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the magazine for democratic psychiatry

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**LAW REFORM, MEDS AND THE
CHALLENGE OF DEMOCRACY**

Just Rather Scream Into The Winter Night

VAL POSPISCHIL



“I am happy...” – “Maniac!”

“I’m sad...” – “Depressive!”

“Sometimes I’m happy, sometimes sad...” – “Bipolar!”

“I am worried...” – “Inferiority Complex!”

“I don’t know what to say...” – “Self Esteem Disturbance!”

“You frighten me...” – “Anxiety Disorder!”

“This doesn’t feel real...” – “Reality Distortion!”

“You are like a monster...” – “Schizophrenia!”

“I’m getting angry...” – “Aggressive Assertiveness Disorder!”

“I feel like pushing you off your chair...” – “Violence Fantasies Psychosis!”

“I just can’t stand it anymore...” – “Denial Defence Mechanism!”

“I will leave the room...” – “Avoidant Escapism Personality Disorder!”

“I feel like hitting my head against the wall...” – “Self-Injury Disorder!”

“I want to drink a pint of beer...” – “Alcoholic!”

“I want to smoke a spliff...” – “Drug Addict!”

“This whole room is eerie and suffocates me...” – “Obsessional Neurotic!”

“I wished you would bite into your own tongue...” – “Sadist!”

“Then I stay to get even more humiliated...” – “Masochist!”

“Doctor, please is there anything I can do to be more normal for you?”

“Yes, accept everything I tell you and take your pills!”

“Any other advice, Mr Doctor?”

“Get private health insurance soon - if you are such a hypochondriac!”



The magazine for democratic psychiatry

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Send creative writing and poetry submissions to:
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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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Editorial

We open this issue with an article by @validconsent which underlines the profound challenges involved in our notion of 'democratic psychiatry'. We couldn't have put these challenges better ourselves. How does one provide a safe space for challenging and diverse opinions to be expressed: at a conference; on a psychiatric ward; on social media; or in the pages of our magazine? Those questions go to the very heart of Asylum's collective struggle. They are crucial for those involved in the review of the Mental Health Act, as well as those who are framing responses to it. They are also key to understanding how debates about psychiatric medication can be conducted in ways that are respectful of deeply held and diverse views. These two subjects take up the majority of this issue of Asylum.

The interim report on the Mental Health Act Review is out now. Unfortunately, but perhaps not surprisingly, two main demands referred to in this issue of Asylum – making legislation rights-based and consistent with the

UN Convention on the Rights of Persons with Disabilities, and the idea of a capacity based Fusion law – have already been taken off the table (see the recent blog by Akiko Hart on www.madinamerica.com). Wide-ranging reform looks increasingly unlikely, though the suggestion that Community Treatment Orders may be abandoned will be heartening to many campaigners. A major question remains: how, in this current climate, will people be able to access support at all, and how can legislation be used to help or hinder that?

We are pleased that some subjects raised in previous issues of the magazine are taken up in this issue – including in our letters pages. Whatever the challenges of democracy, we still endeavour to provide an open forum for debate, so please continue to send us articles, poems, stories, photographs, cartoons, letters, book reviews and drawings. Maybe you could pass on this issue or pin up a flyer (included in this issue).

Jill Anderson and Helen Spandler, on behalf of Asylum magazine

So what is Democratic Psychiatry?

@validconsent

One of our readers who came along to Asylum's conference ASYLUM: Action and Reaction reflects on what democratic psychiatric might actually mean. We welcome more reflections on this theme.

The word psychiatry comes from the Greek roots '*psykhe*', meaning mind, and '*iatreia*', meaning healing, suggesting that literally '*psychiatry*' is '*healing the mind*'. That meaning of the word does not seem to have captured us as a society, as has the idea of psychiatry being '*the study and treatment of mental illness, emotional disturbance, and abnormal behaviour*'. That definition plunges us directly into judgements of normality, questions of who has the power to make those judgements and what end those judgements serve, as well as the use of power to enforce those judgements. The way psychiatry currently operates in our society might be a product of a form of democracy – because it has arisen from the way a majority might like to treat a minority – but it does not seem to me to be one that is democratic in its relationship to those who might be on the receiving end of its services.



Looking back to last year, I think I decided to go to the conference to see what it was all about because the word '*democratic*' alongside the word '*psychiatry*' was so intriguing. I also remember that I was concerned about coming to the conference as psychiatry in our society is surrounded in silencing and bitter conflict: those who believe their lives were saved by diagnosis and those

who feel diagnosis is a form of oppression that caused them profound harm; those who believe the evidence for medication is deeply flawed and misleading, alongside those who feel that the drugs worked for them; those who believe that psychiatry has committed (and continues to commit) serious human rights abuses, and those who feel that those very same restrictions of rights saved their lives; those who can only feel safe if some things are not spoken about and those who feel that their way to healing is through learning how to speak about their experiences; those who believe that when people are in an altered state they are not responsible for their actions, and those who believe that this position confuses our approach to healthcare with our approach to criminal behaviour in a way that is hopelessly muddled.

The dangers for those participating in conversations about psychiatry seem to be immense: the dichotomies are so profound that it so often seems that one person's needs can only be met at the expense of another's. It seems that as one person reaches towards increased safety for themselves, another person is pushed towards experiencing terror and threat. Yet the opportunities for making valuable connections which could potentially create something that might work better are also tremendous. These are fraught and painful tensions to hold. The tensions are so unbearable that – even in a more democratic space, away from the mental health system, where there are more voices to be heard and more opportunities to speak – I wondered if a group of people could possibly bear them.

I do think that the people organising the conference, who were volunteers, put in their personal effort and time because they believe in the project of democratic psychiatry. I do think that the people speaking said things that may have very little forum in mainstream mental health discourse. I did get to hear people who were articulate, brave and interesting. I do think the conference was well organised, well thought-through and enabled many different speakers to present their ideas. I do think that the ideas available at the conference were ones that might otherwise never be heard. The presentations included Soteria, the way the diagnostic manual is structured and community networks. There were opportunities to learn about creative responses to confusion and distress which seem squashed out of existence in our current top-down, power-over Mental Health system. Any place which exists and allows this exchange of information is essential and important. This needs recognition and celebration.

I don't think we managed to make gentle space.

These impressions meant that after the conference I was left thinking: Why did I feel we did not quite manage to develop a space for Democratic Psychiatry? Democracy is a deeply valued term, but it also seems to be one of the vaguest political terms in our current social world.

In my reflections I considered that perhaps it was the arrangement of the conference that felt restrictive: a format of people presenting and giving information while others listened did not give much room for the exchange of perspectives which are the deeply difficult heart of a democratic process. The format of upfront presentation and information-led workshops with little time for talk and reflecting felt like the structures of university teaching. Places of learning have rules of engagement which are deeply learnt; you don't disturb others, you don't leave early or arrive late and, of course, more subtly, your views are not important if you are not presenting. Even more insidiously, in a university setting, there might be a less obvious message that if you are not even a student or have never been a student you do not belong there. Perhaps we are all so steeped in the 'power-over' structures of our society that we take them with us when we try and find out what a 'power-with' approach might be like. In our culture where can we learn about what a truly participatory democratic experience might look and feel like? Considering my experience – of learning institutions, of religious institutions, of political institutions, of the media, of popular culture – I cannot see how any one of us has very much opportunity to



learn about how to have a more egalitarian approach. All our systems are set up so that only certain authorities – such as established members of a group, academics or professionals – provide the information and get the chance to express their views. This means that many people do not get the opportunity to learn how important what they have to say can be. I like the ideas that come from academics and professionals very much, at times. However, new and interesting ideas do not always come from them and without other voices the conversation becomes depleted. The way power really operates in our society is more like an oligarchy where, while some are heard, other perspectives are lost.

My unease made more sense to me when I read articles in Asylum magazine which explored the difficulties some other people had faced during one of the presentations. The understanding I took from the letters was that being asked to bear witness to a threatening, hostile and derogatory Voice being presented in a context where it felt difficult to leave might be democratic, but it certainly did not feel safe. For me, it does not feel democratic for a person who has found a way to present their experience to have to hide or remove some aspect of that experience. That feels like censorship. However, one right in a Democracy is to choose not to participate. Either way, when there are people who are not able to join in, the conversation is less rich and varied. In our current 'mental health' system, we have lost too many important opportunities for learning and lost too many irreplaceable voices.

It struck me then that most of our democratic systems only work by silencing or marginalising some voices. Even in a participatory democracy the majority can also be a tyranny; having the power to wield cruel, unreasonable, or arbitrary forms of control over a minority. It seems to me that the tensions in discussion around mental health already fall into agonising forced dichotomies. This means that any collective of people involved in those discussions may always only be a step away from the anarchy of collapse or animosity. How do we make spaces where we can somehow hold the intolerable tension of needing to listen, but it being unbearable to hear?

I don't think we can continue to

hope that we can reach a form of safety by excluding everything that is potentially threatening. If we cannot directly hear messages that are unwelcome – the voices of terror, distrust, panic, blame, hostility, loathing and criticism – what happens to the communication that we do not receive? If some messages are rejected, there is the possibility some individuals who are part of the group feel rejected too.

Perhaps we need to reconsider the concept of democracy as a model for social organising, with its inherent risks of oligarchy, tyranny or anarchy. Perhaps democracy has its limits when we are dealing in discussions about being human. Perhaps we can only develop new ways forward by creating something I do not think that anyone of us has ever really experienced: spaces which seek ways to be together that are based on power-with, not power-over.

Perhaps what we need is a form of inclusion: where we start from the assertion that ***we all have the right to feel safe all the time.***

So I propose some questions, from this different perspective, as we need to talk about intense and devastating experiences, as well as uplifting and transformative ones:

- How do we promote an egalitarian approach so everyone can be heard and no voices are rejected?
- How do we set up spaces where everyone knows what it means to feel safe?
- How can we design a space where we all feel safe all the time?
- How do we create the possibility of feeling safe, even as we might feel terrified by what we are hearing? ■



MENTAL HEALTH ACT REFORMS:

User/survivor perspectives and proposals for a ‘Fusion law’

The Government is currently undertaking an Independent Review of the Mental Health Act 1983. Liz Maitland, Director of Recovery Assistance Dogs, gives her view. Dorothy Gould, who has been campaigning for more user consultation within the process argues that the current review of the existing Act leaves little room for the consideration of alternatives. One such alternative, the ‘Fusion Law’, is outlined by retired psychiatrist George Szmukler. However, Lucy Series, a law researcher and lecturer, strikes a note of caution. We finish this section by including information about the campaign by the National Service User Network (NSUN) for a rights-based Act.



Helen Spandler (Asylum magazine) joins a panel with Colin King and John Read at the Hearing Voices Network Annual meeting to discuss Human Rights and the Mental Health Act (April 2018)

VIEWPOINT BY LIZ MAITLAND

Theresa May wants to stop ‘Unnecessary Detentions’ by introducing a new Mental Health Act. This begs the question, what does she want to replace the existing Act with? Just before the election, in June, 2017 she said she would replace “in its entirety the flawed Mental Health Act”, which “too often leads to detention, disproportionate effects and the forced treatment of vulnerable people”. So, now that she is Prime Minister, we are watching to see how she is to change an Act made in 1983 that makes us all feel uncomfortable and some of us downright anxious and unsafe as it blurs the line between treatment & legal proceedings.

