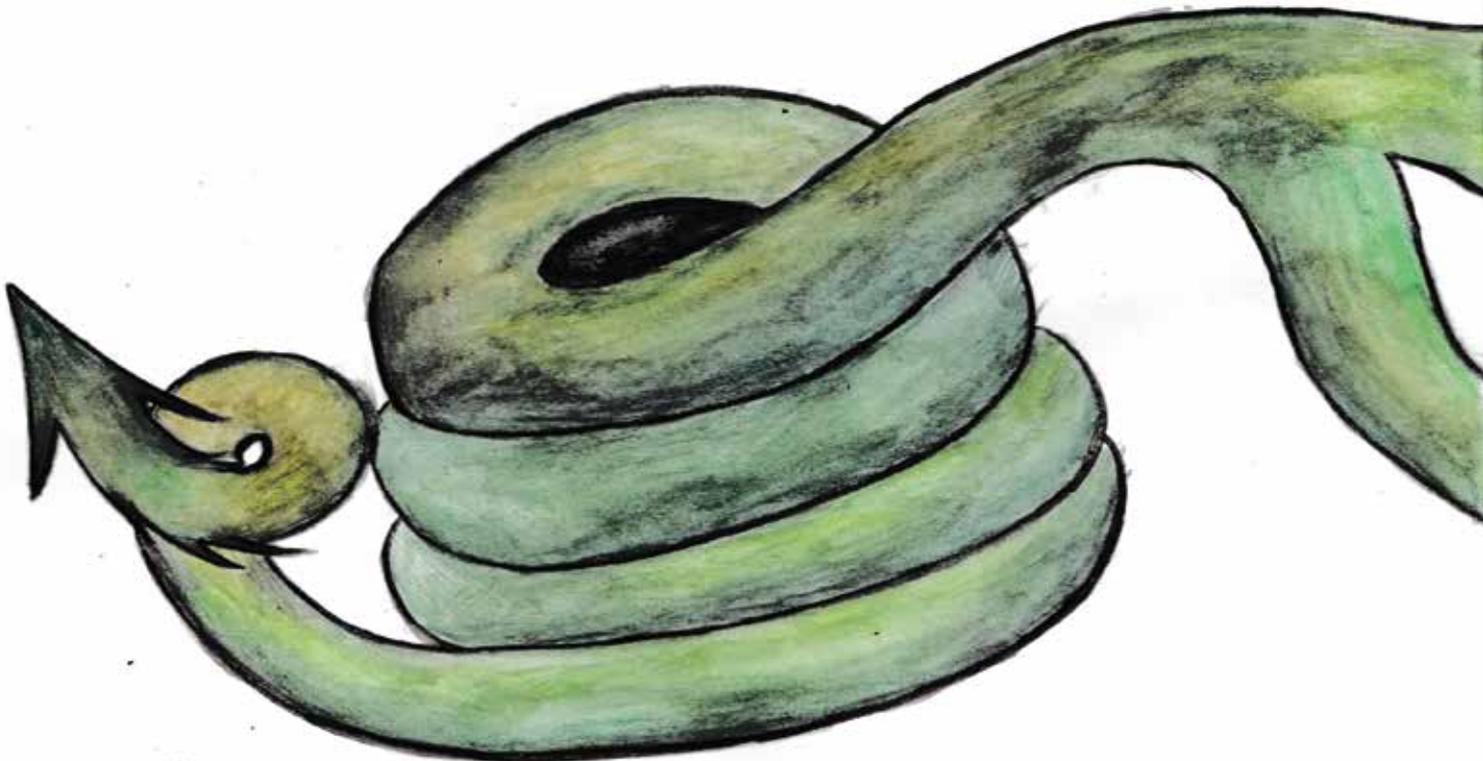
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