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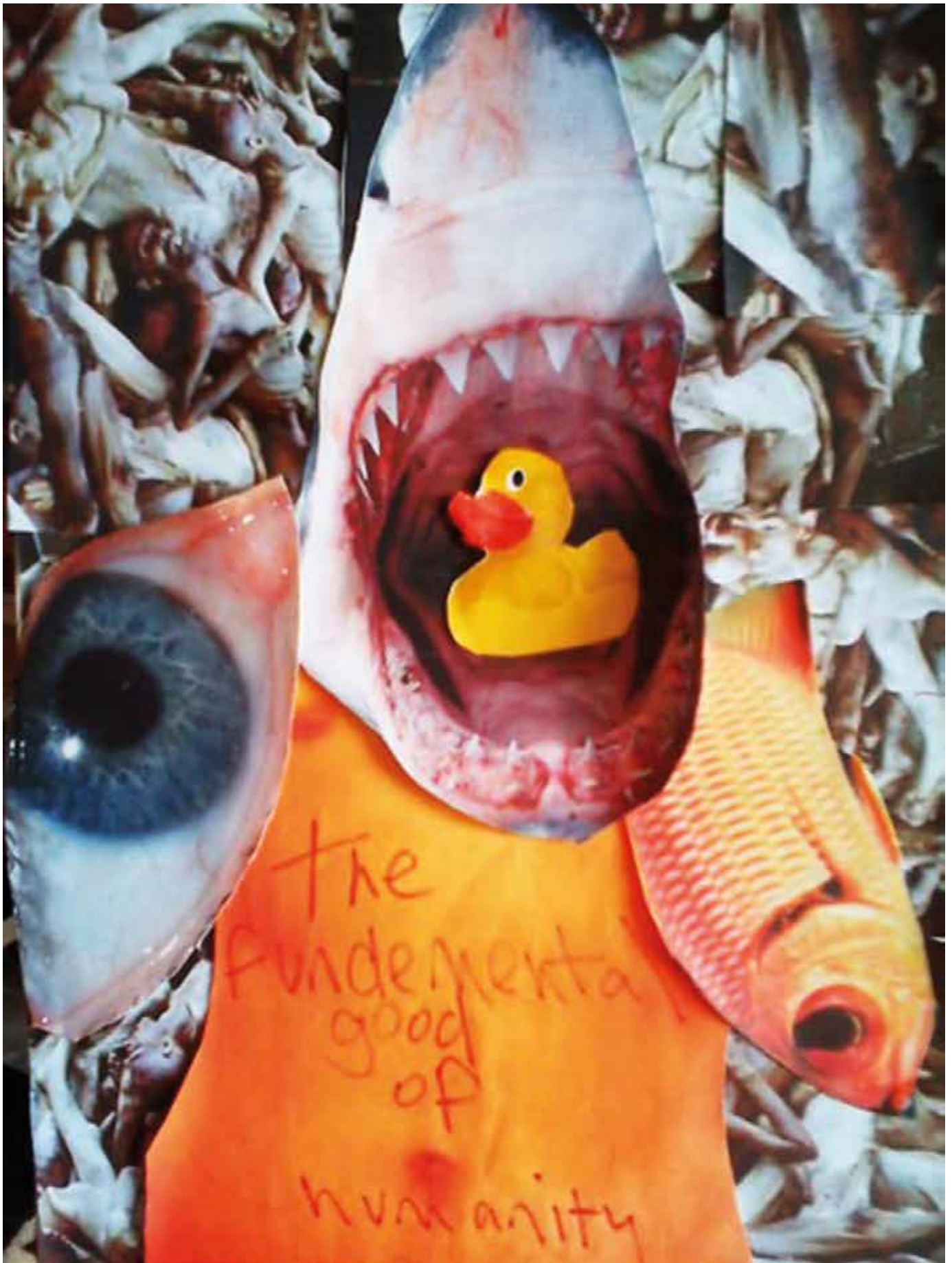
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the magazine for democratic psychiatry



**WELFARE REFORM SUICIDES
MAD PRIDE & DEPRESSION
PSYCHIATRY IN CANADA & NZ
& MORE**



The Fundamental Good of Humanity – Dolly Sen



The magazine for democratic psychiatry

Volume 24, Number 2, Summer 2017

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Front cover and image on p. 7 by Sonia Soans

Back cover image by Dolly Sen

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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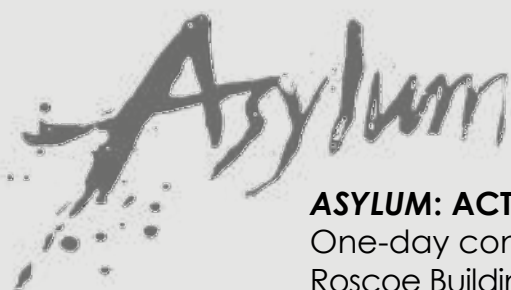
Editorial

For the last two editions of the magazine we mainly focussed on the development of Mad Studies, and several contributors now respond to that theme. We do hope to continue these discussions, but this time there is no distinct thread to the contents. This is because we also want to ensure that we cover a range of topics relevant to our diverse readership, especially our loyal supporters from the user/survivor movement. Andrew Roberts from the Survivors History Group raises some of these issues on our letters page. Suffice to say, we remain *the magazine for democratic psychiatry* (not Mad Studies...).

We always welcome contributions, whatever the topic or point of view, so if you have ideas or opinions you would like to share, don't be shy in coming forward! We are

pleased to have an international section this time, reporting on the state of the mental health services in Canada and New Zealand. We hope that future issues will include reports from our conference in Manchester, *Asylum: Action to Reaction*, to be held at the end of June. If you are interested in attending, see the advert below for details.

Meanwhile, it is clear that our Government is determined to demonise the distressed and disabled, making life as hard as it can for them, no matter what the human costs – after all, few of them are ever likely to vote Conservative. The human costs are high and rising, with the yearly number of suicides now increasing again, and we are pleased to report examples of resistance that are rarely featured in the mainstream media. ■



CONFERENCE 2017

ASYLUM: ACTION AND REACTION

One-day conference – Wednesday, 28 June 2017: Registration at 9:30am
Roscoe Building, University of Manchester, Brunswick St., Manchester, M13 9PL

Confirmed speakers include: Sean Burn, John Read, Jen Kilyon, Suman Fernando, Cheryl Prax, Diana Rose, Joanna Moncrieff, Phil Thomas, Rufus May, Yasmin Dewan, David Morgan, Alex Dunedin. And there will be many others in talks and workshops, and with groups and stalls through the day.

This will be very special – a conference to celebrate more than thirty years of ***Asylum: the magazine for democratic psychiatry***. We have kept the entrance fees as low as possible. We estimate the registration fees will just about cover our costs. Entrance includes refreshments.

We ask only £10 if you already subscribe to ***Asylum magazine***. The full £30 rate also buys you a year's subscription to the magazine!

The theme of the conference is 'Action and Reaction'. We have in mind a range of possible meanings, including:

- the kind of political action we need to engage in so as to defend rights and build better services,
- the struggle against reactionary attacks on mental health provision,
- the kind of collective action that we take, and
- responses to what ***Asylum magazine*** has been doing so far.

We invite you to be with us and many other activists, survivors and their allies. This is a chance to take stock and discuss what we do next, to share information about the many different kinds of activities and networks people may be involved in, and to strengthen the bonds between us.

In the evening a celebration event organised by Alex Dunedin of the Ragged University, and crowd funded through donations, will take place at Gullivers in Manchester city centre – a chance to celebrate with music, food and good company. More information at the 'Asylum Conference 2017' link on www.pccs-books.co.uk

Tickets:

£10.00 for *Asylum magazine* subscribers

£30.00 for non-subscribers

(includes a one-year subscription to *Asylum magazine*)

Contact: asylumconference2017@gmail.com

Conference Facebook page

www.facebook.com/events/117183712033425/

Conference registration is at:

www.pccs-books.co.uk

Click the 'Asylum Conference 2017' link

DEAD PEOPLE DON'T CLAIM

UK welfare reform suicides

PAULA PETERS & CHINA MILLS

On the 30th of March 2017, during a Unite Community Benefit Sanctions and Benefit Cuts meeting in Parliament, a minute's silence was held to remember all those who have died as a result of welfare cuts and the austerity measures since the financial crisis of 2007–08. Disabled activists, including those from Disabled People against Cuts (DPAC) held a banner outside Parliament that read 'Dead People Don't Claim'. One minute's silence is not long enough to remember all those whose deaths, including suicides, are linked to the austerity measures.

In 2013, suicides in the UK reached a thirteen-year high, and population data links the increase to the Government's austerity policies (Barr et al, 2015). It is estimated that each month an average of eighty people die after being found 'fit to work'. This makes death central to the UK's benefits system (Ryan, 2015). Department for Work and Pensions (DWP) mortality statistics show that after being found 'fit to work' 2,380 people died between December 2011 and February 2014, and a further 7,200 died after having their Employment Support Allowance (ESA) made conditional on participation in groups supposed to prepare them for employment (DWP, 2015). The private company Maximus carries out Work Capability Assessments (WCAs) for the DWP. The extent to which suicide has become normalized within the welfare system became apparent recently

when *The Disability News Service* reported that Maximus assesses eligibility for Personal Independence Payments (PIP) by asking people if they have considered suicide. One person reported being asked: "Can you tell me why you haven't killed yourself yet?" (Pring, 2017).

In 2013, a senior coroner for Inner North London, Mary Hassell, concluded that the suicide of Michael O'Sullivan, a disabled man who hanged himself after a WCA, was a 'direct result of being ruled "fit to work"' (Pring, 2015a; McVeigh, 2015). This is 'thought by campaigners to be the first official link of WCAs to suicide' (Chakelian, 2015). Since this verdict, during the period 2010–2013, the WCA process has been associated with an additional 590 suicides (5% of all suicides) (Barr et al, 2015b). Despite these damning figures, the DWP keeps no record of the circumstances surrounding such deaths, and is quick to point out that the statistics do not point to any causal link between benefits changes and mortality.

Activism, especially by disabled people's groups such as DPAC, *the Disability News Service*, and by family and friends affected by welfare reform suicides (such as the Black Triangle Campaign and Calum's List, which maintain websites listing deaths linked to austerity) has been key to informing people about how austerity and welfare cuts are actually killing people. In 2012, under article 6 of the



UN Convention on the Rights of Persons with Disabilities (UNCRPD), DPAC submitted testimonies to the United Nations concerning the impact of welfare reform policies on disabled people. The subsequent confidential investigation into the effects of the welfare cuts is the first of its kind, and its findings are due for publication this year.

Paula Peters, a member of the national steering group of DPAC, and a member of Mental Health Resistance Network, gives an account of the meeting and protest at Parliament on the 29th and 30th of March:

Today in Parliament, during the Unite Community Benefit Sanctions and Benefit Cuts meeting, MPs John McDonnell, Ian Mearns, and Debbie Abrahams joined in a minute's silence to remember the thousands of disabled people and job-seeker claimants who have died due to benefit cuts, being found fit to work by WCA, and benefits sanctions.

Just before our meeting, a young man in psychological distress jumped into the Thames from Westminster Bridge. He was pulled out of the river by the river-boat police. We don't know any more than that, but our thoughts are with him and his family, and we

hope he is ok and getting the support he needs. It was heartbreaking to hear of another person in deep distress trying to take his own life, and all of us present today fell silent to think of him, and our thoughts are with him tonight.

We also remembered Laurence Bond, who died on the way home from Kentish Town Job Centre, a few months ago. We remembered every single claimant going through hell with sanctions and the horrors of the PIP and ESA assessments.

We performed my piece of poetry, 'Cracks in the System'. This is about benefit sanctions, the traumatic outcomes, and being left in deep psychological distress. It was performed in front of many Unite community activists and MPs John McDonnell, Ian Mearns and Debbie Abrahams. This was filmed and is available on YouTube (www.youtube.com/watch?v=zXITZf6s-KM). Please watch it and share it, as am sure many people could relate to how benefit sanctions affect thousands of job-seekers claimants and disabled people.