At Recovery Assistance Dogs (RAD) we filled in a response to the Independent Review of the 2007 Mental Health Act. The review was about when a person can be admitted, detained, and treated in hospital without their agreement. We made our point that people should have the Human Right to a Fair Trial before they can be locked up against their will. The Law says that only people who are a danger to others or themselves should be detained involuntarily. Yet at the moment people have to submit to ‘unnecessary detentions’ for being ‘high’, unable to answer the question correctly or other reasons that a Court of Law would dismiss.

The last Mental Health Act, in 2007, caused more problems for Mental Health Survivors fraught with concerns for freedom from force and fear, with its contentious Community Treatment Orders. The only improvement was the right for everyone who is sectioned to have a Mental Health Advocate. In the New Act increased provision for funding to improve the availability of Mental Health Advocates should be introduced. The new bill should guarantee that all stays in hospital have some litigation, and tribunal or court protection for individuals before they are locked up. Tribunals added on afterwards, when it is too late to protect an individual, have to stop. As Mark Brown, newspaper reporter, says “The bill could lay out the provisions for those who wished to refuse treatment, and build new models of consent and care”.

Many RAD Clients are doing well with their Doggy companions, and coping OK in the Community. They do not need the added discrimination, restrictions and monetary problems of doctors pushing them around and depriving them of their liberty or the company of their best friend. I am longing for a new covenant that commits the UK to protecting those that are in Mental Health distress and helping them to get the therapy & support in the community to nurture and heal. ■

More haste, less speed?

DOROTHY GOULD



Dorothy Gould – a survivor researcher, trainer and consultant – criticises the involvement of people with lived experience in the Independent Review of the Mental Health Act 1983.

There are positive aspects to the involvement of people with lived experience of mental health problems/mental distress in the Mental Health Act Review, including the involvement of those who have been made subject to the Act, for example:

- The emphasis in Review documentation on the importance of involving service users and carers closely in all aspects of the work
- The appointment of a Vice Chair for the review (Steven Gilbert) who has lived experience of issues which African and African Caribbean service users, in particular, may face under the current Mental Health Act

- The setting up both of a service user and carer group and of an African and Caribbean working group.

However, there are some strong concerns amongst many of us with lived experience about the limited influence which people with lived experience are having on the Review in practice:

- The terms of reference for the Review¹ emphasise the need to deal with rising rates of detention, the over-representation of people from black and other minority ethnic groups amongst detained patients and ways in which some processes related to the Mental Health Act are out of line with a modern mental health system. Important though these points are, they fall short of the fundamental reform of the Mental Health Act for which many people with lived experience have campaigned over the years. For example, many of us would like to see the

government take full account of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), including the recommendations which the Convention's Committee made last October². The latter included adoption of a human rights model of disability (as opposed to the medical model which is predominant in this country) and the bringing to an end of detentions, substitute decision-making and compulsory treatment.

- Review consultation material such as the surveys for people with lived experience and carers, the guidance pack for focus groups, questions asked at stakeholder events and the projected topic groups seem rather more designed to draw out opinions about improvements to the existing Mental Health Act than to solicit more far-reaching views. Given the stated purposes of the Review, this emphasis is not surprising. However, failures to make adequate provision for all viewpoints ignore representations made by a number of people with lived experience about the content of consultation material and would appear to represent a lost opportunity. As many of us think that the terms of reference for the Review are too narrow, adequate opportunities for us to express this and to appeal for more fundamental changes to the Mental Health Act seem vital.
- Information about alternatives to the Mental Health Act 1983 has not been made widely available as part of the Review process, despite the fact that quite a few of us have been emphasising the need for this; we have found that many people are unaware that there are other options which they could suggest. For example, mental health law in Scotland might reasonably be described as more rights-based than the Mental Health Act 1983. Under the fusion approach provided by the Mental Capacity Act (Northern Ireland) 2016, the criteria for others taking over decision-making are the same for both mental health service users and people with physical health conditions. Thus, this law has moved markedly in a human rights direction, though a number of us would have reservations about some aspects of it; for example the provision for professionals to make decisions based on a person's 'best interests' may rest too much on professional interpretations of such interests. Then there are the recommendations made under the UNCRPD itself. If people are not aware of other options such as these, they are unlikely to be in a strong position to put forward informed preferences about reform of the Mental Health Act 1983.
- It is positive that membership of the Review's Advisory Panel includes people with lived experience.

However, representatives from professional groups considerably out-number those with lived experience, which makes it harder for those of us with such experience to have the influence which we would like. In addition, the influence of people with lived experience on the Review would be stronger if there were increased service user representation within the Review team itself, for example a co-chair with lived experience of detention and compulsory treatment under the Mental Health Act and an understanding of conflicts between human rights issues and the Act.

- As indicated above, there has clearly been an attempt to take on board the fact that people from black and other minority ethnic communities are often particularly disadvantaged under the current Mental Health Act. Nonetheless, there are shortfalls in their involvement and that of people from other groups who experience more than one type of disadvantage. For example, the surveys for service users and carers have not been made available in a full range of languages, nor have interpreters been provided, and the content of the surveys seems more suited to people who have had good access to education than to all people with lived experience. Demographic information sought for the surveys and topic groups has not included people who were described as intersex at birth, nor people who identify as transgender, and there has been no real focus either on the implications of socioeconomic differences. People with learning difficulties/disabilities, including autism, have also spoken of feeling marginalised in the Review process; they have rightly drawn attention to the fact that they, too, can be made subject to the Mental Health Act.

The short time span which the government has set for the Review has itself created barriers to involvement. The rapid pace of the Review makes it harder for people with lived experience to play a meaningful role within it and especially hard for those who face multiple disadvantages. Considerably more time will be needed if the fundamental changes to the Mental Health Act which many of us want are to be explored and if there are to be realistic recommendations about ways of incorporating these into future legislation and practice. ■

1. <https://www.gov.uk/government/publications/mental-health-act-independent-review/terms-of-reference-independent-review-of-the-mental-health-act-1983>

2. http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GBR/CO/1&Lang=En

The Fusion Law Alternative?

GEORGE SZMUKLER

George Sz mukler is a retired psychiatrist with a long-standing interest in mental health law and human rights. His book *Men in White Coats: Treatment under Coercion* shows how conventional mental health law discriminates against people with a mental illness when compared to all other patients in healthcare, how such law gives expression to discriminatory stereotypes of people with mental illness. Taking into account the UN Convention on the Rights of Persons with Disabilities, it proposes a non-discriminatory framework, a 'fusion law', that purportedly places all patients on an equal standing.

This is what he says on his website:

If you're an ordinary medical or surgical patient – or any patient other than a psychiatric patient – you can refuse any treatment that is being offered to you if you don't want it – even if the outcome might be grave. However, there is one situation where despite your refusing, you can be forced to have the treatment. If you are incapable of making a treatment decision due to an impairment or disturbance in the functioning of your mind, and the proposed treatment is in your 'best interests', then you can be treated involuntarily, against your will. 'Best interests' gives regard to what you would choose according to your deep values and commitments and personal life goals. A disturbance in the functioning of your mind might be due, for example, to a stroke, a head injury, a serious infection or the confusion commonly experienced after an operation. Restraining people like this is common in medical practice.

Now, if you're a psychiatric patient, you can be treated against your will for entirely different reasons – reasons that have nothing to do with your ability to make a treatment decision for yourself or what is in your 'best interests'. You can be detained and treated involuntarily if you are: first, diagnosed with a 'mental disorder' – usually vaguely defined; and second, you are judged to present a risk to your health or safety, or to the safety of other people. What constitutes a 'mental disorder' can be difficult to define, while the assessment of risk is subject to troubling inaccuracies, especially so for rare events like a suicide or serious violence.

The rules, then, governing involuntary treatment are entirely different in psychiatry to all the other specialities. They haven't changed for the last 200 years or so, while those in the rest of medicine have evolved in the last 50 years as we have come to value patient autonomy more and 'doctor knows best' paternalism less.

Comparing the different rules in psychiatry versus the rest of medicine points up a stark discrimination against people with a mental illness. First, the psychiatric patient's

autonomy, self-determination or right to refuse treatment is not respected in the same way as that of the ordinary patient. Second, the reference to risk to other people in the risk criterion, means that people with a mental illness can be detained and treated on the basis of a supposed risk alone; the rest of us have to have committed an offence before we can be deprived of our liberty (or be strongly suspected of having done so). People with a mental illness are unique in being liable to this form of 'preventive detention'.

How is it that we have accepted such discrimination for so long? The reason is that stigmatising stereotypes of people with mental illness are deeply embedded in our culture – that having 'diseased minds' they are incapable of ordinary thinking or judgement and thus their treatment choices are not to be taken seriously; and, that dangerousness is part and parcel of mental illness. Mental health law reinforces these prejudices. Research emphatically fails to support them

Well then, is there a legal framework that does not discriminate against people with a mental illness? Yes, there is. It is a 'Fusion Law'. A key point is that it is 'generic'; that is, it is the same law for everyone who may develop a problem with decision-making, whatever the diagnosis – 'physical' or 'mental' – and in any setting – medical, surgical, psychiatric or in the community. There is no need for a specific 'mental health' law. The framework is based on 'decision-making ability and a form of 'best interests' which gives paramount regard to the person's deep beliefs and values (or 'will and preferences'), but tweaked with a few additions to make it applicable across all of medicine, from psychiatry to orthopaedics.

Being a generic law and thus applicable to all patients, the criteria for involuntary treatment must be workable in all settings. Practice will need to change in some respects – but for the better. The patient's voice will be better heard. The need for coercive interventions – at present increasing alarmingly year on year – will likely be significantly reduced.

Finally, the Fusion Law is as close as one can realistically get to meeting the challenges of the UN Convention on the Rights of Persons with Disabilities (2006), which has been ratified by the UK. Some authorities claim this Convention effectively rules out 'substitute decision making', that is, decisions made in the place of someone who is deemed not able to make a decision. Such a position is, at least at present, not credible. The 'fusion law' aims to eliminate discrimination, as does the Convention, but leaves a morally defensible place – as a last resort, when all attempts at support have failed – for involuntary treatment. ■

Is Fusion Law the Way Forward?

LUCY SERIES

Fusion Law is having a moment in academic and policy circles. Its proponents say that it is more empowering and less discriminatory than the Mental Health Act 1983, and better reflects the spirit of the UN Convention on the Rights of Persons with Disabilities. However, its detractors say that Fusion Law is still discriminatory, and fails to comply with the disability Convention because it still permits mental health detention and treatment without consent.

Fusion Law looks increasingly possible, even likely, in England and Wales. It already exists in Northern Ireland. Scotland and many other countries have something similar. We urgently need input from users and survivors and disabled people with lived experience of (or at risk of) mental health detention and treatment in these discussions.

There are some credible reasons for supporting Fusion Law over existing mental health laws. Under the Fusion Law, a person assessed to have the mental capacity to make decisions about care and treatment would be able to refuse admission to hospital or treatments. They could make legally binding advance decisions refusing specified treatments in the future if they should lose mental capacity, and nominate a person they trust to make decisions on their behalf by making a Lasting Power of Attorney.

Mental capacity does not simply mean being able to say what you want. A person also has to demonstrate to others that they understand the information relevant to the decision, can retain it long enough to make a decision, and can 'use and weigh' it in making a decision. People should be presumed to have the mental capacity to make a particular decision unless it is shown otherwise. 'All practicable steps' should be taken to support a person to make a decision before concluding that they lack mental capacity. Mental capacity assessments should not be based on whether a person makes an 'unwise decision', although in practice professionals find it hard to distinguish 'unwise decisions' from 'incapacity'. For example, must a person share clinicians' views on diagnosis and treatment options to demonstrate 'understanding', or give the same priority to health or personal safety to show they can 'weigh' the options appropriately?

A 2013 study estimated that up to a third of patients detained under the Mental Health Act had the mental capacity to make decisions about some aspects of their care and treatment. If Fusion Law came to pass then these patients could be afforded substantially greater freedoms to make choices about care and treatment than they have at present. However, 'mental capacity' is a nebulous concept, some say it is 'in the eye of the

beholder'. Would clinicians apply the capacity test in the same way if it became the main criteria for involuntary admission and treatment?

When a person is assessed as 'lacking capacity' others can make decisions on their behalf in their best interests. Best interests decision makers must consider the past and present wishes, feelings, values and beliefs of the person. There are examples of courts prioritising the person's own point of view over other factors such as health or safety. However, best interests decisions can also be very paternalistic, and in some cases best interests offers a *lower* threshold for involuntary admission and treatment than the Mental Health Act. In fact, one of the arguments for Fusion Law is that it would permit earlier 'preventive' detention and involuntary treatment before a person meets the risk thresholds of the Mental Health Act.

The Fusion law may liberate some people – probably more articulate and educated people – who are presentably detainable under the Mental Health Act. However, it might also mean some people become *more* detainable, particularly people who are less articulate, experiencing psychosis, or who have cognitive impairments which make it harder for them to satisfy others that they have mental capacity. It is hard to predict whether Fusion Law would reduce the rising numbers of detained patients.

Fusion law places a greater emphasis on engaging with the person's own point of view, but it still allows their point of view to be overridden by others. This is one reason why some say it does not comply with the disability Convention.

Another risk of Fusion Law is that 'capacity' may increasingly become an excuse for not providing support and services to people experiencing mental distress. There are anecdotal reports of people being denied access to support and services on the basis that they 'have capacity' to make decisions around suicide and self-harm. This actually has no basis in law – 'capacity' is not the same as eligibility for treatment and support; it is a device to legitimate treatment without consent. But there is a worrying perception in some places that those 'with capacity' are not really in need of help, even where they are requesting it, and it may be used illegitimately as an indirect means to ration increasingly scarce resources.

Is Fusion law less discriminatory than the Mental Health Act? Under the Mental Capacity Act a person can only be found to lack mental capacity if this is *because of* an 'impairment or disturbance in the functioning of the mind or brain'. This means that although it can be applied to people without a diagnosed mental illness or impairment (e.g. a person with concussion), diagnosis

still plays a role in decisions for many. In fact, detention under the Mental Capacity Act is *only* lawful if a person has a diagnosed 'mental disorder'.

Even if we got rid of these diagnostic criteria, people experiencing mental distress, illness or impairment would be more likely to be treated without consent than the general population. The *kinds* of treatment or interventions they face would be very different to treatment for concussion or similar. Whether or not this is discriminatory depends on your point of view: are these interventions *ever* justified and proportionate, and is 'mental incapacity' a sufficiently objective basis for them? These are the key questions that we must answer when considering the Fusion Law proposals.

The UN Committee on the Rights of Persons with Disabilities takes the view that laws based on capacity and best interests still discriminate against disabled people and violate their rights. Their position is closer to an absolute prohibition on detention and treatment

without consent. Research in the UK indicates that many, perhaps even most, users and survivors of detention and compulsory treatment do not want an absolute prohibition on compulsory detention and treatment, but there is deep dissatisfaction with current practice and the current law.

Users and survivors of mental health services face a bewildering array of options for potential legal reform. The recent survey by the Mental Health Alliance reported contradictory findings about the views of those who had experienced detention in relation to compulsory treatment and capacity. This suggests that the implications of a shift to capacity based mental health laws are not widely understood. Consultation with users and survivors on the future of the MHA is vital, but we need to raise awareness of what the options being consulted on mean. Forums like *Asylum* magazine are vital for raising awareness and having much needed conversations about the future of mental health law. ■

CAMPAIGNING FOR A RIGHTS-BASED ACT IN PLACE OF THE MENTAL HEALTH ACT:

A CALL FOR SUPPORT FROM THE NATIONAL SURVIVOR USER NETWORK (NSUN)

The government has set up an Independent Review of the Mental Health Act 1983. However, the current focus of the Review seems to be on improving the Act, not on transforming it into a rights-based Act. As a user-led organisation with a strong emphasis on human rights, NSUN wants to see a change in this approach: for the Act to be made compliant with the United Nations Convention on the Rights of Persons with Disabilities. This will mean focusing on a human rights model of mental distress (instead of a medical model) and on bringing detentions, substitute decision-making and compulsory treatment to an end.

We will be writing about our concerns to the leaders of the main political parties, to the All Party Parliamentary Groups on Mental Health and on Learning Disability and to the Chair and Vice Chairs of the Mental Health Act Review. We will also be putting together a press release about the issues.

If you think that you or your organisation can support NSUN by signing up to the letters and the press release, please **urgently** contact Dorothy Gould at gould.dorothy@gmail.com. Dorothy has a lead role at NSUN for Mental Health Act issues. Please also copy your email to Sarah Yiannoullou, NSUN's Managing Director at sarah.yiannoullou@nsun.org.uk

Undergird

FLEUR BEAUPERT

Remembering my dance school's first day
back when it was still in the street it was named after
back when jazz was cool and hip hop was chilling
in the wings. Way back when. Fast forward –

Dancing and yelling like crazy
twirling my belt in homage to rhythmic gymnastics
waving around in faery flash dance in a university foyer
clinical file translation *threatening onlookers with a belt*

I attract the attention of a bored security guard
refusing to end my cummerbund routine and booty shaking
I am pinned to the floor, arm twisted behind my back
pain snakes along the right-hand side of my body

Injection | when I wake up I am in the hospital
where my grandmother died. My unruly disco continues
Pas de chat! Pas de cheval! Jerky in a ghostly gown
imperceptible trance moves winnow my captors

When the wait lasts too long I unleash my choreography
zombies gasp as I kick the emergency room doors
rotating | mother attached to one hand, nurse to another
we fall sideways around my axis of spin | slow mo

Injection | when I wake up I am in a new hospital
'involuntary' this time round. The walls are whispering

Clinicians speak in tongues so I limp away from them
improvising uneven gait on the theme of automimicry
undulating in taciturn motion, tracing invisible lines
along the whimpering wall towards my holding cell

A woman is ululating *I want to die! I want to die!*

'How often do you feel sad?' They ask
when we begin to reply they tell us to tick a box
'How often are your memories extracted from your head
and reassembled topsy-turvy?' They ask
We look to them for answers

One, two, you know what to do | keeping pace
with the time step I hold in my heart. I am Spider tapping
up the wall, shimmying through the depths of dislocation
folding and swaying. Yes. A pirouette knows how to land
even if you stumble inside it

Two psychiatrists reflect on the recent debate about the efficacy of anti-depressants. Joanna Moncrieff is a leading figure in the *Critical Psychiatry Network* and Linda Gask is a retired psychiatrist who has used anti-depressants. These articles are reproduced from their respective blogs.

Antidepressants: Challenging the new hype

JOANNA MONCRIEFF

The extraordinary media hype over the latest meta-analysis of antidepressants puts the discussion of these drugs back years. Despite the fact that 9% of the UK population are taking antidepressants, and rates of prescribing have doubled over the last decades, the authors of the analysis are calling for yet more prescribing. John Geddes suggested in *The Sun* newspaper that only 1 in 6 people are receiving adequate treatment for depression in high income countries. In *The Guardian* he estimates that 1 million more people require treatment with antidepressants in the UK but, by my maths, if 9% are already taking them and they only represent 1 in 6 of those who need them, then 54% of the population should be taking them. I make that another 27 million people!

The coverage was almost universally uncritical, and said little about the terrible adverse effects that some people can suffer while taking antidepressants, or while trying to get off them. Even *The Guardian* claimed that the new 'ground-breaking' study will 'put to rest doubts' about antidepressants.

But there is nothing ground-breaking about this latest meta-analysis. It simply repeats the errors of previous analyses. Although I have written about these many times before, I will quickly summarise relevant points.

The analysis consists of comparing 'response' rates between people on antidepressants and those on placebo. But 'response' is an artificial category that has been arbitrarily constructed out of the data. When the actual scores are compared, differences are trivial and unlikely to be clinically relevant.

Moreover, even these small differences are easily accounted for by the fact that antidepressants produce more or less subtle mental and physical alterations (e.g. nausea, dry mouth, drowsiness and emotional blunting) irrespective of whether or not they treat depression. These alterations enable participants to guess whether they have been allocated to antidepressant or placebo better than would be expected by chance. Participants receiving the active drugs may therefore experience amplified placebo effects by virtue of knowing they are taking an active drug rather than an inactive placebo. This may explain why antidepressants that cause the most noticeable alterations, such as amitriptyline, appeared to be the most effective in the recent analysis.

Antidepressant trials often include people who are

already on antidepressants. Such people may experience withdrawal symptoms if they are randomised to placebo, which, given that almost no antidepressant trial pays the slightest attention to the problems of dependence on antidepressants, are highly likely to be classified as relapse.

The analysis only looks at data for eight weeks of treatment, whereas in real life people often take antidepressants for months or even years. Few randomised, placebo-controlled trials have investigated long-term effects, but 'real world' studies of people treated with antidepressants show that the proportion of people who stick to recommended treatment, recover and don't relapse within a year, is staggeringly low. Moreover, several studies have found that the outcomes of people treated with antidepressants are worse than the outcomes of people with depression who are not treated with antidepressants, even in one case after controlling for the severity of the depression.

Calling for antidepressants to be more widely prescribed will do nothing to address the problem of depression and will only increase the harms these drugs produce. Thankfully, the more severe effects are probably rare, but they will become a more significant problem if prescribing rates increase further. The harm caused by encouraging people to consider themselves as having a disease requiring long-term medical treatment is difficult to quantify.

As the debate around the coverage highlighted, many people feel they have been helped by antidepressants, and some are happy to consider themselves as having some sort of brain disease that antidepressants put right. These ideas can be reassuring. If people have had access to balanced information and decided this view suits them, that's fine. But in order for people to make up their own minds about the value or otherwise of antidepressants and the understanding of depression that comes in their wake, they need to be aware that the story the doctor might have told them – about the chemical imbalance in their brain and the pills that put it right – is not backed up by science, and that the evidence these pills are more effective than dummy tablets is pretty slim.