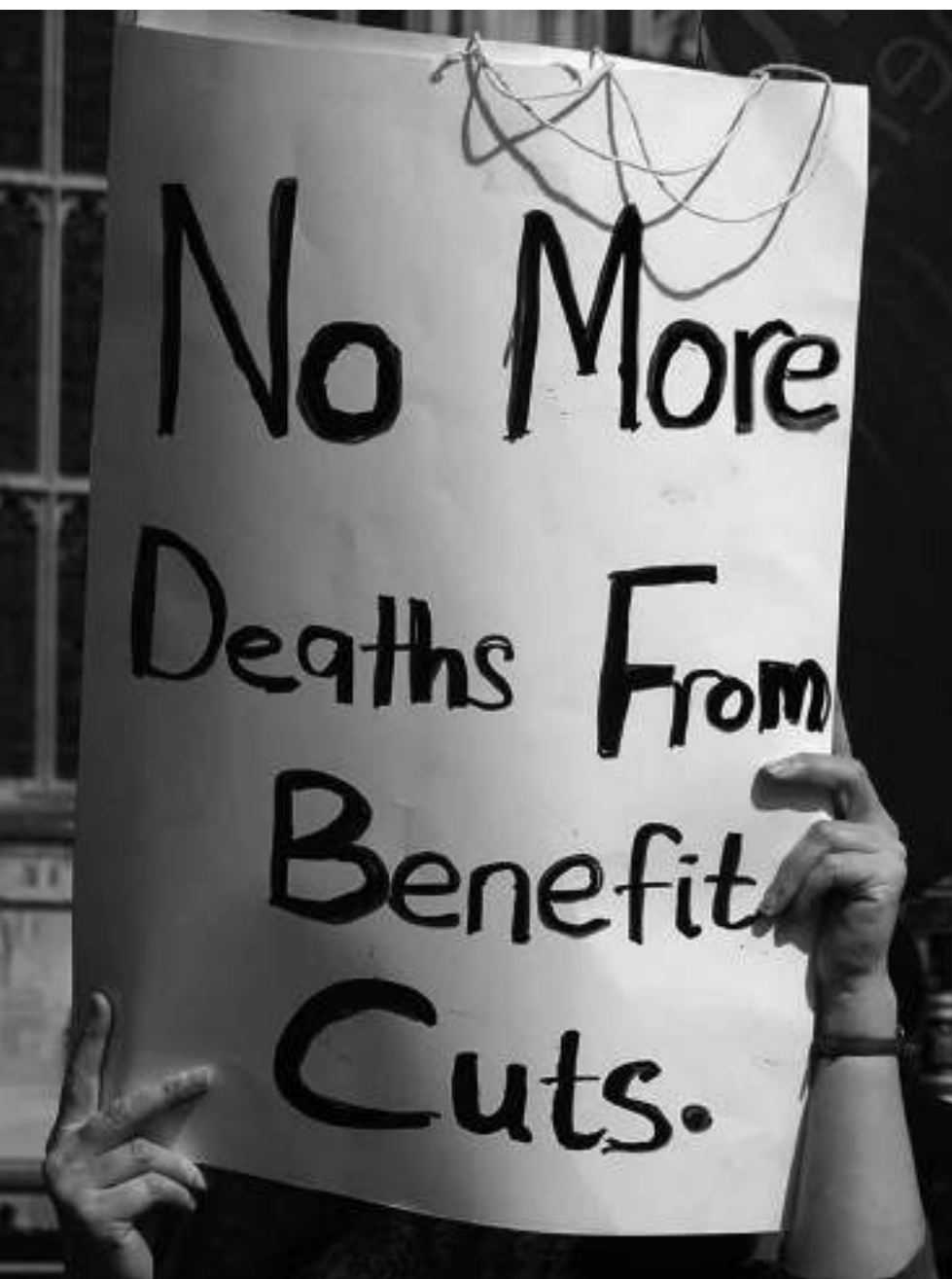
We had broken Parliamentary rules, and snuck in banners. Vince Laws's banner said: Dead People Don't Claim. We tied it to TV monitors and left it there.

We shared personal stories about benefit sanctions, the WCA, and the deep distress they cause. When the MPs left to go to an emergency PIP debate, Ian Mearns shouted out to us "Don't let the bastards grind you down!"

As we came out of Parliament, the world's media was on College Green, interviewing a lot of MPs about Brexit. So we crashed the Green and got out the Dead People Don't Claim banner. Six of us held it up so the press gathered on College Green could see it. Some photographers took pictures.

We could see Iain Duncan Smith talking to a journalist, obviously his thoughts on Brexit. On the banner, below Dead People Don't Claim it said 'Iain Duncan Smith should be in the dock'. We shouted out that the UK government was guilty of grave and systematic human rights violations of disabled people, that its policies were killing disabled people, causing mass homeless, and making thousands go hungry, that the same government which evoked Article 50 to leave the EU were guilty of grave and systematic human rights violations under UNCRPD.

Many journalists heard us and looked over, so we got under the barrier and turned our banner closer to the journalists and the media tents. The police came. One was aggressive and said we were trespassing. We told him we did not care, we wanted the world to know what was happening to disabled people – that thousands of disabled people were dying and the Government was guilty of grave and systematic human rights violations.



We were threatened with having our banner confiscated, and told that there was no such thing as a peaceful protest and we were causing anarchy. But we stood in a row holding, Vince Laws' banner in front of the world's press, telling them the truth, the truth that they and the police simply did not like.

Later, more Unite community activists arrived with another banner to show the press. A group of us decided to wander into the media camp in order to target MPs talking to reporters, and to ask if they would wear a No Benefits Sanctions sticker. Hilary Benn took one. We saw Jon Snow in the Channel 4 tent. He waved, and after a while came and talked with us. He took a sticker, and we told him about the Unite Community National day of action on benefit sanctions. He had a few photos taken with us.

It was a bizarre day: PIP emergency debate, benefit sanctions meeting with MPs, and the triggering of Article 50. But we all came away with one thing – tomorrow we will be back on the streets raising more awareness of the impact of benefit cuts, the deaths of disabled people and the horrendous psychological distress that the cuts to benefits and services are causing.

The fight continues... We have no choice.

We are in a fight to live – a fight to survive. ■

* Work Capability Assessments (WCAs) are used to reassess recipients' of out-of-work disability benefits, i.e., Employment and Support Allowance (ESA). They were originally introduced by the Labour Government in 2008, and subsequently rolled out by the Conservatives. More than one million people were reassessed by WCAs between 2010–2013.



MAD PRIDE AND DEPRESSION: How can we take pride in negative experiences?

JONATHAN BEAZER

Introduction: What good is there in depression?

According to the ideals of Mad Pride, people should treat me with justice, according to my human rights, not according to my mental “disability”. I agree. However, who wants to take pride in “symptoms” that include depression, panic attacks and extreme mania? Many other marginalised groups do not seem to have intrinsically detrimental aspects to their being, as the social model of disability has demonstrated for differently abled people¹. It’s fine to speak of Black Pride, for example. There is nothing intrinsically unpleasant about being black. Any negative or unjust treatment of black people can be clearly attributed to social causes. By contrast, some behaviours and feelings during madness are unpleasant, and possibly harmful to the self and others. Sometimes these behaviours seem to be an intrinsic part of ourselves, regardless of how they are caused².

For example, while I have been free of serious “depression” for a few years, thankfully, in my worst times of darkness I felt locked at the bottom of a black tunnel with no ability to see any future. I actually experienced a blackness at the edge of my vision, and contemplated suicide. Or, when extremely elated (“manic”), I had amazing energy and creativity, but also displayed a lot of anger and poor judgement. So much so, that I can attribute losing close relationships to this high energy state, because I was so hard to live with. I have friends who suffer “anxiety attacks” so severe it debilitates them and causes endless insomnia. As mad people, how can we say we take pride in experiences like these? In this article I attempt to sketch out some possible directions.

Understanding pride

I think, first, we have to clearly distinguish what we mean by “pride”. Our understandings of the word may need to be more nuanced. Writings on ethics may help unpack the understanding of “pride” as value, or of madness as a “good”. However, I have not investigated philosophical understandings of “pride”. I think mad pride is fundamentally about human rights, not about celebrating everything that mad people experience or do. Beresford (2016), for example, argues that Mad Studies’ social model of madness and distress should also be a rights-based approach, highlighting barriers that restrict the rights of mental health service-users. Yet this social model need not celebrate all mad experiences. Mad Pride might say, “I am a human being with rights, and should not be forced into compliance with social expectations.” Mad pride might also say, “I am OK just as I am. I am valuable even with

my madness, and do not need to change.” However, Mad Pride should not say, “Everything I experience is good.” Nor should it say, “Everything I do when I’m in an altered state is good.” I think we can take pride in our difference, but not necessarily in negative expressions of this difference.

For me, the word “mad” hints at energy and excitement, and by reading some Mad Pride authors one could be forgiven for thinking that there is nothing negative about any expression of madness. Perhaps these (few) overly-positive perspectives explain why some people living under diagnoses do not wish to identify as “mad”³. So my current preferred descriptor for those who experience altered realities is MMD – those who live with Madness and Mental Distress – because I think the distress also needs to be acknowledged. In this article, when I abbreviate MMD to “madness” it is with the understanding that distress must also be understood as part of the mad life. An example of an approach acknowledging the dark side of madness is Lucy Costa’s recent discussion of violence perpetrated by some mad people (Costa, 2016). Another example which explores diversity within mad experience is Nev Jones’ and Timothy Kelly’s (2015) chapter. With such diversity, inevitably some experiences of madness and distress will be negative.

However, I can also see how including negative experiences might be strategically unwise for the Mad movement. In spite of twenty or more years of mad activism, I suspect the majority of those with a “mental disorder” diagnosis do not yet see the positive side of madness, and do not even know that Mad Pride exists. Let alone those in the wider “normal” world, who often treat madness with stigma and injustice. So if we were to develop a more nuanced view of madness which also includes negative experiences, would this hinder efforts to gain justice and a valued place? Or maybe this nuance would attract those who don’t currently identify as mad? I don’t know. It does seem that many people don’t understand the fine distinctions, and just want a simple sound-bite: “Mad is good.” In order to achieve full human rights, perhaps for the time being “mad is good” is preferable to “mad is good – but complex”.

Further, if we cannot take pride in negative experiences in themselves, would this also undermine pride in positive mad traits, such as creativity or energy? If we are able to distinguish between valuing the experiences themselves and valuing the *results* of those experiences, perhaps not. For example, I think the experience of elation or hearing voices can in itself be a fulfilling part of life, much the same

as the enjoyable experience of LSD might be considered a good in itself. However, my times of black depression were not enjoyable in themselves, and I would not wish them on anyone. However, out of these experiences I have learned compassion, patience, and perseverance, which are of benefit me and anyone interacting with me. It is the *results* of madness I value, even if the madness itself is sometimes painful. In fact, many traditions find value in suffering, and I suspect a case could even be made for understanding black depression as a good. But it requires a great deal of personal maturity and life experience to develop this perspective, and I won't attempt to make that case here. (Please don't ever tell someone in "depression" or "anxiety" that they should endure because it develops character!)

So, perhaps taking pride in the *results* of our madness can sidestep issues around the value of madness itself. But I confess I'm not entirely satisfied. Without wanting to enter debates about essentialism, madness sometimes appears to be a core part of us, and my suggestion may devalue it. In turn, this relates to what it means to have a mad *identity*, which I hope to continue in a future article. As Peter Beresford (2009) has indicated, we need more work developing a philosophical and theoretical base for Mad Studies. Whatever such deeper understandings may be, if it is to represent all of us, Mad Pride must be able to incorporate experiences of suffering.

Conclusion

I suggest that an understanding of pride in being a mad person might be based not on madness itself, but on the results of madness. This might allow those who have come through the horrors of "depression", "anxiety", hateful voices, and "mania", to claim that they too, are proud of who they are. However, if madness is believed to be a core part of our being then this may not be a satisfying solution, and further work is needed. Regardless, Mad activism might benefit from coming to terms with negative experiences of madness.

I wrote this as an initial think-piece, so as to formulate my thoughts and feelings around this topic. No doubt I have missed out on writings that could improve this article, and I welcome corrections and suggestions for further reading. ■

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1. Disability Studies now includes views which challenge the "merely" social aspect of disability and puts more weight on people's lived physical difficulties, such as chronic pain.
 2. I favour the view that madness is more social than biological, and that conventional medical views of the mad are restrictive. See Timimi (2014).
 3. Diamond (2013:68) notes that, "language is used in multiple ways by psychiatrized people, reflecting different perspectives and experiences of psychiatry". Mad Pride has thus far avoided imposing a single language style on all its adherents.
-

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References

- Beresford, P (2016) Mad Studies 2016: A situation report. *Asylum* 23:4.
- Beresford, P (2009) Developing a social model of madness and distress to underpin survivor research. In Sweeney, A et al (Eds) (2009) *This is survivor research*. Ross-on-Wye, UK: PCCS Books.
- Costa, L (2016) Mad Studies needs to examine its silence on violence. *Asylum* 23:4.
- Diamond, S (2013) What makes us a community? Reflections on building solidarity in anti-sanist praxis. In Le Francois, BA et al (2013) *Mad matters : A critical reader in Canadian Mad Studies*. Toronto: Canadian Scholars' Press.
- Jones, N & Kelly, T (2015) Inconvenient complications: On the heterogenaities of madness and their relationship to disability. In Spandler, H et al (Eds) (2015) *Madness, Distress and the Politics of Disablement*. Bristol: Policy Press.
- Timimi, S (2014) No more psychiatric labels: Why formal psychiatric diagnostic systems should be abolished. *International Journal of Clinical and Health Psychology*. 14 208–215.