Many people will be wondering why on earth we are reacting to the increasing burden of human misery in this way. Why are we not asking why it is that so many people in the modern world feel miserable and stressed? What are the pressures that people are under that make coping with life difficult? I could name many – insecure or inadequate employment, finances and housing, loneliness, increasing pressure to perform and reach ever higher targets at work and school and the disappearing nature of community in many areas. These are the things we need to focus on to stem the 'epidemic of depression' – not doling out ever more placebos with side effects! ■

Recovery during a war on depression

LINDA GASK

There has never been an easy time for people with severe mental illness (yes, I am calling it that) to get the help they need to recover, but at the present time it seems harder than it has at some other times in my life. The terrible impact of austerity on the provision of mental health care, combined with the redefining of 'recovery' as being capable of economic activity, has discriminated against those who are disabled. The results have led too many people to take their own lives.

I have experienced episodes of depression throughout my adult life but I acknowledge that I am fortunate to have been able to retire from work, and to embark on what David Karp the sociologist describes as *defining depression as a condition that one can get past*. When I am well, I find it hard to remember just how awful I felt the last time I was severely ill. But what I've been working at over the last couple of years is trying to reclaim recovery for what I always originally understood it to be. Not 50% reduction in my scores on the PHQ-9, or my ability to work, but re(dis)covering the life I've glimpsed at times but never managed to reclaim – because I've learned how depression cruelly deceives you by whispering that there is nothing left in life for you. It's so much more than unhappiness. It's a way of being.

The current discourse about 'depression' hasn't helped. I've spoken on social media about how there seems at times to be a *war on antidepressants*, but actually I think it's more than that. I think it's a war on what I, and many others experience as *depression*. There is a real sense of denial of experience – of depression itself (it's really just 'misery' and 'unhappiness'); of the cause (it's all about power, threat and meaning – the body doesn't come into it); and the treatment (antidepressants don't work – and anyway they aren't antidepressants – they just numb and sedate you).

At the moment we are in the midst of a debate between those who say there is incontrovertible evidence that antidepressants work, and those who still say that it's mostly a placebo effect. I believe they do work for many people, but not for others. I guess one of the problems is that if you accept that medication works on *depression* then you have to believe that some physical process is

at work in the brain, at least for *some people some of the time*. As I've said above, I think there is, but many will never be willing to consider that.

Some people experience problems with antidepressants – they can make you feel worse. I experienced awful agitation on fluoxetine. You can also have major difficulties withdrawing from them but I don't think we yet know the true extent of this. Anecdotal evidence or internet surveys with their inherent bias, are not enough. *But I believe that people experience this*, and I don't think my profession has, in the past, taken it seriously enough.

I've no doubt from my own experience that people with adverse childhood experiences are less likely to respond to medication and need access to sufficient good quality therapy. The kind I had access to, longer term, one-to-one, is now rarely accessible without payment. Yet I cannot see how recovery can be possible, with brief interventions only, for people who need time to build up trust because of what has happened to them in early relationships.

Getting access to the right treatment *for you* is essential. I don't think depression is homogenous. In my experience the part played by physical, psychological and social factors in its aetiology can change between episodes and over a lifetime. And treatment needs to be similarly tailored. When I was younger I benefited from dynamic psychotherapy in helping me to make sense of my difficult early life. Later, CBT helped me to cope with everyday living. And I needed medication – and still do. I'm still learning from the therapy I had in the past. I am rebuilding a life and finding meaning in existence again.

I am very lucky to be able to do this. It would be wonderful if those who espouse those simple absolutes – about what *depression* is and what *recovery* involves – might reflect on what it is like when no-one will listen to how awful you feel, and people just tell you what you *should* be believing and doing (what they fervently believe themselves or is economically expedient), when that seems impossible and intolerable to you.

This is not mental health care and, if it were all I had received, I would not be recovering from depression now. ■

On the RADAR

LIAM KIRK

Liam Kirk reports on being part of 'Research into Antipsychotic Discontinuation and Reduction [RADAR]' - a unique new research trial.

Confusion in the consulting room when my consultant thought my friend was the patient and I was a mental health professional to the point where the doctor addressed my friend claiming he remembered him. It was my fault for having a bath, putting on a freshly ironed shirt, and carrying a copy of Dr Joanna Moncrieff's *The Bitterest Pills*. This was no bog-standard psychiatrist appointment. It was my first as part of a research study into reducing the amount of antipsychotics patients take, and with the dynamic changed, my psychiatrist duly complied by trading in levels of sexual dysfunction. It had been agreed ahead of the appointment that I would be taken off the injectable depot Zuclopenthixol decanoate and be prescribed the oral tablet olanzapine.

Patient: I consider myself to be fortunate to be selected for the RADAR project.

Doctor: For how long did you take olanzapine in the past?

Patient: Years.

Doctor: For years. Did you have any side effects?

Patient: I had side effects of weight gain

Doctor: How much weight did you gain?

Patient: ... I don't know for I never weighed myself but my waist size went up to forty-two inches.

Doctor: Forty-two inches?

Patient: Yes.

Doctor: How much are you now?

Patient: Thirty-four. Thirty-three, thirty-four.

Doctor: Thirty-four.

Patient: It affects sleep. It does affect diet. I had sexual dysfunction on olanzapine as well, but different type of sexual dysfunction than from Zuclopenthixol decanoate.

Doctor: Have you heard of aripiprazole?

Patient: I've had so many drugs that I don't know the name of them all.

Doctor: I think you have taken that one. It is milder than olanzapine and people don't gain weight, no sexual dysfunction. The only side effect I've seen in people is you become a bit restless.

Was I tempted with the offer of a drug that my psychiatrist claimed prevented weight gain and did not interfere with



the male reproductive system? I could have told of being in a state of apathy, emotional disinterest, and cognitive impairment as side effects. Foremost in my mind was the need to avoid withdrawal-induced psychosis and the fact the drugs suppress mental activity indiscriminately, and no doctor has ever forewarned about sexual dysfunction, the word libido is outside a psychiatrist's vocabulary. I want to live a drug free life, one without feelings of being retarded. Did the doctor address my concerns? Is it a case of, "Trust me, I'm a doctor, all you will feel is a bit restless."

This was my initial meeting of the Research into Antipsychotic Discontinuation and Reduction research study, where my psychiatrist should agree a drug reduction schedule with me for the next twelve months. Never before have I been in a situation where the pressure is on a cut in medication, previously the reverse held true, the pressure was always either on an increase of medication or a change in medication.

Patient: When does the trial start?

Doctor: The trial has started already. The aim of this treatment is for you to slowly try and reduce and, if possible, stop taking your antipsychotic medication.

Many consider that the RADAR research is needed to increase the understanding of people using antipsychotics in the long term and what is best in terms of treating people. I had been at the end of the hypodermic with no alternative being offered or considered, aware that unilaterally withdrawing from psychiatric services could result in a drug withdrawal psychosis, and would result in a Community Treatment Order with mandatory injections. As an alternative to the illusion of voluntarily agreeing to being injected, the possibility of being drug free was a lifeline: a lifeline that if the research proves to be successful will be available to so many others who presently live in the shadowy world of psychiatric services.

Now I am back on olanzapine: known for its powers to induce sleep. Like a classic Freudian I will have plenty of opportunity for dreamwork, where I am assured it is good for your health to develop a relationship with your dreams. One revelation to come out of the consultation is that the Sexual Health Unit of St Mary's Hospital, London W2 will only take a referral from a GP. The community mental health team cannot refer for the treatment of drug-induced sexual dysfunction. My first night back on O and I slept twelve hours, waking up too late to telephone my GP's surgery to arrange an appointment for the drafting of a referral letter to a psychosexual therapist. The struggle goes on. ■

Ethical Drug Disposal

MH GUERRILLA



Fake It (To Make It)

In the quiet afternoon anonymity of the lounge of The Everyman cinema on Baker Street, a poet, Jerry, engages me in conversation for the first time. Gaining Jerry's confidence instantly, by disclosing that I had been under the care of over three hundred psychiatrists and listing my top seven diagnoses, I ask Jerry if he is under the care of a psychiatrist? Jerry confesses he costs the taxman a lot of money, by collecting his monthly prescription then with it creating an art installation. On the west facing wall of his living room is a growing array of multi-coloured boxes called *The Inherent Drama of an Obsessive Focus in the Creative Product*, representing the wasted lives of the men in white coats. Each month the pile of boxes grows one box higher. Jerry prefers the inscrutable art of unused meds with its neurological contortions rather than losing the representation of having your arm twisted up behind his back by flushing away his *con-scription*. Faking adherence to his medication regime has the additional benefit that the lie makes the quiet life easier, no-one attempting to micro-manage one's entitlement to welfare or pushing one to find a job. At fifty-five, Jerry the self-harming poet is content to be parked-up on benefits, fulfilling the aspiration awarded him by the psychiatric profession. Jerry's beef with life is: if only more than five people would turn up for his poetry recitals...

Dirty Water

Fear of the system lies at the heart of a dilemma for the ethical mental health guerrilla who frets on how to dispose of unused meds safely. Not all can be like Jerry the Poet, by creating their own *The Inherent Drama of an Obsessive Focus in the Creative Product*. The drama, should a home visit from *The Team* discover

boxes of unused meds, is fuss most in the system want to avoid. The logical argument that the boxes represent a long period of unnecessary antipsychotic treatment is bound to fail, as would asking a psychiatrist to give up their addiction to treat people with antipsychotic drugs. Aesthetically speaking, having one's own art installation is not to everyone's taste and best left to poets who can wax lyrical on the growing artwork. For others with a growing collection of unwanted pills the choice of how to get rid of the ghastly meds poses practical and moral difficulties.

Chemists supply instruction to return unused medications to the chemist shop for them to dispose of. Fear of being found out prevents an open return of the drugs. One course of action could be to enter one's local chemist shop when not busy and to quietly leave a bag of meds on the counter of the shop for the chemist to dispose of. This would result in an investigation. The guerrilla would be easily traceable via the batch number printed on the drug packaging. You would either hear sirens or those whirling helicopter blades one hundred yards behind you.

Another option is to bin the drugs, allowing the local refuse collection to process the removal and destruction of the neurotoxins. The unknown factors - of whether the poisonous substances will be used as landfill, or disposed of at sea, or incinerated - are concerns guerrillas fret about. Again, there is the possibility of being traced by the packaging, when disposing of unwanted boxes of meds in the household waste.

The toilet is considered the safest route to get rid of the unnecessary antipsychotic treatment. They say London's tap water is recycled eight times and that you are drinking someone else's urine. What is the difference at the water treatment facilities between chemical compounds excreted in urine and those same chemical compounds fed directly into the sewage system. Tests are performed by the water company as to the purity of London's drinking water and it stands to reason that any drugs flushed away are processed out of the water supply. The pharmaceutical companies are responsible for new life in the form of microbes: microbes that devour the unique chemical compounds of olanzapine and other drugs have been created at the water filtering plants.

The moral issue of the cost is taken out of the hands of the guerrilla but is still a burden felt. Learning from the internet that olanzapine is on sale in the USA at nine pounds a tablet. At that price one could sell them on the black market to anyone who wants cheap psychiatric medicine; twenty-five percent off the price but full strength. Olanzapine comes in three sizes of dose: 10 mg, 5 mg, and 2.5mg. The cost per pill is the same regardless of the dose size. I am prescribed 17.5 mg. By the psychosexual therapist, to aid overcoming premature ejaculation, I am

prescribed 20mg fluoxetine. I am costing the NHS over a thousand pounds a month for drugs that are flushed down the loo. There is the direct expense of the drugs themselves and the indirect costs of a psychiatrist's time to monitor my "adherence" to my medication regimen, the chemist's time to dispense the medication, and my General Practitioner's time to prescribe. Every time

this guerrilla learns of a patient being denied life saving treatment on the basis of cost this creates a sense of anguish over the waste of their own pointless drug regimen.

Not a serious proposition: recycle it back into the system and feed the drugs to the psychiatrists. It's called re-psychiatrying. ■

Bitter Pills to Swallow?: a response



Terry Simpson responds to Jeffrey Brooks' piece, in the last issue of Asylum 25(1),

Dear Jeffrey,
Thanks for writing "Bigger Pills To Swallow" in the last issue of Asylum magazine. I like the openness and clarity of your story, and found it very moving. I was invited to write a response because in that article you urge people to take medication, and I'm involved

in a project to help people come off drugs.

I thought it would be useful to tell my story, to explain why I came to a different conclusion from yours. I came from a relatively poor working class family, and when I was eleven won a scholarship to a prestigious grammar school in my city, where the majority of kids were from rich backgrounds, and paid to be there. I was split between trying to be middle class like other kids at school, and working-class life at home. After 7 years I felt like a strange hybrid, neither one thing nor the other. It was a lonely place, and didn't get better when I went to university, (which was largely middle-class), where I used alcohol and street drugs like LSD. I kept it together somehow, and got an honours degree in Philosophy with the best grade in my year, but I was a wreck, and a few months later tried to take my own life (with pain-killers and anti-depressants). I didn't succeed, and instead, (long story, cut short), was admitted to a psychiatric ward, where I was restrained and injected again and again until I had no memory of who, where or what I was. The brutality of that treatment and other experiences in admissions over the following 10 years fuels my campaigning.

It's deeply tragic what happened to you and your family, and I've nothing but respect for the way you've dealt (and are dealing) with it. But psychiatric drugs don't always stop people killing. In recent years there have been a lot of well documented shooting incidents in Europe, Canada and the US where young men have killed dozens of people while being known to mental health authorities and prescribed psychiatric drugs.

Even if drugs took away all risk of hurting other people,

there are still big risks for the people who take them. A sizeable percentage of the estimated million people who kill themselves every year globally do so with prescribed drugs, including psychiatric drugs.

Apart from suicide, drugs put people under a big, potentially lethal, health risk. In a British Medical Journal debate reported in the UK newspaper the Guardian on 12th May 2015 Professor Peter Gotzsche of the Nordic Cochrane Centre in Denmark said more than half a million people over the age of 65 die as a result of the use of psychiatric drugs every year in the western world. Long term psychiatric drug use is linked to decreased life expectancy for younger people too.

Personal responsibility is a big theme in your letter, and one I agree with. We have choices, and make our own lives. No-one made me take the street drugs that made everything so much worse. But I also think we do things in a context, and if we don't understand the context, our stories will never make complete sense. Every school day for 7 years I heard disparaging comments about stupid, ignorant working-class people, then had to go home in the evening to those very people, my mother, my father, my brothers. That had an effect. I tried to assimilate to be "normal", but there were contradictory versions of "normal" and I couldn't be both. It was "mad making". Class wasn't the whole story, but it was a big factor in my "craziness".

I think most people who find themselves in the mental health system have a version of this. You don't talk about race, but I think racism must be a factor for anyone black and labelled mentally ill in the US today. I read Claudia Rankine's book "Citizen", which documents the everyday drip of living in a racist society, and how mad-making that is. We can't blame social injustice for the things we do, but if we simply blame ourselves, then classism and racism, (not to mention all the other ways one set of people is demeaned and oppressed by another), will continue to drive people "mad".

There are risks attached to not taking psychiatric drugs, and risks attached to taking them. Dina Poursanidou makes the point that for most people there is no alternative at the moment, and while that is true, it's a terrible indictment of the current system. In the long run we have to create alternatives, and the best is to imagine and work towards a world that doesn't drive us crazy.

Thanks for making me think and write about all this.

Terry Simpson

Interpolation

Fleur Beaupert

Alien	why do they make the rooms look like holding cells?
Of art	odd shapes, white walls devoid swept unreal walls. Walls that could close in on you
Like in an Indiana Jones movie	it must be a conspiracy
Sometimes every word you reach for is	forbidden
absurd	a violation
I remember	conversing with a dream that was real
Lips moving In explosive gestures	I remember
The green EXIT sign A mythical symbol	thrumming in my hospital room all those years ago the way I still occupy these foreign spaces
Pressed into smooth white walls	Prescription We don't want you writing late burning the midnight oil
Doctor: I can see you're very careful Patient: So are you Doctor: I was worried you had an agenda Patient: Everyone has an agenda	with your words
Doctor: Try swallowing the agenda	(But) it's the quickest way out of here
you	You don't need to know what it'll do to you we don't even know what it'll do to but let us help you sleep deep
Doctor: You you you you you you you you are you will all you will will you show you will you you you will and you will	
Patient: Are you you are you you will you we you are you will be in and are all you you are you are in your you and	
Doctor:	You don't want to be known as the mad one This must be very humiliating for you



Sam Shakes and the survivor spirit

Andrew Roberts writes about one of a new generation of creative survivor activists, and sets her work in the context of survivor history.

Sam Shakes was born in the maternity unit of Hackney Hospital in January 1972. Nearby “F Block”, in the same Victorian workhouse, had been a psychiatric unit since 1967 and in 1974 Alan Hartman chaired the first meeting of Hackney Hospital Mental Patients Union. The long history of survivor action in the hospital was under way. Baby Shakes was naturally unaware of all this, as she was of her own future as a creative survivor.

Sam, whose parents come from Montserrat and Jamaica, has lived in Hackney all her life. The first of their four children, she started her education at London Fields Primary School and then went to Kingsland Secondary School in Shaklewell Lane (now demolished), re-sitting GCSEs at the Sir George Monoux Sixth Form College in Walthamstow. She began her career as a sales clerk in 1989, first selling bathrooms in the City of London and then with Dudley Stationery (now defunct) in Bow.

University challenge, an unwanted shit hole, and a journal.

An Access course enabled Sam to study English Literature at Middlesex University, starting in September 1997. She was excited and enthusiastic, but in her second year was “hit with raging Ulcerative Colitis”. She struggled to be well and study, but her colon had to be cut out in November 1998. Only 26 years old, from now on shit would drain through her stomach wall into a plastic bag.

Sam’s operation was the start of a new life. She took a year out to recuperate and during that time, realised that “without knowledge of health one does not know

anything!” She transferred to Health Studies, starting afresh in October 1999.

Sam compared herself to a rotten apple: “I feel fake as I sit with a ... plastic bag stuck on my side... I might look good, but really I’m portraying a rosy apple (my appearance) with a rotten core (the stoma)”.

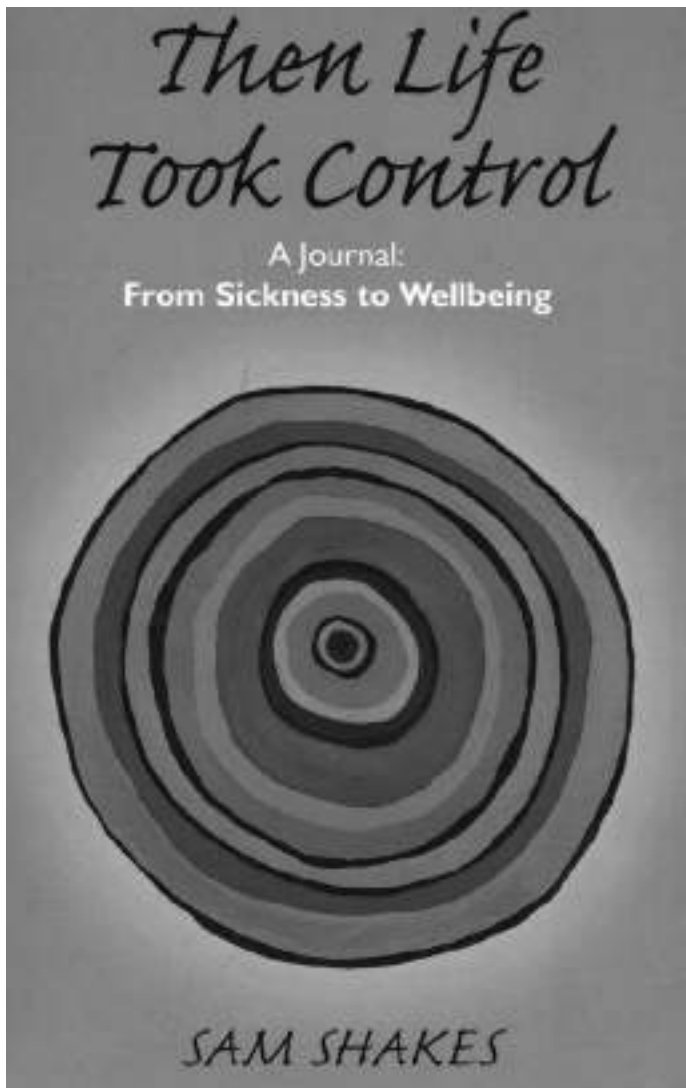
She later painted herself as two halves: one clothed and smiling; the other, naked, “revealing the damage”. In a note to the picture she said “In all this suffering there is something refreshing... As time passed - the spiritual was being awakened (the core essence of us)... “

Journal writing plays an important part in Sam’s life and, she says, it “seemed natural” to write a book “because my episodes of disease and wellbeing were so vividly recorded in my journals”. As part of her journey of self discovery, she told me, she first shared extracts with friends, one of whom, Nadia Ismail, urged her to re-write it for a wider audience.

Madness at the millennium

As the old century died, the slowly abandoned buildings of Hackney Hospital helped to generate Core Arts and (indirectly) Robert Dellar’s *Mad Pride: A Celebration of Mad Culture* (June 2000) with a chapter by Robert called “Turning The Asylum Into A Playground”. Once again,





Sam knew nothing of this. She was absorbed, as she put it, in “managing” [her own] “madness”. These excerpts from her diary give us some feel for what she was going through:

“**Saturday 1.1.2000** 3.30am: still listening to music and dancing alone. I’ve drunk loads. And feel ‘happy?’ ... 8.45am: woke up feeling very miserable. **Wednesday 5.1.2000** 10.30am: delivered the Patients’ Perspective talk at City University. **Friday 7.1.2000** 5.30pm I travelled all the way to Ponders End campus - to be away from home, at the time Trevor suggested we meet. 11.30pm: felt something crawling in my head - an insect, but when I tried to brush it away, ‘there was nothing there?’”