An apology

Tim Wilson has asked us to point out that in his article, 'Mad Studies? A response' (*Asylum* 24 1, 20–21), at one point in the editing we managed to change the sense and get it wrong. On page 21, the word 'real' was inserted into Tim's phrase 'health problems' – we had it printed up as 'real health problems'. This was not what the edit had intended, either: trying to reduce what was read as an ambiguity in a long sentence, it seemed that the author meant to distinguish 'physical

health' from 'mental health'. This was a mistake. When he had written to suggest abolishing psychiatry and '... replac[ing] it with more doctors of medicine (MDs), [since] they are trained to deal with health problems...', this is exactly what Tim meant.

We apologise for this mistake, and can only plead that the editor received the article only just before the whole issue was due to be laid-out, had to rush the edit, and didn't have time to refer it back to Tim for checking.

Sonic

ERIN MUELLER

You know how in the old Sega Genesis game Sonic, that came out in the 1990s, you spend the entire game trying to accumulate as many rings as you can and then you get hit by a wasp or fall on spikes and you lose all the points you got? That's me.

In a regular person's world you strive to get good things: a job you like, a house that feels like home, a respectable grade on a term paper, have a pleasant meal with your mother, go on a picnic or romantic dinner with a date, etcetera. And if something sets you back you get past it and move forward. Not everything is bad; just that one moment in your life, and you have the perspective to see is as just that. One moment, one tiny little thing. Like

maybe missing a flight or bombing a paper? And it sucks, but it's manageable.

I'm not at all like that.

I'm Sonic: one spike hits me and I'm finished. I lose all the goodness, all the rings, if you will, and I'm done. *I'm empty.*

I feel like if one more wasp hits me or one more thing gets thrown at me I'm dead. I spiral uncontrollably until there is nothing left. I drop a folder, I think I should kill myself. I cut someone off on the freeway and feel stupid. I sleep in too late and miss doing some mundane thing I had to do that day, I cry.

And I hate being Sonic. ■

erinashleymueller@gmail.com



Image by Róisín Curé

SOUL RELICS MUSEUM

VANESSA

I am developing a storytelling and mental health platform with the ultimate aim of curating a museum exhibition.

Soul Relics Museum is a platform for people to read and tell stories through objects that help them connect to an experience they have had (past or present) with their mental health. The object can range from anything personal to something in the system. It's a unique and creative idea to help people come forward and share with others what mental health problems have been like for them - a safe and constructive way to read about others' experiences while being brave enough to share your own. Together, we can create a collective voice for raising awareness about mental health!

An object is a good medium: when we see a thing, memories related to that object may readily come to mind. For example, when I see a key I might think of home. Some of those who submitted material found it really interesting to view their story with mental health by using an alternative perspective. For example, they told me things like, "Oh yeah, I remember when I was very ill and no one seemed to understand me, and a smile from a stranger on the street made my day," or "I felt things were so out of control, then one day, I picked up a pebble on the street and it felt so soothing, because I was holding something solid." And so on.

I hope to get as many perspectives as possible in relation to this topic. Different people interpret "mental health" differently, and may view it critically. The idea is to encompass as many perspectives as possible.

Here's an example of one of the stories:

Object: **Drum**

Title: **New Beginnings**

I remember many years ago I was very ill and I was in denial. My parents were absolutely mad at me and could not understand me. My dad even broke part of my drum kit, something that I deeply treasured. I could vividly remember that scene when he was so infuriated, shouting and threatening to throw the instrument away. I just sat there, crying with angry tears, feeling helpless and not understood.

Months later I agreed to be voluntarily sectioned, and on the ward I met one of the friendliest people I have ever met. The doctors and nurses understood that my music exam was coming up, so they let me take the drum set to a quiet room in the ward to practise. Everyone said I was talented. Being well enough to attend the exam then became one of my biggest motivations, and I ended up with a high distinction.

Memories (painful ones and joyful ones) come back to me every time I rehearse and practise, but the drum has now provided a new definition and narrative to my life.



If you agree with the initiative, I would be super grateful if you could take a look:

soulrelicsmuseum.me

Perhaps you could write a short personal story. It can be any story and any object that evokes memories of asylum, or anything to do with psychiatry or mental health. Send it to: soulrelicsmuseum.me/Contribute



Madness in New Zealand: A conversation

MARY O'HAGAN

*This article is edited from a conversation between Mary O'Hagan and Professor Catherine Coleborne, a historian of 'madness' in Australia. In the late 1980s, Mary was a key initiator of the psychiatric survivor movement in New Zealand, and between 1991 and 1995 she was the first chairperson of the World Network of Users and Survivors of Psychiatry. She was a full-time Mental Health Commissioner in New Zealand from 2000–2007, and is now director of the international social enterprise PeerZone. Mary has written an award-winning memoir, *Madness Made Me*, and in 2015 was inducted as a Member of the New Zealand Order of Merit.*

Contribution to the Mad Movement

When I started my involvement in the movement thirty years ago, you set up a network or an organisation outside the system. I set up Psychiatric Survivors, in Auckland. This was a peer-supported advocacy group, initially independently funded, though we did get some funding from the Auckland Area Health Board. I was the first Chair of the first network of users and survivors of psychiatry, in the early 1990s. So I did a lot of advocacy outside the system. Gradually the system recognised that the voices of people who use services were quite important. So they started creating positions for people inside the system.

I had a job in England as a user consultant for a year, in the early '90s, and then I came home and got a job in one of the regional health authorities. I still had involvement with the world network of users and survivors, so we did a bit of work with the World Health Organisation and the United Nations. In 2000 I got a job at the Mental Health Commission; this was for six-and-a-half years. That was kind of within the system, although the Mental Health Commission was a little bit to one side in a way – it had some autonomy. It was a small organisation so it had potential that most other jobs wouldn't have had for me. The contribution I tried to make in that role was at a more systemic level. It was about how do we articulate a recovery approach, and how do we translate that into actual service delivery.

At the end of that time, I was pretty disillusioned, and I thought "This is a sucker's game." Trying to change a

system that doesn't want to change, that has the resilience of a cockroach when it comes to having any outside influence come in and try and change things. So I had a bit of a mid-life crisis after that, and I thought "What am I going to do now?" I steered away from any form of advocacy or trying to change what goes on in the mental health system, because ultimately it was such an unrewarding experience. Now instead of battling away with the forces of darkness, I make things! I much prefer this. I've always had a strong desire to not so much to destroy through critique but to create alternatives. I quite enjoyed destroying through critique, but I think it's a bit mean just to run things down without at least articulating what could replace it.

I remember being a young Pakeha [white European] woman in New Zealand. That was the heyday of Maori activism. They'd say "Well, you need to implement the Treaty of Waitangi." And the Pakeha people would say "How do we do this?" And they'd say "Oh well, you fuckin' work it out for yourselves!" I've always remembered that, and I've always been quite careful that when I do destroy by critique that I actually show an alternative. You need the critique in order to do the remaking, but ultimately I get more enjoyment out of making things than critiquing them.

Now we develop peer-to-peer workshops on mental health and addiction, called PeerZone. We train facilitators to deliver them, and it's going in Australia, New Zealand and Canada. Over the last two-and-a-half years we've trained more than 130 facilitators. The other big project I'm embarking on is Swell, an online and paper-based recovery tool for people with mental distress and those working with them. I'm probably a lot happier doing that stuff than doing advocacy work that doesn't really lead anywhere.

Defining Madness

People often say: "Why do you use the word 'madness'? It's a stigmatising word." But it's a reclaimed word, in much the same way that 'queer' is in the Gay Rights movement. It's just a common, everyday word. Whereas if you start talking about 'schizophrenia' and 'mental illness' and things like that you're taking on the words of the people whose world view you don't particularly agree with.

So what does ‘madness’ mean as a concept or experience? In a way, I use it as a replacement word for what people commonly might call, in that awful language, ‘serious mental illness’. They are experiences that affect everything – your intellect, your sensory experiences, your sense of having free will... They affect you physically, they affect your relationships. They’re kind of extreme, overwhelming states of mind that affect all those things. They affect your behaviour as well. But I think they’re states of mind that have been totally devalued and shunned. You can see at a superficial level why people do that, because it’s scary and it’s weird and it’s frightening for onlookers and for people who are going through it.

But I think these are experiences that we can a) learn to manage and b) derive meaning, experience and value from. Being able to derive meaning and value from them might actually help us manage them.

Sometimes these states of mind put you in vulnerable positions. There’s no doubt about that. But I think the state has used very clunky tools to manage these risks. My broad idea is that we need to manage these risks by being with people all the time. People sometimes need someone with them 24/7. But I think we should manage those risks through people rather than locks and keys. The locks and keys are the most expensive options you’ve got. We have a Mental Health Act. I actually believe that if you looked at the whole picture, would the world be a better place without them? I think it would.

Personal experience of madness

When I first had these experiences, they were overwhelming. I didn’t have a name for them, I didn’t know how to make sense of them. I went along to some experts who told me they were probably a result of some brain chemistry problems or genetics, and there wasn’t really anything much they could do. They could give me pills, which might help, but I’d had this for life. I’d have to really lower my horizons because I had this condition that was genetically pre-determined. They gave me a real ‘fading life chances’ story. I tried to accept that for a while, but then I thought the treatments really aren’t doing anything for me. I read a lot of anti-psychiatry and some early literature from the service-user movement, and I realised there’s another way of viewing these experiences.

It was an incredibly powerful, profound experience, but a very difficult one. I don’t want to romanticise it. It was incredibly difficult. Since I’ve moved on to other parts of my life, I just haven’t had anything that comes close to it for difficulty. But it shaped the whole way I view the world, and it helped to shape me as a person. I learnt a lot of resilience from it. I learnt a whole bunch of life skills I wouldn’t have otherwise learnt. It gave me a much broader picture and a broader human experience than most of us have who just get up and go to work, and are quite blinkered. It’s quite good to be quite blinkered but when you take those blinkers off, as happens in madness quite a lot, you just see these other worlds, or have these other experiences, and they broaden you out as a human being.

For instance, this experience they called depression. I had

this thing about being in a black box. All the meaning I’d built up over my life had been stripped right back – and there was nothing there. I had this huge sense that it was a total illusion, everything. And that still remains with me. I’ve got this sense that we decorate our lives with all this meaning, but what’s behind it? Now I think that we have to decorate our lives with all that meaning, but there are these bare black boards behind it all. I’ve learnt to live with that, but I didn’t get up one morning and say that was a total delusion. I sort of learnt to live with the idea that actually we create meaning and there may not be anything objective that we can see behind it.

The mental health system sees madness as a kind of tumour. If they could have cut it out they would have, but they couldn’t because it wasn’t located anywhere they could find. So their attitude was: “This is bad and we have to eliminate it.” I thought instead of trying to cut out this tumour that they think I’ve got, metaphorically speaking, could I make friends with it? I thought of the image of this boarder coming to live in your house, and you realise they’re an alien. You don’t really like them very much but they’re there, and you have to make the most of that relationship, understand them, learn to respect them, and learn how to manage the whole thing.

By this stage I was thinking this might happen for the rest of my life, so I have to find a way of living as well as I can with these experiences. When I started going into those deep depressions, I started getting better at being in them and not getting so frightened. Then I started to manage the highs as well.

The medical people said this was like a growth that was disrupting the self, that it wasn’t really part of my self. I framed it as something that was sitting outside my self that kind of came in and invaded it. But I never got my head around where it fits with the self. I think it’s very easy to see it as separate from your self. Especially if it’s stigmatised and shunned. But all those experiences *came from my self*.

One thing that helped me was that I never experienced self-stigma, which is very common. People who go through the mental health system deserve a medal. They should be recognised for the incredible internal battlefields they have to negotiate.

The role of medical professionals

I’ve never ever said we shouldn’t have any psychiatrists. I use the analogy of a household. If I own a house, I’m the project manager of the house, and when things go wrong I call on different experts at different times to help me fix it up, if I feel I don’t have the skills to do it myself. And that’s how I’d like to see the mental health system: so that I’m at the centre, the project manager of my own services. The psychiatrists and the medical people need to get out of the hub and just be one of the spokes. ■

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They Call This “Help”

One man’s tears and the horrors of a Canadian psychiatric institution

OTTO DOUGLAS

I am an inmate of St. Joseph’s Psychiatric Hospital, Hamilton, Ontario. Although still trapped in the intricate web of the forensic “mental health” system, I consider myself a psychiatric survivor. After all, I’ve made it this far, but I realize that more time is needed before I’m finally able to extricate myself from the forces of psychiatric oppression. Before entering the system, I knew virtually nothing about the philosophy and practice of psychiatry. After about a year and a half of being subjected to an endless, humiliating barrage of psychological and physical abuse, I have come to loathe and despise this pernicious and evil form of pseudoscience.

At first, I fell into the deepest fog of despair I had ever experienced, paralyzed by the emotional and physical pain I was forced to endure at the hands of my psychiatric keepers. Since I realised how evil psychiatry is, I now spend almost all of my waking moments completely devoted to making sense of the bizarre and irrational world in which I find myself. How, I wonder, are psychiatrists the world over allowed to abuse their “patients” with impunity? Any time I have to spare, I devote to spiritual matters.

Who am I and what am I doing in this institution? This is my story.

I’m a middle-class native of Brampton, Ontario. I first attended university in the mid-1990s. I started studying humanities but didn’t graduate until 2014. Originally, I wanted to study law at Osgoode Hall Law School, York University, but for various reasons, enrolled in a master’s in education. But before I was able to begin my degree, I was arrested on a bail violation. What led up to this?

In 2013, I had been feuding with some neighbors. In August, they called the police and, although I claimed self-defense, I was arrested for a number of minor criminal offenses. The next day I was bailed out by my father, but we were forced to move and live elsewhere. About a year later, in August of 2014, I was arrested again but my father refused to bail me so I remained in the provincial jail while my lawyer and the crown negotiated a plea bargain. When I heard it involved about a year behind bars, I was horrified. I’d served about 20 days in prison some ten years before, but this seemed totally unreasonable. I felt I could not survive that sentence so I asked about pleading not guilty. However, the lawyer felt I could lose and be sentenced to up to two years for “wasting the court’s time over a foregone conclusion.”

In desperation, I tried to find alternatives. Someone mentioned going to a mental hospital instead of remaining in jail. I was told by a number of former psychiatric inmates

that inmates had their own rooms, could order takeout and play videogames. They said it was easier than doing time in jail.

“How hard would it be to get in?” I asked one of them.

“Not hard at all,” he said. “If you tell them that you’re suffering from auditory and visual hallucinations they’ll find you not criminally responsible (NCR).”

“Won’t they know I’m lying?” I asked. “Won’t they know I’m an imposter?”

“No,” he said, “not at all. You can tell them you’re suffering from delusions and they’ll believe it, almost without question. It doesn’t matter if you don’t have any history of psychiatric illness or hospitalization, just make up some nonsense about hearing voices and they’ll swallow the whole thing hook, line and sinker. If you want a guaranteed, automatic NCR, tell them that you’re seeing things. They’ll really believe you then. And remember, they can’t prove whether you’re lying or not.”

At the time, it seemed great but I now know this was the worst possible advice. I now realize I over-reacted to my fears. I had no idea what I was getting myself into. I should have realised that if it was so easy, why wasn’t everybody doing it? But I was desperate to avoid jail so I didn’t look into it properly. I didn’t ask for “hospitalization”, I asked my lawyer to mitigate any sentence by requesting some form of mental health diversion. Apparently believing that my lawyer’s plea for mental health diversion was just malingering, the judge decided to have me transferred for psychiatric assessment to the Waypoint Centre for Mental Healthcare, Penetanguishene. I asked my lawyer how long this would take. He said it would probably take about as long as a jail sentence, maybe a bit longer. He did not tell me that once committed to a “hospital”, I could be held indefinitely. Nor did he tell me about such routine practices as forced administration of drugs and electroshock, or the mechanical restraints and solitary confinement that could be imposed as punishment for the most trivial infractions. If I had known this, I would never have gone this way.

At first, I found that the living conditions at the “hospital” appeared to be much better than jail. After all, you did have your own cell, as well as being able to order takeout and play videogames throughout the day. I did not know that these seemingly better conditions came at such a terrible price.

Sticking to my story, I lied to the examining psychiatrist about hearing voices and other perceptual disturbances.

Even though I knew next to nothing about schizophrenia or any mental disorder, I told him about seeing purple elephants and men in pink bunny suits. Despite my fears, he appeared to believe everything I told him, no matter how ridiculous or improbable. Once again, no one told me that commitment was an indefinite sentence with involuntary treatment. I was never told of the dangers of their so-called "treatments". Only much later did I learn that psychiatry was not really a branch of medicine, just a form of social and psychological coercion disguised as "medical treatment".

As for my stay in this "hospital", I can only describe it as the most brutal, vicious and degrading "treatment" that I have ever experienced. My (limited) experience of jail is that it is easy compared with the daily psychological and physical tortures visited upon the "criminally insane". For example, in a "hospital", inmates have practically no privacy. Every 15-30 minutes, cell doors are flung wide open, which means the occupants are constantly on edge. Rooms are stripped and searched weekly, sometimes more often. There are also routine body-cavity searches. Inmates are asked the same questions over and over again, to assess whether they are a danger to themselves or others (the so-called "mental status examination"). The same questions can be asked over and over again in a single day, but whatever its justification, it is nothing more than a particularly intrusive, degrading and infantilizing form of harassment.

Trivial infractions, such as failure to return a plastic spoon to staff, can lead to a barrage of abuse, more intensive surveillance, and even additional room and body-cavity searches. Other offences such as "raising your voice" or pushing away a chair in a supposedly "threatening manner" can lead to loss of "privileges", such as they are. Looming behind this is the ever-present threat of violent physical restraint by guards, forced drugging, mechanical restraint and solitary confinement.

It was only during my civil commitment at St. Joseph's that I began to realize what complete and utter bullshit psychiatry is. The nurses seemed to be incredibly ignorant of how the drugs and electroshock were supposed to work. When I asked them how forcing someone to do something against his will could possibly be considered therapeutic, they said that it is "just hospital policy". I asked them to define "mental illness". None of them could do so. Perhaps they were playing dumb, but it was very convincing. Eventually, I realized that the nurses' ignorance was simply a reflection of the serious underlying methodological and empirical deficiencies of psychiatry as a supposedly legitimate medical discipline.

Many times the nurses would become angered by my persistent questioning, to the point of taking away my few "privileges". Eventually, they stopped answering and told me to ask the psychiatrists. They said that "mental illness" was caused by "chemical imbalances" in the brain, but when asked for conclusive scientific evidence, they were unable to provide any. Because I refused to accept their

seemingly authoritative pronouncements, they decided I was paranoid. By that stage, I had realised that psychiatry is just pseudoscientific quackery and that psychiatrists are delusional "true believers".

Even though I am subjected to degrading and dehumanizing ill-treatment on an almost daily basis, I do everything in my power to avoid doing anything that might lead to any direct confrontation with my psychiatric torturers. Given the highly arbitrary and subjective concepts of "dangerousness" and "aggressivity" that are routinely deployed by staff, this is not easy. The slightest disagreement is easily blown out of proportion and can be interpreted as aggressive behavior, requiring immediate physical restraint and injections, followed by mechanical restraints and solitary confinement. Because of this arbitrary abuse of power, I feel that I am in constant danger. I have no choice but to do everything I can to get out of this system. My lawyer is appealing the original NCR finding in the summary court, but I am also trying to get people to pressure the hospital administrators to have me released.

I want to get out of this medieval torture chamber in one piece. I do not want to come out with brain damage, a neurological disease such as tardive dyskinesia, cognitive impairment, cardiovascular problems, shortened life expectancy or severe psychological trauma – and with nothing but a monthly disability check and government subsidized housing as "compensation" for my sufferings in this brutal system.

The longer I stay in this madhouse, the more I realize that my health, safety and even my life are in jeopardy. I can understand why some inmates turn on the hospital staff, who are supposed to help them but who hurt and humiliate them. I see now that a long prison sentence is better than this abuse. Who cares about the iron bars and orange jumpsuits of the federal penitentiary? At least your mind and spirit will be free of all externally imposed chemical, mechanical and electrical restraints. Better a drug- and shock-free imprisonment where one can finally be left to one's own devices than therapeutic "treatment" in some "hospital".

In retrospect, I realize how incredibly stupid I was, even though I honestly did not know what I was getting into. I should have known better. I should have been sceptical. If I had known about the indefinite nature of the sentence, the humiliating daily surveillance, the routine infantilization, the daily physical and psychological abuse, the forced drugging, forced electroshock, physical and mechanical restraints and solitary confinement, I would have run to the nearest jail and banged on the gate to get in.

Since being committed to the "hospital", my life has been a terrible nightmare. Imagine beginning each new day sweating, your heart pounding, sick inside from a life that is beyond horrifying, an endless series of sufferings from which there is no relief. I cannot describe this torture. I accept that I deserve to be punished for what I did. I accept full responsibility for my actions, but I do not deserve this. No one does. ■

What The Watcher Did

MARIA ANN SNOW

“Life’s greatest gift is the freedom it leaves you to step out of it whenever you choose.”

André Breton, *Anthology of Black Humor*

According to Andre Breton “Life’s greatest gift” saved my sanity.

Memories of my childhood are quite vague, with loads of gaps. I know that when I was two the family (including my



Figure 1 – This is my Gravatar which shows a side view of a tissue and wire face casting a big shadow. The shadow symbolises the unseen drama behind the façade.

brother, five years older than me) moved down to Wales from a town in Staffordshire. This was so that my dad, an electrician, could work with grandad in the Royal Ordnance Factory. I also know that I had a mental breakdown at the age of seven, and then again at thirteen.

My parents’ attention was always focused on my older brother since he was always in trouble. He was like a bull in a china shop, with no conscience. I called him The Golden Child because my mother idolised him. While he was out raising hell, from the age of seven I spent

my spare time in my bedroom, reading or painting.

Despite many problems in childhood, I emerged from school with good qualifications and went to train as a biomedical scientist, working in a bacteriology department at a nearby pathology laboratory. I qualified with a HNC three years later.

Eighteen years, one husband, two daughters and a dog called Bella later, at the age of 36, I started to have problems that initially came out at work. At that time I was working the evening shift as a chemical analyst in a pharmaceutical company. I started to have arguments with my boss, who was also a friend. This escalated until I left, sick with stress and anxiety. I had been approached by a small pathology firm, and went to work for them. A year later they sacked me, over the phone, and I took them to a tribunal. I won the case, but the rot had set in. This was the beginning of an avalanche of failed jobs and work tribunals. In all, I went through five jobs and two tertiary colleges (including the Forensic Science Service and L’Oreal), before I came crashing down and sought help.

After intense counselling and later psychotherapy, with the aid of left-hand writing and art therapy I became aware that I had created three inner children and ten entities. These beings lived in an alternative reality which had absorbed the effects and provided a barrier to serious sexual abuse by many men and an incestuous relationship with my brother.



Figure 2 – I call this the Pineapple Head The central figure shows ten profiles of a face. These correlate to the ten entities created. There are five on each side. The central eye shows that they all belong to the same person and The Watcher lies coiled at the base on guard duty. The fronds of hair reach out into a maze which indicates the complexity and patience needed to unravel each entity’s identity.

My world crashed down around me. Everybody thought I was mad. My husband ran off with a work colleague, and I lost my career and so many jobs. Because I was too ill to fight the divorce, I was made homeless with my two daughters. I then started spending a lot of time in the local mental health hospital. I approached the police and gave them ten names of the responsible men, including my brother. Although they believed me, there was no forensic evidence. My brother tried to have me sectioned for life.

The three Children who I contacted through left-hand writing were Hazel aged seven, Emily aged thirteen and Paddy aged sixteen years. Hazel told me the details of the gang rape at the age of seven where two other children were involved, and Emily told me of the gang rape at the age of thirteen. I had had a nervous breakdown at both these ages. Paddy covered the incest from thirteen to sixteen.