Sam’s recovery of her “core essence” involved her health studies, changing attitudes to relationships, re-thinking who she was (in dialogue with counsellors), eating better foods, exercise, confidence that there was an “alternative and better”, and seeking and chasing that. When Sam graduated in Health Studies with Race and Culture in 2002, she was already a popular part time tutor at City University – drawing on her perspective on having a pouch, and how to cope with the emotions and

social interactions it involved. She carried on developing a career and qualifications in the self-management of chronic disease and her self-exploration through painting and writing became a conversation with others as she published her work.

Painting emotions and publishing her journal.

Sam describes herself as having “a particular interest in human behaviour and the drama of life experiences”. That drama is an emotional one and Sam sees emotions as being social as much as individual. Her wildest emotional rides are rooted in interactions with neighbours and friends, and the stability she achieves is reached through understanding the society of which she is a part. At the centre of everything is the spirit within, the “core essence of us”, that can reassert itself in our suffering. In her first book this is expressed as life taking control. The journey to this book was by way of an intense period of painting.

On the first day of 2008, Sam began a series of paintings exploring emotions. The first was triggered by the death of a friend and it was sufficiently significant to become the cover image of her book in 2010. Called *The Cycle Of Life*, it portrays depression, anger, jealousy, love, friendship and joy as concentric circles of colour. *Flaming Spirit* followed in March and *A ‘Rosy Apple’ with a ‘Rotten Core’* (above) in May. In June she painted *My ‘Colon’ or ‘Me?’* and *No Limit*.

.Then Life Took Control: A Journal: From Sickness to Wellbeing is a three part journal for 1998 - 1999 - and 2000. Its focus is on how Sam coped with the “ruthless remedy” of having her colon removed, the change in who she was, to “an unrecognisable me”, the emotional consequences (managing ‘madness’) and life’s re-assertion. Most of it is based on the edited words of her diary at the time, and preserves the freshness and raw impact of her emotions, but the happy romantic ending is not her story. Sam’s turbulent emotional life continued and she found a new medium to explore and express it in “fairy stories” for adults and children that allow her to include the complexities of her real life.

Fairy stories: Listening to what is happening.

The Happy Man who Refused Love and Help, published with pictures by Judy Clarkson in 2014, is a fairy tale for all ages that tells how the benevolent Leon cannot accept Teresa’s love and murders her. Are you capable of murder? it asks. Time to listen to what is going on in your head? The book is dedicated to Sam’s close friend, Philip Morgan (1965-2017), who taught about the importance of identity for healthy living. Highlighting the consequences of suppressing our emotions, Sam’s message is that we must listen to our own needs as well as helping others. The collaboration with Judy Clarkson appears seamless,

as Judy uses her knowledge of the body to convey the emotions that Sam describes.

Sam's next fairy story was *The Woman with a Fish in Her Head* (2016). This is a graphic conversation between voices. The fish hears the world's injustice and we hear what it is to drown sorrow in alcohol, and to dance under its influence, but other voices speak comfort and, in discussing these with others, the woman satisfies her fish (spirit) in a new way.

Sam Elbow - Naughty!, the third fairy story Sam has published, was told to her by her niece, Sade Oladejo when she was only four years old. Sam wrote it down for her and Judy Clarkson drew the pictures. It is a larger format than the other two. Although Sade says it is "for other children", this old man, for one, find that it makes thought provoking reading. It is about a girl who painfully "elbowed" other children, and what she and others did about her naughtiness. As Sam cooperates with her parents and teachers in overcoming the hostility her elbowing has provoked, "the children started playing with Sam. She was very happy and so were all the children. Just the way we are supposed to be!"

Dancing and skipping on the shoulders of the past.

It is now 2018. Alan Hartman has been fronting Manchester Users Network for over a decade; Core Arts still flourishes in Hackney; Robert Dellar published his (semi-fantasy) account of life in and after Hackney Hospital in *Splitting in Two: Mad Pride and Punk Rock Oblivion* (2014), two years before his death; and Sam is one of a new generation of survivor writers and artists publicly exploring the heights and depths of emotions. She does this in a way that might not have been possible without struggles such as those in Hackney Hospital that made the voices of mental patients part of our cultural conversation. ■

The photograph of Sam was taken by Cheryl Prax at the Loonies Fest on 9.9.2017. Books discussed can be bought direct from sam.shakes@natureinspiredbooks.co.uk and Sam is developing an interesting website with reviews, events and further information at <https://samshakes.wordpress.com/>



F.E.E.L. (Friends of The East End Loonies)

KIERAN BRADLEY

I'm a Friend of the East End Loonies
You can take my word for that
I was told that I was mental
As in the loony bin I sat

I'm a Friend of the East End Loonies
I'm more batty than a bat
Due to the rising hate crime kindly
Keep that under your hat

I'm a Friend of the East End Loonies
We've always been treated bad
Nothing ever changes for the better
It's no wonder that we're mad

I'm a Friend of the East End Loonies
And that is no word of a lie
I'm a Friend of the East End Loonies
Will be one till the day I die

At the Friends of the East End Loonies
There is a welcome on the mat
I'm a Friend of the East End Loonies
Quis Separabit? and all that

(Previously in Poetry Express Newsletter no.50)

Behind closed doors

Georgie Lopez went into psychiatric hospital with life-threatening anorexia. She is now haunted by her inpatient experience

When I was admitted to Huntercombe psychiatric Hospital, Maidenhead, I never thought my life would take the turn it did. I thought it would never end: being tube fed, self-harming, over exercising, numerous stints in hospital. Although these admissions saved my life, at the same time they ended it. My mum actually said to me just last week, at one point in my admission at Vincent Square she wished I would just die because seeing me live like that was just too painful. Now she is glad I lived. Four and a half years of inpatient treatment later and I am finally back on my feet (or moderately sane I suppose you could say). I have not only gained almost 20kg, but gained some semblance of a normal life (in the form of studying A levels at college and balancing that with a bubbling social life). It definitely wasn't, however, the treatment prescribed by the consultants and nurses in the 3 placements I was detained in that have me typing this today.



In amongst the horror I faced living in these institutions there is one specific night that still haunts me and most probably will forever.

I had been crying – a pretty standard sight in a psychiatric hospital as you can imagine. When the Health Care Assistant looking after me called the head nurse, she began to spite me: “you’re hopeless; you’re selfish; you’re ruining your family’s life; don’t you know how much worse some people have it; is this just for attention?; are you not smart enough to think of anything else but what is inside your brain?”. Should a person trained in psychiatric nursing not have some understanding of the torment that mental illness can stir up inside one’s head? I became really worked up. The only thing that I felt I could use to hurt myself and make it all stop (the thoughts in my head and the vicious nurse in

front of me) was the brick wall. Thirty minutes later, I was still whacking my skull against the relentless wall, with the nurse continuing her monologue of hate. Eventually, she tired of this bullying, I suppose, and left.

Looking back at a picture of the results of my own self-destruction as a result of this verbal abuse, I am quite honestly shocked. I was unrecognizable – my face black with bruises and swollen to double the size it should have been. Two days later, when the nurses finally thought that they should probably check out if my skull was cracked, I was sat in A&E repeating the events in my head.



The physical and emotional consequences were ignored by all senior staff. Even violent restraints for tube feeding continued, where my bruised head was in a tight grip – I can honestly say I have never felt pain like it before. When my mum visited a day later, blissfully unaware of what had happened, she was speechless. She was told a convincing story that I had managed to lock myself in my room to self-destruct not allowing intervention. I was too scared to speak up, and it wasn't until recently I have been able to outline what actually occurred that night.

Anorexia and depression, both of which are diagnoses of mine, often (and definitely for me) stem from self-loathing, doubting one's self and feeling that one is undeserving of anything even remotely good. So, to have a nurse solidify that idea, especially in a time of need, was the perfect excuse to destroy myself. If a parent did this to their child, a teacher to a student, a husband to a wife, would it not be considered abuse? So why is it OK for mental health patients to go through this? If senior nurses cannot accept and understand mental health, how can we expect an ordinary person to?



Verbal abuse from senior psychiatric staff is only one of the obstacles faced by patients; another being an absence of hope. I don't know how many times I heard that I was the 'worst case of anorexia' they had ever seen or that there was 'no point' in helping someone who was so hopeless. In the end I was discharged with the message 'do what you like, you're a hopeless case,' with the prediction I would either die or be readmitted elsewhere within a few months. If someone as qualified as a consultant thinks you are not worth the time, effort and commitment it takes to recover, then what exactly are you worth? Maybe starving yourself and harming yourself is exactly what you deserve. No-one is a hopeless case, absolutely no-one, and consultants shouldn't be able to determine who they feel deserves help.

The people I saw on my journey were heartbreaking: girls as young as 12 shut away from their parents; mothers distanced from their children; wives parted from their husbands. There were young women who had graduated university with first class degrees, writers, artists, musicians, and all of them had one thing in common: what they had lived for had been taken away from them and for what? To sit staring at the same four walls, being repeatedly told they are worthless? What exactly is the point of isolating someone for such a long period of time and doing nothing but tell them how much of a despicable human being they are; eventually chucking them in to the big bad world, with the exact same problems, just enhanced and exaggerated?

Life becomes terrifying after that long being so restricted. When I was discharged, even the thought of going to Tesco's was too much to handle. Life is scary enough for young adults, never mind taking them out of it for long periods of time, where they cannot learn the ways of the world. I understand that hospital is often required to save lives, for me it certainly was, but would it not be wiser to re-feed the sufferer and discharge them, even if

this meant another (or several more) short admissions? Once the sufferer is at a higher weight, their brain begins to function better again and not only do the symptoms, like dysmorphia, lessen, they are surrounded by people who love and care for them, and they can direct their focus onto productive activities like education, employment, hobbies, socialising. THIS is how I recovered, not by being pinned down by six men to be injected so that I conked out on the spot or having a feeding tube stuffed up my nose. And it certainly was not by being separated from those who knew who I really was and what I was really capable of.

Lastly, drawing from articles in previous editions of *Asylum*, relating to professionals' use of medication as a quick fix, I would like to reiterate that medication is not the answer. Yes, it can be used to supplement the process of recovery, but not as the sole feature. I was injected three or four times a day at one period, entirely against my wishes. It was, quite frankly, terrifying to be injected and multiple hours later return to consciousness in a different room with absolutely no understanding of how I had got there. Is this laziness on the part of the psychiatrists? Medication used to shut a sufferer up, or simply because the nurse is at a loss as to what to do next, is not ok – it implies sufferers are subhuman or are animals. Again, if any sane man or woman was held down and injected it would be wrong – so why is this not? The use of drugs in these institutions needs to be better regulated. Obviously, if there really is a danger to anyone in a situation I agree that, as a last resort, it may be used, but not every day, multiple times a day. This overlooks the deeper causes of the torment the person is experiencing. It is, as I have said, a quick fix and there simply is no such a thing.