The ten entities emerged from the second gang rape, when I was injected with drugs.

The main character to emerge from the entities was *The Watcher*, characterized in my pictures as a one-eyed snake, or even just an eye.

The Watcher was the one who took over when I couldn't cope anymore, and prided himself that he looked after me and aspects of my personality when I fell apart.

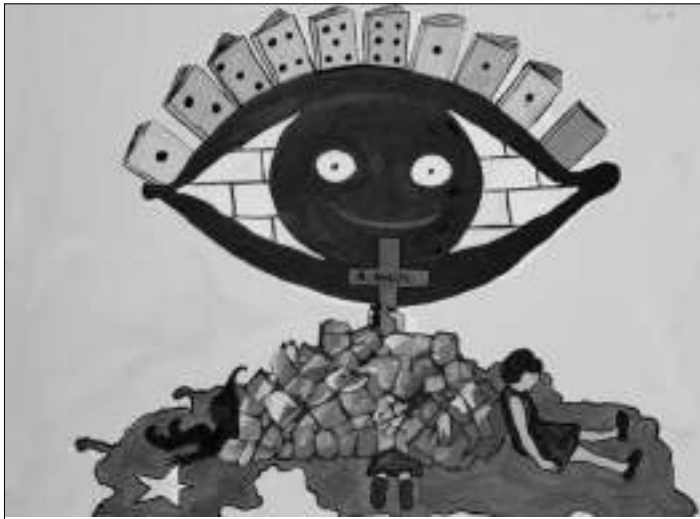


Figure 3 – This picture shows *The Watcher* as an eye with the entities balanced on top in numerical form as books. Below around the bottom of the cross displaying A.ANON is a pile of rubble which has flattened Hazel, whose feet you can see sticking out at the front. Emily on the right and Paddy, the leprechaun type figure on the left, has been knocked out too. This picture explains that when I couldn't cope in the abusive situations, *The Watcher* stepped in and looked after aspects of my psyche.

At this time, in therapy I painted a very detailed picture which contained all thirteen of the gang but in different symbols. Over the years I have painted my way through and uncovered all the different characters, ten of which originally appeared as dominoes, and were coded numerically. Between each session I would move on slowly uncovering each one by following the numerical trail with paint. *The Watcher* was always present and sometimes would try to stop the personalities from emerging. At these times I would get very ill and end up in hospital again until I could move on. The thing is, I would get the need to paint, and felt great relief when I had painted the picture. Then I would move on, and the pressure would lessen.

Another key entity is called Orange. Orange's number was five, and he represents my artistic creative side.



Figure 4 – This is Orange. Orange takes the form of a silent movie star like Charlie Chaplin or Marcel Marceau because he cannot talk. He is very clever and creative and as can be seen from the

dotted lines can connect with the other entities, shown here as numbered segments of a circle.

I came to a grinding halt on the last entity but one. I had been with a psychotherapist for many years, and the time had come for him to move on. Even though he had to finish the psychotherapy, I vowed I would get to the end of this process, and I have. Last year the final entity emerged in ceramics, and she's called Layla.

Figure 5 – This is Layla and she represents the link between the entities and real life. She looks part monkey which in my mixed up brain makes perfect sense.



So twenty years later my life is completely different. I live in a small social housing estate in South-East Wales and I am a grandmother to two adorable grandchildren. I have another dog, this one called TJ. During the last twenty years, I have pulled myself out of the black hole by my fingertips. I have completed a National Diploma in Graphic Design and a BA (Hons) in Art Practice. Unintentionally, all the art work in these two qualifications was linked to my past, but the pressure of the art work helped push me through to the end.

I volunteer at the local Art Centre with an alzheimer and dementia group, and I am religious. Many times I've prayed to God when things have been bleak, and I have often felt His quiet presence by my side and in my paintings.

The past does haunt me and I get bouts of PTSD and anxiety in which I re-live horrendous events. But they are getting fewer. When I look back through the last twenty years of my life, I think was that really me? Did I do that?

Having listened to people who have been victims of abuse, the main thing they want is justice for their ruined lives, and the second most important thing is to be believed. Justice is out of the question but I want to be believed and get some sort of closure, and maybe, just maybe, this article will help somebody out there who is facing a similar black hole. The message is that if you can keep going there is a light at the end of the tunnel. ■

Conquering the Stigma of Mental Illness

ERIC LEVY

I'm what's known as a 'functioning' person with bipolar disorder. It often doesn't feel that way, but I've held jobs for thirty years (with several disruptions along the way).

I worry about the costs of disclosing my bipolar disorder, particularly at work. So for now, I devote much energy to keep it hidden. With the exception of one former co-worker with whom I formed a friendship, I've never told anyone at work. Maybe some suspect, but I doubt it. I've learned to cover it well, whether I'm on the manic or depressive end. When I'm somewhat manic at my workplace, people flock to me, wanting to be the beneficiaries of my off-the-edge humor and irreverent remarks. When I'm down, interactions are more formal and much less interesting. That's why I've become such a good actor, with the ability to perform as if I'm up when I'm down. I also take a cocktail of bipolar and anti-depressant meds, which keep me somewhat stable. I no longer have long bouts of mania or depression. They come and go, lasting relatively short periods.

Why is it that mental illness is such a stigma? Simple: people are terrified of it happening to them. We are our minds. To lose your mind is to lose yourself, the most critical part of being human.

That's why we hide our disorders with the impenetrable masks we've taken so long to create with the greatest of care. Those who come out of the closet, as Sifu Casey Blood writes in *Science, Sense and Soul*, "are so tired from faking it." Then there are many of us who have elected to stay in the closet. In her book, *A Course in Miracles*, Helen Schucman writes, because "our greatest fear is being discovered."

Gary Zukav, in *The Heart of the Soul: Emotional awareness*, articulates what I particularly fear about having people find out about my disorder, especially at work: "You make a good impression at first and assume people won't like you once they get to know you better, so you push people away, anticipating inevitable rejection... Intimacy paralyzes you because it [reveals] the truth of who you are." In my case, and I suspect for many readers, that truth is often seen as a defect, a limitation in our social interactions that we pretend not to have.

The misinformation and stigma surrounding mental illness was widely broadcast in 2015, when Andreas Lubitz, a Lufthansa co-pilot, intentionally crashed a commercial plane in the French Alps, killing himself, 144 passengers and six crew. In a frantic search for an explanation, the media quickly began to blame Lubitz's treatment for depression, and speculated about his "suicidal tendencies". Some of the media reported that Lubitz had bipolar disorder. A CNBC TV reporter described Lubitz as "a troubled man who became a mass murderer."

According to the news reports, Nublitz did not disclose his mental illness to his supervisors. If he had, the logic goes, the management wouldn't have allowed him to co-pilot the

plane and it wouldn't have crashed, thereby avoiding the death of so many innocent people. The message seems to be: Those of us who have mental illness are capable of mass murder. Watch Out!

Whether or not to disclose is an issue that plagues many people with mental illness. Patrick Corrigan and Robert Lundin, in their book, *Don't Call Me Nuts: The stigma of mental illness*, write that you can consider your disclosure successful if you changed your attitude when talking about your mental illness, which no longer evokes a sense of hesitancy or shame. "Most people," they write, "are coping with some kind of personal trial or tribulation, even if it is not mental illness. They may be fascinated by your ability to cope and respect you for it. You may be pleasantly surprised to find out that others have similar problems. Frequently, people discover that when they admit to their psychiatric problems, others respond: 'me too.' Given that more than twenty percent of the population are struggling with some kind of mental illness at any one time... it is likely that you will have 'me too' experiences when you tell your story."

Workingwelltogether.com outlines three levels of disclosure: low, medium, and high. Low disclosure is providing facts to people, not too personal, and easy to share. Medium level provides biographical facts, opinions, and is sometimes risky to share. A high level of disclosure is very personal, risky to share, used only if you trust the other person, and if the other person is willing to listen.

The Working Well Together staff outline the benefits of disclosure:

- Not having to worry about hiding experiences with mental illness and being more open about day-to-day affairs.
- Finding others who express approval, including those with similar experiences.
- Finding someone who can provide assistance in the future.
- Promoting a sense of personal power and acting as living testimony against stigma and discrimination.

David J. Miklowitz, in *The Bipolar Disorder Survival Guide*, addresses an advantage to disclosing your mental illness at work. "Disclosing to your boss early on may set the stage for later changes in the structure or demands of your job... If your employer knows ahead of time, you can problem-solve with him or her about what accommodations seem reasonable during your period of illness." He writes that there may be instances when you feel you must disclose your disorder to your boss, such as when you've had multiple absences or a clear deterioration in your productivity. "Some people decide to wait to see if their performance actually does slip, and then disclose the disorder to his boss when asking for time off or other work adjustments.

An open letter from a PTSD sufferer

SHARON LOWRY

I am a lot of things.
I am a daughter, a sister, a girlfriend.
I am a feminist, an equalist, an animal lover.
I am a writer, a psychology graduate, an avid cook.
I am a pessimist, a joker, an adventurer.

I am a PTSD sufferer.

Of all these things, it sometimes seems as if society sees me as only one thing: someone with mental health difficulties. And very often the stigma and preconceptions have been more limiting than the illness itself.

You don't need to know why I have post traumatic stress disorder. It is the first thing that everybody asks. But you need to understand that, for people suffering from it, revealing our reasons can lead to people to view us in ways we do not want – or deserve. I am not a victim. I am not weak. I am not a liar, or an attention-seeker. Nor can I just get over it, move on, deal with it. I wish I could. But it's not that simple.

So I have been having anxiety attacks for twelve years. They started when I was fourteen. I don't have the attacks all the time. In fact, some years I have only two or three. The problem is that I have also had periods of debilitating anxiety that have lasted months. School, work, housing are all affected. Anxiety rips through my life like a wildfire and destroys everything. As a result, when I manage to somehow pull myself out of it, I am left living back with my family – without a job, having to pick up everything and to try this whole business of being an independent adult again. Feeling like a failure.

Last year, I had one of these bad times. But I also had a breakthrough. I went to a psychiatrist, and although I have seen many before, this one asked the right questions and realized something: I have post-traumatic stress disorder. And probably I've had it for twelve years. That's my entire teenage and adult life.

Perhaps you wonder how somebody could live so long with an illness like this, and not be diagnosed. That's a bit complicated. Firstly, post-traumatic stress disorder is largely understood to affect war veterans, people who have been in accidents, or just targets of violent crime. (Notice I never use the word victim: it's a very unhelpful way to think of oneself.) However, I had kept my traumas secret for years.

Secondly, it's to do with how people perceive the nature of the disorder. In films, a character 'zones out' and a big action scene starts – gunfire, explosions, etc. In fact, flashbacks don't have to include all the senses; neither do they have to last minutes, or result in the sufferer not knowing what they are doing or where they are. I don't know

if other people have flashbacks like that – I imagine that for some people it may be close to the truth, but probably not for the majority.

For me, the flashbacks are very similar to anxiety attacks, except they only happen when something reminds me of an incident from the past. They start with a quick flash of an image, a smell, or a sound. Sometimes, I feel pain from old injuries, but fresh and new, as if it's only just happened. This lasts a few seconds. Then every muscle in my body tenses. I feel like I can't breathe. At this point, I usually go to a quiet spot to calm myself down by using 'grounding' exercises. But if I cannot leave the situation, I start to hyperventilate. My legs cramp up. I get dizzy. I sit down and curl myself into a ball. I am unable to talk. I cry. This all lasts as long as it takes.

These, I was always told, were anxiety attacks. Nobody figured out they were flashbacks, because they didn't ask what was happening in my mind – what triggered them. Nothing too dramatic. No explosions. Just a girl sobbing in a bathroom. If I am allowed the space to calm myself down, then after ten to fifteen minutes, I'm able to go on with my day as usual – just a little tired and needing space.

People on the outside also believe that someone with PTSD is somehow dangerous. Of course, we may all have seen news reports about this, but for the most part anyone with PTSD ends up exerting great self-control for fear that their disorder will affect those around them. It is hard to relax when you're scared that you might hurt somebody, overreact to something, frighten somebody. If PTSD sufferers are involved in violent incidents, it is usually around alcohol or drugs. It's unfortunate that people do not get the help they need, and may turn to substance abuse to relieve the pain.

Because I was not diagnosed for many years, I have had lots of jobs I probably would not have been able to do with the stigma of a PTSD diagnosis. I have worked with non-verbal adults who had brain injuries, as a nanny for infants and small children with epilepsy, and in an HIV clinic. I loved all those jobs, and although each was sometimes very stressful, I never once raised my voice or lost my temper. I know when I am at my limit, and I know to walk away for a few minutes to calm down. I hate the fact that some people would judge me unsuitable for those jobs now I am diagnosed with PTSD, or they think I'm somehow dangerous, when I have lived with this for a long time and it has never led to me hurting anybody.

Yes, I have had PTSD for twelve years. I have worked with children and vulnerable adults. I got a degree, developed friendships – and relationships. I have lived in three countries, and travelled through countless others. I have talked openly about my experiences. I have read my

stories and poems out to rooms full of people. I have lived a life that, although unsteady at times, has not been limited and has been filled with moments of pure joy.

Many people would see a PTSD diagnosis as something terrible, but after years of suffering, it was something positive. After all these years, there is a chance of recovery through EMDR therapy.* And although therapy has been really tough, it has worked, and I find myself vastly improved. I have disarmed a lot of situations that would have previously given me a flashback. I have cured phobias. And I no longer feel that I have to avoid certain situations. I am more at ease in social groups. I do not jump when touched. I have been able to develop a loving relationship, and now I trust my partner in ways that were not previously possible.

Though I have done many amazing things, until I started to get better I never knew how restricted I was by this illness. I learnt to trust my friends more, and to reach out to people when I was going through hard times. I was surprised to find that people were supportive. They weren't judgemental or pushy. They did not need every detail explained to them. They just let me know that they were there if I needed them, and forgave me when I needed to draw back from them for a while. My partner's reaction when I told him was to say that it doesn't change anything. Then he started singing 'Fixer Upper' from *Frozen* – one of my favourite movies.

I know that I now have the tools to deal with my PTSD if it comes back again. I know the people I can turn to. I know what exercises and activities will help keep me healthy, both physically and mentally. I know how and when to give myself time with friends, and when to spend time alone. I can figure out when to take time to work and time to relax. And I can make time to be creative or active. I know what situations I can cope with, what situations I need to work on, and when to ask for help. Though I will always have this illness on some level, I know that I am getting better, and that I have a whole life ahead of me to enjoy my new-found freedom.

I am sending this out as an open letter to anybody who cares to read it – with a simple message. I have PTSD. It's an illness. It doesn't define who I am. I am neither victim nor survivor. I am just a person, like any other. My illness does not make me weaker, or stronger. I strive everyday to be healthier, happier and more fulfilled, not because I have PTSD but because everyone should strive for these things. ■

*EMDR therapy: Eye movement desensitization and reprocessing is a set of standardized protocols incorporating elements from many different treatment approaches. Devised by Francine Shapiro in 1987, it is to help people process traumatic memories, and is gaining in popularity, especially for PTSD.

PERSONALITY DISORDERS

– Allowing the change

JOHN MYHILL

I became interested in Personality Disorders because they were turning up more often in court when mental health trusts defined them as “untreatable” and therefore not suitable for a Mental Health Order. In Family Courts they were the most common reason for taking a woman's child or children into care. I worked with addictions, and our residents also regularly had a PD label. Back in the 1980s, when I ran a mental health hostel and day centre, most of these same people would have been regarded as schizophrenic or bi-polar. Paranoia, hallucinations, anxiety and delusions are now said to be PD, because the person seems unable to manage, seems untrustworthy and lacking in insight, appears not to be suffering but causes others to suffer, or seems unwilling to give up an obsession which professionals decide is delusional. Everything about

the PD and Borderline PD diagnoses looks sloppy and subjective.

We all know that back in the 1960s Erving Goffman showed that many symptoms of mental distress are behaviours learnt in total institutions such as hospitals and prisons. RD Laing also showed how the impact of family life produced symptoms that psychiatrists interpreted as the signs of schizophrenia. Certainly in the early days of the Hearing Voices Network, it was clear that most people who suffer from hearing voices spoke of childhood experience of abuse. It is generally recognised that being labelled with a personality disorder or psychotic will have a huge impact on an individual's ability to live a supposedly normal life. Even a diagnosis of anxiety, depression, or stress can make a person's career more difficult.

It is important to recognise that most people who have experienced mental distress wish it was purely a result of a physical disease which might in the future respond to some form of medical treatment. Just because so many dreadful things have been done by psychiatry in the past, in the name of cure, this does not mean that miracle drugs may not be on the way. There is no doubt that the symptoms of acute distress are more quickly held in check by modern drugs than ever before. But it is also clear that there is no cure, and that the emphasis on getting people back to work, by means of a bit of CBT and some tablets, is a process driven by economics rather than science.

So let us spend a bit more time considering how we might improve our society to accommodate these remarkably talented people who from time to time cause others extreme mental distress. No, not politicians – people said to have a personality disorder!

They can of course be sociable, energetic and gain worldly success. It is a label many have applied to dictators, the super-rich, terrorists and murderers. But I am considering the less successful, who end in our prisons and occasionally our hospitals, or just cause problems in communities. Is it best to respond to those who seek attention as if they were four years old? Would they be less histrionic if we were more responsive? Is it true that their egotism prevents them from supporting each other? After all, depressives and those suffering from schizophrenia have gained hugely from self-help groups.

How do we respond to anyone driven by an obsession? Who are we to decide that their obsession is a delusion? From the Wright brothers to Alan Turing, most great inventors were obsessive, and often regarded as delusional. Is their paranoia partially a projection by us, expressing our fear of their intensity? What makes us so dull, so lacking in their energetic fire? Would we want to reduce a Leonardo or a Beethoven to our level?

Narcissism is something I can happily plead guilty to (by writing this article), but I justify it by the belief that I have something new to say. Are we really looking for something new in the PD person? Or are they just a bit too clever for us, too challenging to our set ways and habits? Like Animal Rights protestors or members of CND, disturbing our assumptions that the world cannot be different from the way we experience it.

Projection is a defence mechanism: we get rid of our unpleasant thoughts by attributing them to others – personality traits that we fear exist within us usually become the characteristics we dislike most in others.

Repression prevents the retrieval of unpleasant

memories, so they remain fresh and recur in dreams or flashbacks, as if they had only just happened. Here I am indicating the professional or the ordinary person who represses memories of the person with a PD label, so that their subconscious rejection of the PD person increases.

Disassociation of the self from an early traumatic experience can leave any of us with a hidden personality that will explode on to the scene – given the right stimulus – taking over from our regular patterns of behaviour. Awareness of these hidden personalities within each one of us should make us more sympathetic and helpful to anyone labelled PD, whose whole life may be dominated by such personalities, which hide the still undeveloped child within.

Paranoia and depression are surely traits that we should encourage, and focus on things in the real world that we should be depressed about: the prevalence of market economics, the extent of poverty, climate change, the surveillance society. These are all things we avoid facing up to. Who are we to tell the PD person that she is not facing up to her failings? Some things are too terrible, and talking about them is too painful. It is possible for nightmares and drug-induced hallucinations to become fixed as if they were real memories. So can we treat real memories as if they were dreams – leave them behind, so that we can concentrate on the here and now? Unless we can do this, how can we expect others to do the same?

Is there so much change in our everyday lives that we wish to believe those around us are immutable? We diminish them with labels and diagnoses so that we can keep them as they first seemed to be. After all, if they can change, we can change. Is it our fear of loss of identity, our unwillingness to consider that we are in a rut? Should we be looking at *our* assumptions and habits, rather than theirs?

Perhaps we are not all automatons, driven by random genetic chance and mechanical responses. Not Pavlov's dogs, conditioned to live the way we do, but free individuals capable of radical change, penetrating to deeper consciousness, discovering how to live in harmony with creation, responsive to compassion; even perhaps playing a part in a universal transformation.

Consider the PD person when they were five or ten years old. Was she the person she is now? Were you? How would it affect you if they suddenly changed? Would you deal with your insecurity by saying: "They are a one-off. This is a rare case"? Think of the people you have lost touch with, people you had known well. Did you lose touch because they had changed, and were no longer the person you assumed they were? ■



IMPORTANT URGENT PRODUCT RECALL

Sanity!

Sanity has been recalled due to several defects and safety issues.

Safety Issues:

People who are not driven mad by how the world is currently functioning are a danger to themselves and others.

It also carries many defects, such as:

**denial
collusion
inequality & discrimination
damage to environment
war & famine
Boris Johnson & Donald Trump**

Meditation on a Bus Seat

EILEEN POLLARD

First I thought the handle was orange. Actually, to be honest, first I thought meditating using a bus handle was silly. Then, I thought it was orange. Then I thought the light on it was interesting. The light on the bus handle danced, and it danced in different ways as the bus moved along. Then I noticed that the light danced differently in different places because part of the handle was shinier than the other part, as if from a different level of use. Which led me to think about all the hands that had touched the handle, thousands and thousands of hands, hands from all over the world, brown hands, black hands, white hands. Something about humanity came next. How all these people had clutched and grabbed the handle in just the same way, for support and to steady themselves, as the bus swayed and jolted, using it to stand up, to rise.

Then I noticed that both sides of the handle were attached to the seat with mouth-like suckers.

I began to feel that the orange handle was like a very long elongated telephone receiver neatly hung up on the base of the bus seat. I imagined holding this phone to my ear and making a call. What kind of strange supernatural voice might emanate from the other end? How might I address such an unknown interlocutor, who may perhaps resemble a giant triffid? After that I wondered what other objects the handle resembled. A huge yet very thin pair of headphones, perhaps? I remembered a poet I had read seemed to mind that on a Pendolino train the handle resembled a Mickey Mouse ear, and I smiled. Parts of the handle, where it joined the seat, were dirty, and parts were clean. This led me to imagine what it was like when the bus was deep-cleaned, and how deep such a clean might really *be* - having been bitten by fleas on the back seat of a bus before.

I remembered that bus seats were more like benches when I was a child, and the hard metal handle ran across the top of both seats. I felt something about how the two seats were now separate, distinct, packaged. You sat as an individual, not with another person who shared the same seat. And the bus handles reflected this separation. Each seat had its own handle, none were shared. I started to think about how the bus seat, and its handle, were fixed while the bus moved, slowly, complacently, potentially even towards disaster, breakdown, collision. They were always passive, always facing forward, unable to look away. Bus seat and handle were welded together

yet remained distinct from one another. Different colours, made of different materials, probably from different parts of the world. That the handle was stationary and subject to the movement of the bus. That it both moved and was still.

I began to feel that I was writing a poem in my head, and wondered vaguely whether this was the purpose of meditation, or if perhaps I had somehow missed the point. By now I was so invested in the bus seat handle and the thought experiment it had accidentally provoked that I did not care if I was somehow meditating in the 'wrong' way. Fuck it! At least it was interesting and I was not worrying. Hard, really, to worry about a bus seat handle. I suddenly wanted to touch it. So I did. Adding my DNA, touch, fingerprints, dirt, grease, grime, smell, scent, humanity to all the rest, to everyone else's stuff. Feeling connected somehow with all these people, all those hands, unified by travelling on the bus and needing at some point to grab the handle. Now I noticed the other handles, each atop their own seat, and I began to feel that the handles were like people, fixed yet constantly moving on, like babies, once alive, caught in a perpetual forwards movement, with the perception of control, but only the perception. Constantly retracing the same bus routes, over and over and over.

In this scenario, the driver was like God. Which made me wonder about God. Bus drivers being rather hard done by, and yet also impatient and selectively blind and deaf on occasion, too. It made me consider briefly the song lyrics "What if God were one of us, just a slob like one of us, just a stranger on a bus, trying to make his way home, back up to heaven all alone, and no one calling on the phone, except the Pope maybe, in Rome". Perhaps that was it. Perhaps the Pope was on the other end of this very long elongated, orange, supernatural and peculiar telephone receiver hung up on a bus seat? The handles also, I suddenly thought, would have different experiences, depending on where they were positioned, of say, for example, a crash. Some may be totally unaffected, some damaged, some destroyed. This seemed to me at the time quite profound. I felt rather sorry for the handles, and hoped that mine would escape disaster and remain unhurt. Then, almost unconsciously, I used the handle to help me stand up and get off the bus. ■

YOUR TRUTH

APRIL BERGIN

I don't fully understand your experience.
How could I? I am not you.
I wasn't there.
I don't share your experiences.
But I have heard you.
I have read your essays, your tweets, your comments.
I have heard you speak.
I have been in awe of your ability to speak calmly when entitled to scream.
I have listened and tried my best to understand your experience.