Given my experience, I would like to see better regulation of mental health institutions. I think this begins with stricter regulations of the actions of trained psychiatrists who make decisions in these placements. ■

Peer Support in a Psychiatric Ward – A Shared Experience

BEN GRAY



like creative writing or music therapy, I became closer to *people* (not as a diagnosis of schizophrenia, bipolar disorder, or depression but as human beings with complex problems, emotions, and difficult past histories). We talked about our personal experiences, emotions, and difficulties and supported each other's gradual progress and journey toward recovery. Importantly, I realized we were all in it together – I wasn't alone.

I especially connected with a 70-year-old woman, Becky, who needed the care of nurses, me, and other people on the ward to make her drinks and just to hold her hand to comfort her distress. She has schizophrenia and dementia and is unable to look after herself. Recently, I took her with me to the chaplaincy group, where she said a little about herself and her two sons, which was the first group she had attended. This helped us both a lot, and we have become good friends.

Friendships – showing a little bit of love and caring for each other – make the time on the ward easier and more rewarding. It can be tough, and not everyone likes going into hospital, but I think the important thing to remember is that we can all support each other. It may seem like a little thing, but having a good relationship with another human being makes all the difference. ■

I have just spent a month in a psychiatric ward. In fact, as I write this, I'm still here. It's my third relapse in 10 years and, the first time, it lasted for nearly a year. Being in hospital is a painful experience, but it's also a personal journey, and for me it was forming friendships on the ward that pulled me through (and continues to do so).

I'm diagnosed with schizophrenia. When I hear voices they are very negative and frightening, often saying things in a demonic hiss like "I'm an abuser" or "I'm coming. You wait until you see what I'm going to do to you!"

Being on the ward is often isolating and frightening, with people shouting at their voices and sometimes being restrained by staff. It would be better in my opinion if there was more therapeutic contact between us and the staff and more time for one-to-one supportive conversations to aid recovery.

The good thing about being in hospital is that I started taking my medication again, which I had stopped for some days (although I am quite against antipsychotic drugs because of their painful, often humiliating and debilitating side effects, such as tiredness, weight gain, tremors, restlessness or the inability to sit still and muscle stiffness). But the main reason I started to feel better was as a result of friendships on the ward.

Befriending other people, getting their support, praying for others, and engaging in group activities, all aided in my recovery. By taking part in group activities



Photos by Jill Anderson

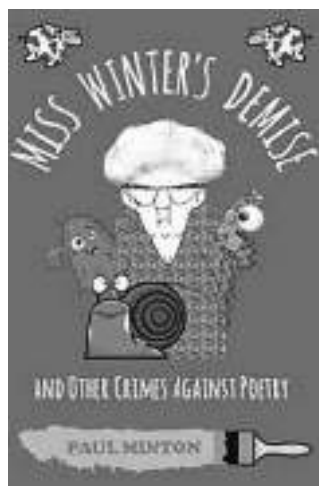
Apology and Clarification

The Asylum collective would like to apologise for any upset caused by a blog that briefly appeared on our website: "Welcome to the CMHT". The authors have apologised and removed content which was considered ill-judged and insensitive. The amended version is available on our website. We are determined to preserve a space for critique and debate and try to be as inclusive as possible of controversial points of view. However, we also take seriously our responsibility to avoid personal attack and to minimise hurt where possible. Sometimes we make mistakes, and we are currently reviewing our editorial policy on this matter.

We would like to clarify that PCCS Books has no connection with our website or the blogs, nor do they edit the content of the magazine – responsibility for this lies with the Asylum Collective. PCCS Books simply manage the magazine print, production and subscriptions.

BOOK REVIEW

REVIEWED BY WILLIAM PARK



Miss Winter's Demise (And Other Crimes Against Poetry)

Children's Poetry by
Paul Minton.

Matador, Imprint of Troubador
Publishing.
www.troubador.co.uk/matador

There's something satisfying and deeply wedded to wellbeing when words drop purposefully into place, like coins in a machine. Paul Minton's humorous and skilfully constructed poems give me that satisfaction.

Mind How You Go

I met a man in my head;
"Will you please get out?" I said.
"I really wish I could comply
But you're in mine!" was his reply.

They're not all so short, but even when ten times larger, they maintain their efficiency and sense of fun.

Sometimes they're educational, like the *Nonets*, a poetic form of descending amounts of syllables. At other times they remind me of the distilled irony and morality of the everyday in Jim Burns's adult poetry, for instance in Minton's poem *Waiting*. Or, as in the poem *Mud*, they have the playfulness and narrative inevitability of the late Matt Simpson's writings for children. I think, also, Roger McGough might chuckle at the lines of *Professor MacCavity*:

Professor MacCavity
Objected to gravity
But his theories failed to convince.
So to prove he was right,
He jumped from a great height
And no-one has heard from him since.

In *Simply Magic*, and all of this collection of 43 poems, Minton weaves a magic spell through assured and lively craft:

I've magic fingers
And magic toes,
Magic shoulders,
A magic nose,
Magic legs
To magic run
Because I am
A magician.

LETTERS

Response to the 'disillusioned Asylum subscriber' from a 'posh working-class boy'

This is a personal response to the letter from 'Adisillusioned subscriber' [*Asylum* 25:1] who feels 'working-class voices are not represented', and 'middle-class people are more likely to be able to articulate their needs'.

I've had comments "Why are you so poor?" and "Not having enough money is a universal problem" by individuals from middle-class homes, super-supported by their parents.

I don't want to concentrate on the struggles and disadvantages of the working classes. I want to celebrate our inner riches, our strengths. I want to remind us of what's possible empowered by a fierce, fighting spirit.

My Dad was a mechanical engineer. My early jobs – as a teenager and in my early twenties – included being a printer, and a typesetter.

As an active (though not on Twitter) member of the *Asylum* Collective, I'd identify myself as a posh working-class boy. This doesn't mean I have any money.

The only reason I wasn't bullied to heaven at an all-male secondary school (known then – and now – as 'the Prison on the Hill') is because the Head of English (who was highly respected) thought I was gifted with words (though not in a 'superior' way). The respect he embodied transferred to me.

I didn't have any 'privileges' from my 'background' but there was a *connection* straight off the bat.

I have found strength, and attainment, in making connections and building on them, finding inspiration in those who've gone before me, many of whom are from a 'working-class' background, including a writer and philosopher – the late Colin Wilson – who I met as a teenager.

In my twenties, I wanted to write and claim a poetry prize that many Oxbridge poets had gained (the Eric Gregory Award) and I achieved this at the start of the 1990s. I had my poetry published or reviewed in several of the leading British literary periodicals. I never went to university full-time, but later garnered 2 post-grad qualifications part-time.

If no one gives you encouragement, *find the encouragement* – in writers, thinkers, pastors, preachers – then actively believe you are special and possess a force within you that can change others and the world.

Something was said in the letter to *Asylum* referring to the privileged position of private psychiatric help ...

In response to this, I thought I'd disclose a fragment of my own psychiatric care. With the same principles I've

outlined above, I've fought passionately to get the care I've needed, arguing and debating with professionals, ensuring I've had the right facts and the right terminology – and the confidence to express those facts and terms – so that professionals will listen. If you're interested in further details of my psychological battles, please see *Asylum* 19:1 *Self-Diagnosis of Chaos*.

But speaking personally, none of my psychiatric care has been 'private'. I have participated in 2 'therapeutic communities' but you wouldn't have heard anything about these – then available on the NHS – from my local GP. As it happens, my current GP is the best I've had, but all that came before him were ignorant regarding mental health, or indeed many physical health matters in my opinion! Physically (along with a mental health impact) I suffer from 2 conditions which aggravate each other: chronic sinusitis and asthma.

I discovered the therapeutic communities (which are now sadly finished due to funding cuts, it's true) through *intense searching, asking, determination, self-education*, not through privilege. The same applies to my knowledge of medication, eventually leading to a consultant and care coordinator agreeing with me to cease all psychotropic medications and confirming this with a written agreement which has been in place for years.

I'm riled by any notion that the working classes can't be self-directed, educated, and achieve their goals. I don't, on the other hand, want to be some 'representative' of the working classes on the *Asylum* Collective.

As I say, I'm posh working class. I have, for many years, followed Buddhism (though this is leaning now towards Christianity, because of the Christian TV channel TBN UK), as well as contemporary poetry, popular amongst the 'middle classes' I hear ... one's interests and outlook definitely don't have to be based on class or society's expectations.

I get the affable but vacuous question: "What *kind* of poetry do you write?" from *every* class of person.

I believe we all have choices to make, whether we're from a poor working-class background, whether we're in the grip of a deep 'addiction' (like problem drinking, which I have succumbed to in the long-ago past) or whether we are lost, uncertain, disenfranchised.

I believe we can choose to make a change; with encouragement I believe that change can bear fruit. I encourage that change right now.

William Park is a part-time adult education tutor.

Dear Asylum magazine,

Congratulations on another excellent edition. It is good to have a magazine in which survivors can join in the discussion, although not yet on equal terms with one another, as “disillusioned subscriber” points out.

Thank you for finding space for two contributions from me. You must be mad – but as Ash E. Rah says (page 19) “insanity has something to offer us all”

And thank you for publishing Jeffrey Brooks “Bigger Pills to Swallow” and the letter from “disillusioned subscriber”. For years I have been convinced that voices like theirs would not be allowed a space in Asylum. You have proved me wrong.

Andrew Roberts – Happy Hackney subscriber.

Is fear the missing link?

Dear editor

In all its years of publication has Asylum magazine ever addressed fear of the system as a patient phenomenon? I have been under the care of more than four-hundred-and sixty psychiatrists. I have had numerous diagnoses from my many physicians and am familiar with each of the standard lines of diagnostic questioning for schizophrenia, bi-polar, depression, and personality disorder. In addition to suffering from the four main categories of mental illness I have also been diagnosed as suffering from Obsessive Compulsive Disorder, post-traumatic stress disorder, and recently, high functioning autism. I spent the first seventeen months of my psychiatric career as a private patient and although I found it strange to talk about myself and my emotions I was open and completely honest with all the psychiatrists who entered my life. I was not prepared for the draconian use of the Mental Health Act.

It is the fear of the powers of the Mental Health Act that drives the terror of the system combined with the bitter experience of being leaped upon, pinned down, and injected in the process called by the professionals ‘rapid tranquillisation’. In the eyes of many of the caring professions rapid tranquillisation is a satisfactory procedure, but it is often from that point on that the patient is wary.

It may make an interesting edition of Asylum if different patient viewpoints, and, if possible, doctor’s views, could consider the phenomena of fear of the system. Especially how fear distorts and twists the lives of those on both sides of the psychiatric system.

Yours sincerely
Liam Kirk

NEWS & REPORTS

TOO MANY PREVENTABLE MH DEATHS

An investigation by *The Guardian* reveals that, between 2012 and 2017, 271 highly vulnerable patients died after 706 failings by health bodies. In many cases patients took their own lives. Coroners, alarmed at the lapses in care that emerged during inquests, issued legal warnings to 136 NHS bodies, including mental health trusts, acute hospitals, ambulance services and GP surgeries. Mental health campaigners have claimed that many of the deaths were avoidable, deeming them a “shocking tragedy”.