Because I am not you, I would never tell you what is best for you.
But others have not hesitated to tell you what you need.
Medication.
Meditation.
Exercise.
Fresh air.
Be more resilient!
Have you tried this therapy?
Make some friends.
Paint a picture.
If only you could just learn to relax.
A good night's sleep would go a long way.

See, so many think the flaw lies within you,
Therefore it's your job to fix it.
To follow their prescriptions and suggestions.

They fail to look for, or choose to ignore, the truth.
Debates on brain chemistry and physiology ignore the truth.
Your truth.
The important truth.
The painful truth.
You were tortured, tormented, taunted.
Traumatized in some way.
And maybe it broke a little part of your spirit.
Maybe it broke a big part of your spirit.
And those who ignore the truth or fail to ask you about it
Also break your spirit.
And it's not fucking fair.

So I'm hear to tell you that,
Should we ever cross paths,
I'll sit with you if you like.
On your terms.
As equals.
And I'll listen.
I will try my best to really listen.
I won't advise.
I won't prescribe.
I won't dismiss you.
I will be quiet and try to understand.
I will try to help in any way I can.
Because you deserve that.
Because I believe your spirit can be repaired.

LETTERS

Asylum: the magazine for what?

In a recent editorial (23.4), Helen Spandler rather provocatively suggested changing the sub-title of Asylum to: the magazine for Mad Studies. Very few people responded positively to this suggestion! Equally provocatively, Tim Wilson (24.1) suggested we change it to: the magazine to abolish psychiatry. Until there is agreement on a suitable alternative, we remain: the magazine for democratic psychiatry. We appreciate some readers might object, believing that psychiatry can never be democratic. While we are sympathetic to that view, democracy is central to our aspirations. Hopefully, the magazine can continue to be a space where disagreements and divergent views can be heard.

Andrew Roberts, Secretary, Survivors History Group

writes:

Dear Editors,

I'd like to respond to the suggestion (Editorial, *Asylum* 23 4) to change *Asylum's* sub-title to 'the magazine for mad studies'.

Whatever the deficiencies of the present subtitle, 'the magazine for democratic psychiatry', I hope you keep it because the straightforward interpretation of democratic includes the possibility of *Asylum* providing a space (somewhere) for the diversity of survivor views.

I think a change to 'the magazine (or journal) of mad studies' would be a serious mistake from the point of view of providing a platform for survivors. It would remove the ambiguity about what the magazine is, in a way that would exclude people who are not academics (or aspiring academics) and who do not feel comfortable with a magazine that sees itself as primarily 'a challenge to psychiatry'.

I do not want to see a magazine with a primary focus which is either pro- or anti-psychiatry. I would like to see a magazine that welcomes survivors' views without charging an ideological entrance fee. *Asylum* is ambiguous about its position. For me, it is better that it remains ambiguous than committing itself to the primary aim of promoting 'mad studies' in opposition to psychiatry.

Of course, meanings are open to question. If 'mad studies' (or 'our mad history') was understood the way it is in Scotland, it would indicate a platform for ordinary survivors. But Mad Studies in the pages of *Asylum magazine* (I refer to the two special issues) appears to be modelled on the success of Queer Studies, which has established itself as a legitimate academic area. Mad Studies is part of the power struggle about what can be studied and discussed in universities, and it is also intrinsically committed to an ideological position alternative to psychiatry. I have no objection to that. A space in academia for such debates seems a good idea – but I do not think *Asylum* should narrow its focus and become 'the journal of mad studies'.

The ambiguity about what *Asylum* is allows different people to relate to it in different ways. Cheryl Prax (*Asylum* 23 2) and Don Weitz (*Asylum* 23 4) assess it as a campaign journal pursuing an agenda, which they value. I believe Alec

Jenner, its founding father, thought of it as magazine for diverse views, and in the case of *Asylum*, I think there is value in the ambiguity. Like a broad-based political party, *Asylum* seeks to accommodate people who want different things from it – and I support that.

Can *Asylum* keep people like Don Weitz and Cheryl Prax on board and make itself a magazine that survivors more generally would identify with? Are we prepared to cohabit with people we disagree with? I hope so.

Dina Poursanidou, survivor researcher and member of the Asylum collective writes:

Since my first encounter with *Asylum magazine* I was drawn to the word 'asylum' and the phrase 'democratic psychiatry' (in the magazine's title). The word and the phrase resonate deeply with me, and they carry a particular emotional weight since they come from Greek, my mother tongue. 'Asylum' means sanctuary, safe refuge, a place that should not be violated. For example, in Greece there is the concept of 'university asylum' which entails that the police should not forcibly enter any University space. In Greece, university asylum was brutally violated by the army during the student uprising in the 1967–74 dictatorship, and in the memory of the Greek people this violation has become synonymous with tyranny. 'Democratic' means 'of the power of the people'. In my psyche this is strongly linked to the longstanding struggles of my people to achieve freedom (including freedom of speech), democracy, respect for human rights, and justice for their country.

Because of all these powerful associations of the word 'democratic' – no coercion, freedom, justice and respect for human rights – I guess for me the phrase 'democratic psychiatry' is a particularly powerful articulation of an ideal, or rather a deep longing. That is, for a humane and emancipating psychiatry that refrains from coercion and injustice and has the potential to heal. This is an ideal that certainly stands in stark contrast to the reality of the totally untherapeutic and unsafe psychiatric care I experienced when I was sectioned, back in 2009. I imagine this longing, to a very large extent, explains my involvement with *Asylum* and its mission and values.

MINOLOGUE – CVs

JANE SCARGILL

Only ten CVs?

You're supposed to do twenty.

CVs are important.

Yes, you keep saying about the application form you've been wasting time over. WE NEED CVs!

Stop that! Stop it! You're being petty. Just send them!

We'll get the addresses.

If you don't send CVs, your money will be stopped.

When you go to bed, set the alarm.

Every three hours, you get up and send another CV.

I (*points to self*). . . I only sleep two hours a night.

I *dream* about CVs, about people walking around like zombies because they haven't sent their CV.

I get up and drink coffee.

Why don't you drink coffee? That will help with your CVs.

What do you mean, you can't afford coffee? Well, get a job! Then you can drink as much coffee as you like.

You can get some from the food-bank on your way home from work.

You need to write CVs.

How can I drink my coffee if you won't write CVs?

Minologue (a short monologue)

NEWS & FINDINGS

SURGE IN UNEXPECTED MH DEATHS?

Statistics indicate that the number of unexpected patient deaths reported by England's mental health trusts increased 50% in three years. Based on information from more than half the MH trusts, this equates to nearly 1,100 patients. Unexpected deaths are by suicide, neglect and misadventure.

Out of fifty-seven English MH trusts, thirty-three responded to *Panorama's* Freedom of Information request, and these served most of those in MH care. In 2012-13, these trusts reported 2,067 unexpected deaths, but by 2015-16 there were 3,160.

The Department of Health said the increase was "expected" due to changes in the way deaths were recorded and investigated. "The statistics on suicide are clear: for the last decade the suicide rate amongst people in mental health services has been falling, by more than 30% since 2004, most clearly in in-patient services and more recently in community services. We do not believe that the figures obtained by the BBC reflect the national data most recently published, which suggests that their figures are incomplete and misleading."

The DoH also disputes *Panorama's* funding figures, saying that MH spending by clinical commissioning groups went up by £342m in the last year, on top of the extra £1.4bn allocated up to 2020. But the Royal College of Psychiatrists and several heads of MH trusts say that this money has not actually materialised, and the Health Foundation estimates that, in real terms, English MH trusts have had their funding

cut by £150m over the past four years, compared with a rise in national health spending of £8bn.

Hutchinson, S (2017) Unexpected mental health deaths up 50% in three years. *BBC News* 7 Feb.

DISCHARGED PSYCHIATRIC PATIENTS AT RISK DUE TO SLOW FOLLOW-UP

Nice guidelines say patients discharged after hospital treatment for a mental health crisis should quickly receive a visit or phone call to assess their needs: they should be contacted within a week, and those thought to be at risk of suicide within 48 hours. Last year's National Confidential Inquiry into Suicide and Homicide found that when psychiatric in-patients are sent home, most of those who committed suicide did it on the third day after release.

But figures obtained under freedom of information laws by the charity Mind show that at least 11,000 people a year who have recently been mental health inpatients (10%) are not followed up within a week of going home.

Dr Paul Lelliott, the Care Quality Commission's deputy chief inspector of hospitals said pressure on mental health services, including to discharge patients to free up beds, should not compromise the aftercare they received. "Patients should only be discharged from specialist mental health services when there are ongoing care arrangements in place for them. Failure to do so can put the person at risk of harm, their condition can relapse and it can mean they are more likely to go going back into hospital."

Separate Mind research about the experience of after-hospital care, among 850 patients, found that those who were not followed up were twice as likely to attempt to take their own lives and a third more likely to harm themselves;

they are also more than twice as likely to end up back in A&E suffering another crisis.

Campbell, D (2017) Lack of post-hospital mental health care 'increasing risk of suicides'. *The Guardian* 13 April.

11% INCREASE IN ECT OVER FOUR YEARS

Shock treatment is enjoying a revival. Statistics covering four-fifths of English mental health trusts shows that more than 22,600 individual ECT treatments were carried out in 2015-16, a rise of 11% in four years. (Figures for private clinics are not included.) The number of patients treated also rose, albeit more modestly, to more than 2,200. This suggests that on average individuals undergo more ECT than before: the average number of treatments per patient rose from 9.6 in 2012-13 to 10.1 four years later.

Almost two-thirds of the 44 NHS trusts providing information reported a rise in the number of ECT treatments carried out over the four-year period. Changes in the use of shock treatment were more striking in some parts of the country than others. The number of treatments carried out by Mersey Care NHS trust remained fairly constant over the last four years, but in the Lincolnshire Partnership NHS foundation trust there was a 75% increase.

"The decision about whether ECT is to be used or not is based on the quirks of the local psychiatrist," said Richard Bentall, professor of clinical psychology at Liverpool University. "There are some places where psychiatrists think it works, and they just do it lots of times, and there are some places where people think: 'Bloody hell, I don't think the evidence for this is very good,' so will only do it in absolutely desperate circumstances... My view is that ECT is a classic failure of evidence-based medicine. I don't believe that there are adequate clinical trials of ECT to establish its effectiveness."

While some psychiatrists argue that historical ECT trials show a benefit from the treatment, Bentall believes their design was not up to scratch, and that there is a need for large randomised placebo-controlled clinical trials. But some champions of ECT argue that would be unethical. Bentall responds: "It is clearly unethical to pass electric shocks across people's brains unless it is effective [and] helpful to do so and therefore there is an ethical requirement to show that treatment is effective."

Some doctors suggest the increase in number of ECT treatments could be down to a change from bilateral to unilateral therapy, where the electrodes are applied to one side of the head, rather than at both temples. "That has slightly fewer side-effects and is less likely to cause memory impairment," said Andrew Molodynski, consultant psychiatrist at Oxford Health NHS foundation trust, and national mental health lead of the British Medical Association's consultant committee. "It is also slightly less powerful, so it might be that if more people are having that then they are needing slightly more treatments."

NICE currently advises ECT be used only as a last resort for those with prolonged or severe manic episodes, who are in a catatonic state, or who have severe depression or moderate depression when other treatments have not worked.

There is a dearth of information on how widely ECT is used. Using the Freedom of Information Act, *The Guardian* requested data from every English MH trust, for a 10-year period between 2005-06 and 2015-16. Few of them could provide data for the full 10 years, so the report had to use data beginning in 2012. Three trusts refused the request outright, saying the staff time required to comply with the request was too great, while seven trusts could not even provide consistent data from 2012-13 onwards. Very few trusts kept ECT data in a systematic and completely trustworthy manner, and two of them provided data that turned out to be completely incorrect, only providing accurate figures after multiple contacts.

Davis, N & Duncan, P (2017) Electroconvulsive therapy on the rise again in England. *The Guardian* 17 April.

CHILDREN'S MENTAL HEALTH GETTING WORSE?

Children's Mental Health Week was in February, and the NSPCC reported that 50,819 youngsters had contacted Childline for a serious mental health problem in the year to March 2016. This was 8% more than four years ago. There was a 36% increase in calls for help with depression and other disorders, and also a rise in the number feeling suicidal.

One-third of the calls were from those aged 12-15, and girls were almost seven times more likely to seek help than boys. The Children's Society says their research finds a widening gap between the well-being of adolescent girls and boys; there are many factors, but girls are particularly likely to experience emotional bullying such as name-calling.

One 16-year-old girl told Childline: "I want to know what's wrong with me. I have been seeing a counsellor about my mental health issues recently but they just told me to eat and sleep better and forget about the past, which didn't help me at all. I wish I could speak to someone who actually cared about me and I felt comfortable talking to."

The charity Young Minds says far more needs to be done to prevent mental health problems from developing in the first place. For a start, we urgently need to rebalance our education system so that schools are encouraged to prioritise well-being and not just exam results. But living under the shadow of debt is also very damaging to children's mental health. Research by the Children's Society finds that children in debt-ridden families are five times more likely to be unhappy than those in families without debt troubles, putting them at greater risk of developing mental health problems. And in England and Wales, an estimated 2.4 million children live in households which have big problems with debt - where the parents owe money to multiple creditors, from utility companies to stores, banks and payday loan companies.

Summers, H (2017) Rise in calls to Childline for mental health issues prompts call for action. *The Guardian* 6 Feb; Reed, M (2017) Debt is damaging children's mental health. *Huffington Post* 6 Feb.

ENGLISH SYTEM FAILS ABUSED CHILDREN

We now know there is a clear and high correlation between childhood abuse and the development of serious mental disorder.

New research commissioned by the Children's Commissioner for England warns that most victims of sexual abuse within families are let down by the system. Young people often have to report the abuse themselves when the authorities fail to pick up on the signs, and even when the abuse is disclosed, investigations often take "considerably longer" than offences against adults. Victims often have to face long waits for therapy, and many are prevented from having counselling before their court cases.

It is reckoned that 2/3rds of all child sexual abuse happens within the family, and only 12% of the estimated number of victims come to the attention of the authorities.

Ann Longfield, Children's Commissioner for England, called for urgent changes in the UK. We should look to Iceland, where child victims are offered specific services to deal with their trauma. In the Barnahaus approach, all the services, from medical examination to therapy, are provided under one roof.

System fails children abused within families (2017) *The Guardian* 20 April.

YOUNG PEOPLE LEAVING CARE RISK EARLY DEATH

Ninety people leaving care in England between 2012 and 2016 died before they reached the age of twenty-two. Young people leaving care are 1% of the population aged 19 to 21, but make up 7% of all 'untimely death' deaths for that age-range. But this is an underestimate since coroners are not necessarily provided with a young person's care status, and many who leave care do not keep in contact with their councils. There are no statistics, but of course many young people who were in care do not survive much beyond the age of 21, either.

Care leavers have cited inability to access physical and mental healthcare as key contributory factors. One young man described being "palmed off with pills" when he tried to get mental health support. After leaving care, he was put on Ritalin, and got addicted. He made several suicide attempts, and during his last attempt it was only a chance intervention that saved his life.

"After care I was all alone, I was in a lot of debt, and I was constantly going out trying to make money, committing crimes to fund my drug habit."

He resolved his problem by making contact with The Prince's Trust, a charity that works with vulnerable young people.

The Education Department says it is "investing nearly £10m over the next four years in improving mental health support for looked-after young people in secure children's homes, and are changing the law so local authorities have to promote the physical and mental health of children in care."

Greenwood, G (2017) Early deaths among care leavers revealed. *BBC News* 15 Feb.

SAME-SEX MARRIAGE REDUCES TEEN SUICIDES

In the USA, suicide is the second leading cause of death for those aged between 15 and 24, with suicide rates much higher among those who identify as sexual minorities. But according to research at Johns Hopkins University (published in *JAMA Pediatrics*), legalisation of same-sex marriage in many US states has the bonus of correlating with a reduction in teenage suicide attempts. Compared to states where the law was not changed, among high school students the numbers fell by an average of 7%; among self-identified gay, lesbian and bisexual teenagers there was a 14% reduction.

The study analysed information from more than 760,000 students, collected between 1999 and 2015, with data for states that had passed a same-sex marriage law examined before and after the event. This included 32 of the 35 states that had legalised same-sex marriage by 2015; the change in the rate of attempted suicide was then compared with the 15 states with no such legalisation. This showed that in the years before same-sex marriage was made legal, the self-reported rate of one or more suicide attempts among high school students across all states was around 8.6% a year, with the figure reaching 28.5% among those who identified as gay, lesbian, bisexual or "not sure".

Overall, states that legalised same-sex marriage saw attempted suicide rates fall by 0.6% against states that did not, corresponding to an average drop of 7%. No drop in suicide attempts was found in states that did not enact the laws. These results tally with European studies which show that attempted suicide is more common among adolescents concerned about their sexual orientation.

Davis, N (2017) Liberal gay laws 'help cut suicide attempts' *The Guardian* 21 Feb.

ADULT MH EFFECTS OF CHILDHOOD DEPRIVATION

Long-term research on 165 Romanian children from the orphanages shows that most young children adopted by UK families in the early 1990s still have mental health problems now they are adults. Despite being brought up by caring new families, emotional and social problems are common, with only 20% apparently unaffected by the early neglect. One young woman spent two and half years in a Romanian orphanage before being adopted by a Yorkshire couple. She says she is unscathed by the trauma of her early life, and doesn't remember the orphanage, but she did have issues with water, which she puts down to deprivation of drinking water and the cold baths she was subjected to in her infancy.

Initially, all the children struggled with developmental delays and malnourishment. Many who had spent less than six months in an institution showed remarkable signs of recovery by the age of five or six, but children who had spent longer periods in orphanages had far higher rates of social, emotional and cognitive problems during their lives. Issues include difficulty engaging with others, forming relationships, and problems with concentration and attention

levels - all continued into adulthood. Despite their low IQs returning to normal levels over time, they had higher rates of unemployment than other adopted children from the UK and Romania. This group was also three or four times more likely to experience emotional problems as adults, and more than 40% have had contact with the mental health services.

The research team, at King's College, London, says this is the first large-scale study to show that deprivation and neglect during early childhood could have a profound effect on mental health and wellbeing in later life. Prof Edmund Sonuga-Barke says that "something quite fundamental may have happened in the brains of those children, despite the families and schools they went to", and it is crucial to get children out of neglect as soon as possible "and into a loving family". "This highlights the importance of assessing patients from deprived backgrounds when providing mental health support and carefully planning care when these patients transfer from child to adult mental health care."

Prof Frank Verhulst, of Erasmus University Medical Centre in the Netherlands, says many young children could be similarly affected. "This finding is true for millions of children around the world who are exposed to war, terrorism, violence, or mass migration. As a consequence, many young children face trauma, displacement, homelessness, or family disruption."

Adopted Romanian orphans 'still suffering in adulthood' (2017)
BBC News 23 Feb.

POOR MENTAL HEALTH OF SYRIAN CHILDREN

Save the Children says that the six years of shelling, airstrikes and ongoing violence is having a devastating psychological impact on Syria's children. Its new report, *Invisible Wounds*, says that the psychological impact of the conflict on children has resulted in bed-wetting, involuntarily urination in public, speech impediments and children losing the ability to speak altogether.

Interviews were conducted with more than 450 children and adults from seven of Syria's fourteen regions.

There were reports of increases in self-harm, attempted suicide, bedwetting, hallucinations, speech problems and aggressive or withdrawn behaviour. 89% of those interviewed said children have become more fearful and nervous as the war has gone on.

Mental health experts say that prolonged exposure to the traumatic events of the war is putting Syrian children at high risk of toxic stress – the most dangerous form of stress response, which can lead to developmental issues and lifelong health problems. There is likely to be life-long devastation of children's mental and physical health since toxic stress disrupts the development of the brain and other organs, and increases the risk of heart disease, substance abuse, depression and other mental health disorders into adulthood.

After nearly six years of war, two out of every three children in Syria has lost a loved one, had their home bombed or been injured; many have seen friends or family members killed in front of them. The children's emotional distress is compounded by dire shortages of food, clean water and medical care.

An aid worker in a besieged town described how children are "psychologically crushed and tired... When we do activities like singing with them, they don't respond at all. They draw images of children being butchered in the war, or tanks, or the siege and the lack of food." A teacher said that the children "wish they were hit by a sniper, because if they got injured they would go to the hospital and leave the siege and eat whatever they want."

Save the Children says the country's child mental health crisis is reaching a tipping point. With family support structures and official services collapsing, children's chances of fully recovering are dwindling. There is now a generation at risk, although the work of Save the Children has shown that with the right support and early interventions, children are able to recover from such traumatic experiences.

Invisible wounds: Syria's child mental health crisis (2017)
Save the Children website 6 March.



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**Patricia Priscilla
Chambers
1965–2016**

Patricia Chambers, who was a prominent member of the black and minority ethnic mental health user/survivor movement, passed away in May 2016. Her death, by suicide, has been a devastating shock to many of us, her friends.

For more than 25 years, Patricia worked tirelessly

to address issues at the intersections of ‘race’, culture and madness, and to question privilege and racism in services, in society, and in our collective political work. Many of us remember Patricia as gentle and soft-spoken, but she was fearless when speaking truth to power. She was also invested in exploring and making connections with the history and politics that brought her people first to the Caribbean and then to the UK; her deeply spiritual nature was an inheritance of the pan-African heritage she held so dear.

Patricia was a former manager of Catch-a-fiya, the national black and minority ethnic mental health user/survivor network. Her work was widespread, including BUGS, Black Women’s Mental Health Project, NSUN, RaceEquality Foundation, Shaping Our Lives, The Forward Project, the DRE Ambassadors programme, the Equalities National Council, and many more.

Friends and colleagues gathered at the Rose Pub in Vauxhall on 25th February, to remember and celebrate Patricia’s life. The countless discussions and strategizing we’ve had with each other and with other friends around the dining table at the Afiya Trust were transformative for many of us. Unfortunately, the Afiya Trust and Catch-a- fiya have also passed away, falling prey to the politics of austerity and the continuing lack of political will to address the racialisation and marginalisation of our communities. The fact that many of us had lost contact with each other and our networks speaks to “the state of homelessness” that user/survivors from racialised groups currently face – our networks are decimated, our connections fragile, and our voices barely audible within the broader movement. Many of us are familiar with the depth of darkness that led Patricia to check out of life.

Patricia’s brother, Giles, thinks that she went because she was impatient to join the spirit world. Her family is trying to raise the money to take her ashes to Ethiopia, which she regarded as her spiritual home. I have no doubt that she’ll continue to hold our hands, as she had done in her life on earth, as we continue our struggles for social justice.

Jayasree Kalathil



**Dina Ibrahim
1981–2017**

Dina Ibrahim loved the Sudanese sun burning down on the river Nile as much as I love grey English mists. Born in Africa, she was buried there in February 2017. Although living in London since her early teens, she retained strong links with the Sudan and with Ahfad

University for Women, which developed from a girls’ school established in 1907 by her famous ancestor, Babikir Badri. Only thirty-five when she died, Dina was one of the youngest active members of the London Survivors History Group. She had planned to come to our meeting in January 2017, but flew to Africa instead. Facebook’s Arabic/English translations have linked family and friends since her death, and her cousins Shahd and Mohamed came to our March meeting.

Dina experienced the world through a succession of deep depressions and elation, but mostly depression. Although often exciting, elation made her vulnerable; her depression, although awful, helped her relate to people like me. When her mental life prevented her attending our meetings, Dina remained engaged with us, on one occasion speaking to everyone via her mobile. Overcoming the problems of her mood swings, Dina graduated in Sociology from Middlesex University in 2012. She helped the Survivors History Group with a conference at the University, and sold the *Asylum* relaunch issue at our “Pageant of Survivor History” event at Kingsley Hall in March 2010. The same year a communal bus took us to Birmingham with the Tower Hamlets African and Caribbean Mental Health Organisation to study “health through history”, and in 2014 Dina and her cousin Hagir joined in celebrating the life of survivor poet Howard Mingham.

In 2015 Dina wrote in a report on the paintings of Mary Barnes: “If I could have expressed what I was feeling so openly, I might have overcome a lot of issues.” Dina had the gift of opening our eyes to things we might not have seen. She sought to share what it is to be a survivor in the Sudan and in London, and we had some discussions about this at the Survivors History Group in which Hagir also took part. Dina suggested to me that we might explore what the world is through different cultures. For the Jewish feast of Tabernacles, we were guests at the garden meal of some friends. We went to the Eid celebrations of the Sudanese and Ummah Party Community in Wembley, and to a Quaker meeting.

The picture shows Dina with a Herb Robert, where the foliage had turned red. In different parts of London, we found purple, orange and red Herb Roberts. As they did the poet Charlotte Mew, colours reached out and held Dina.

Andrew Roberts

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