Under the Coroners and Justice Act of 2009, coroners are obliged to issue a “prevention of future deaths notice” (PFDN) if they believe shortcomings by a person, organisation or public body are so serious that other people

may die unless urgent action is taken to tackle them. These were served on one or more NHS body in all these 271 cases. Identified problems included errors, misjudgments, flawed processes, lack of staff or beds, and poor training. Notices included: 72 instances of poor or inappropriate care, 45 cases in which patients were discharged too soon or without adequate support, and 41 in which treatment was delayed. In dozens of cases staff made mistakes with the patient’s medication or failed properly to assess the risk of the patient taking their own life.

These disclosures follow growing concern about the ability of the NHS to cope with increasing demand, resulting in inadequate care and long delays in treatment. NHS services are significantly understaffed. There are

6,000 fewer mental health nurses in England than there were in 2010 and the number of psychiatrists for children and adolescents is falling. Drawing on an analysis of more than 200 complaints about care from last year, The NHS ombudsman, Rob Behrens highlights “failings that have occurred, and continue to occur, in specialist mental health services in England, and the devastating toll this takes on patients and their families”.

Campbell, D (2018) Damning report finds ‘serious failings’ in NHS mental health services. *The Guardian* Mar 21; Duncan, P, Campbell, D & Bawden, A (2018) Hundreds of mental health patients died after NHS care failures *The Guardian* 5 Mar.

ALARMING RISE IN SELF-HARM AMONG IN-PATIENTS

Self-harm in mental health units has almost doubled in five years. A recent Guardian poll of nearly half of the NHS mental health trusts in England, found that the number of incidents of self-harm among in-patients shot up from 15,489 in 2013 to 28,585 last year. Meanwhile, data from the Adult Psychiatric Morbidity survey (published every seven years by NHS Digital), shows that the proportion of 16 to 74-year-olds reporting having self-harmed increased from 3.8% in 2007 to 6.4% in 2014. These increases may result, in part, from better reporting of incidents. Commentators agree, however, that the rise is very concerning and an indication that services are struggling to provide the therapeutic support that people need.

Marsh, S (2018) Sharp rise in self-harm reported by mental health units in England. *The Guardian* Apr 1.

NO HELP FOR 1/4 OF UK WOMEN WITH PERINATAL MH PROBLEMS

The NHS estimates that up to 20% of the 775,000 women a year who give birth suffer from mental health problems related to carrying a child or giving birth, including anxiety disorders, depression and psychosis. Suicide is a leading cause of death among women who are pregnant or who gave birth in the last year. Perinatal mental health services are vital and save lives. Yet, according to the Maternal Mental Health Alliance (MMHA) of medical groups and childbirth campaigners, millions of women across the UK are denied vital NHS care. A “scandalous postcode lottery” means that pregnant women and new mothers in a quarter of Britain cannot access any specialist support. As the MMHA says, “It is profoundly unfair that some women get excellent care whilst others aren’t even asked how they are feeling by health workers.”

Research by the MMHA and Royal College of Psychiatrists has found there are still no perinatal mental health services in 26% of NHS areas. 62 of the 235 NHS health board or clinical commissioning group areas across the UK offer women no help whatsoever from dedicated perinatal personnel, including specialist psychiatrists and nurses. On the upside, that is a lot fewer than the 97 areas that offered no support in 2015, when the MMHA

last surveyed provision and the number of areas providing access to a full range of help has risen, from 55 to 109. Claire Murdoch, NHS England’s national mental health director, reports that a £365m package of investment has helped an additional 6,000 women access care in the past year alone.

Campbell, D (2018) Women across UK denied mental healthcare around childbirth, say doctors. *The Guardian* Apr 19

BIG RISE IN HOSPITALISATION FOR EATING DISORDERS

Amid warnings from experts that NHS services to tackle anorexia and bulimia are failing to help those in need, the number of admissions to hospital of patients with potentially life-threatening eating disorders has almost doubled over six years. The number of admissions of people with a primary or secondary diagnosis of an eating disorder reached a peak of 13,885 in the year to April 2017 - up from 7,260 in 2010-11. The latest data shows admissions are the highest they have been in at least a decade.

There has been a big surge in the number of teenage girls and women in their early twenties: admissions for anorexia for those aged under 19 went from 1,050 to 2,025 over the period examined.

The figures are from NHS Digital, and they come as the UK’s leading eating disorder charity, Beat, said that calls to their helpline were likely to reach 17,000 in the year ending March 2018, up from 7,000 the year before.

Doctors, campaigners and MPs have warned that this rise in hospital admissions of people who are severely unwell, indicates that outpatient treatment has not been working effectively. Campaigners say these figures are only the tip of the iceberg.

Marsh, S (2018) Eating disorders: NHS reports surge in hospital admissions. *The Guardian* Feb 12

MH HOSPITAL ADMISSIONS FOR DRUG PROBLEMS SOARS

English hospitals now treat more than twice as many people with drug-related disorders as they did ten years ago. Ever-rising numbers of children, young people and pensioners in England are being taken to hospital after suffering serious mental disorders as a result of taking illicit drugs such as cannabis and cocaine; and also painkillers, alcohol and solvents.. In the year to April 2017, the NHS reports 82,135 general hospital admissions with a primary or secondary diagnosis of drug-related mental and behavioural disorders. This is an all-time high, comparing with 81,904 for the same period the year before, and it is more than twice the number for a decade earlier.

The biggest rise is among people in the decade after retirement. The number of 65- to 74-year-olds has risen by 502%, from 232 in 2006-07 to 1,397 in 2016-17. Numbers are also up among those aged 75 and over, from 183 to 559 - a rise of 205%. The director of the charity DrugWise says this increase could be due to growing numbers of older

people taking prescription drugs to combat loneliness and depression, pointing to the NHS's inability – due to GP time constraints - to provide support in other ways. Over the last decade the number of under-16s admitted with drug-related mental health problems has almost doubled, from 402 to 799. There has also been a sharp rise among those aged 16 to 24: numbers in that age group have increased from 6,983 to 12,369 - up 77%. On a happier note, the number of people admitted with a diagnosis of poisoning by illicit drugs fell 7% on the previous year, to 14,053, though this was still 40% higher than ten years ago.

Prof Colin Drummond, chair of the addictions faculty at the Royal College of Psychiatrists, said: "The increase in drug-related hospital admissions over the last decade is concerning and mirrors the rising alcohol-related hospital admissions, which have doubled over the same period."

Gayle, D (2018) Drug-related mental health admissions in NHS hit record high. *The Guardian* Feb 7. Campbell, D (2018) Admissions to hospital for drug-related mental health problems soar. *The Guardian* Mar 3.

MENTAL HEALTH STILL THE CINDERELLA SERVICE

A study by the King's Fund finds that mental health is still losing out in NHS funding. Physical health services are still getting bigger budgets, five years after ministers promised so-called 'parity of esteem'. Budgets of NHS mental health trusts in England rose by less than 2.5% in 2016-17, far less than the 6% boost received by acute trusts and those providing specialist care. It is the fifth year in a row that NHS bosses have given physical health services a larger cash increase, even though ministers have repeatedly promised better funding.

Mental health trusts in England received increased incomes averaging just 5.5% between 2012-13 and 2017,

whereas budgets for acute hospitals rose by 16.8%. And an annual survey using freedom of information laws - conducted by the MP Luciana Berger, president of the Labour campaign for mental health - found that half of all clinical commissioning groups (CCGs) actually reduced their spending on mental health provision during 2017-18. (CCGs are the local NHS bodies that hold the health budget for every area and pay the trusts to treat patients.)

... A GLIMMER OF HOPE?

Now NHS bodies that put too little money into improving mental health care have been threatened with "sanctions" in a "crackdown" intended to ensure more cash reaches the frontline. NHS England has written to all 207 CCGs to warn that they must deliver on a key NHS-wide funding pledge in order to meet the rising demand for help. Claire Murdoch, NHS England's national mental health director, has ordered CCGs to ensure they boost spending on mental health by more than the size of their overall annual budget increase; they must also meet the mental health investment standard (MHIS).

After concern that they have endured years of underinvestment, NHS bosses are using the policy to increase funding for psychological and psychiatric services. "This is a landmark moment for England's mental health services," Murdoch said in the letter to CCGs. "The requirement to increase mental health spending faster than overall growth in health spending is not only a crucial enabler of high-quality patient care, but a demonstration of the NHS's commitment to putting mental and physical health on a level footing."

Campbell, D (2018) Mental health still losing out in NHS funding, report finds. *The Guardian* Jan 16; Campbell, D (2018) NHS bodies told to boost mental health funds or face sanctions. *The Guardian* Apr 4.

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Coming soon....

Asylum's Welfare Rights Special issue: "Austerity from above and resistance from below."



We write this in the week where the Secretary of State for Work and Pensions, Esther McVey MP reiterated the government's commitment to the introduction of a rape clause whereby mothers with more than two children will no longer be entitled to child tax credits for any subsequent children unless they disclose and provide details to Job Centre staff that the child was born of rape. To add insult to injury the Secretary of State went on to suggest that this could mean that women get 'double support' from disclosing their experiences to unqualified Job Centre staff although no information about what support was forthcoming, probably because it doesn't exist. The government's callous disregard and cynicism towards people in receipt of social security couldn't be any clearer.

This increasingly barbaric policy formation and implementation has been developing over several decades but has undoubtedly accelerated since 2010 under the guise of Austerity economics, summarized in the words of ex-chancellor George Osborne; "There is no alternative." For those of us in need of welfare because of the debilitating and alienating effects of mental health problems recent reforms have resulted in an increasingly precarious situation. Welfare support is constantly threatened by Work Capability Assessments that, in spite of evidence from medical professionals involved in people's lives, can remove entitlement to receive an ever-diminishing Employment Support Allowance and force people into the labour market. The other threat is the impossible-to-navigate sanctioning system that can leave people derelict at the drop of a hat. We have seen the devastating effect on whole communities and fatal consequences for many individuals.

Academic research in this area has focused on documenting the impact of these welfare reforms and highlighting their economic, moral and health implications. While this work is to be welcomed we are concerned that regardless of the weight of evidence against punitive measures in the welfare system, in the absence of structural political change, these policies are likely to continue.

This leaves us needing to find ways for people with lived experience of the system to find individual and collective ways to resist these reforms and, if resistance is not possible, then at least survive them.

This will be the theme of the next edition of Asylum. We will highlight the multiple ways that people resist and survive on a daily basis. We hope this will provide a platform of solidarity and practical suggestions for people across the country who are struggling on their own. This should also help mental health professionals who are trying to advocate for and support people going through the process. We will also try to honour those for whom resistance and survival has not been possible.

We are still seeking a few more contributions from people with lived experience of the welfare system. Contributions can be written experiences, cartoons, artwork, poems, opinions etc. All aspects of the system are welcome – conditionality, sanctions, assessment procedures or whatever feels most relevant to you. We would especially like to hear about your experiences of resistance – or suggestions about how we can resist.

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