

Re

Fit

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On disability, sickness and health

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www.rethezine.com

Rethink. Reimagine. Recreate.

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In this issue of Re the Zine we explore the themes of disability, sickness and health. Our contributors share their experiences and use art and media that show us new ways of thinking about disability, and the limitations and potential of the human body and mind. We look at how public life excludes those who don't "fit", and how society be changed to re-fit around us, in all our diversity.

Lewis Turner encourages us to think about what it means to accept and welcome difference in a world that is made with the "normal" person in mind. We celebrate words of wisdom from "wobbly" comedian **Francesca Martinez**.

Luke Roelofs explores what it means to be dependent on others in his review of philosophy documentary, *The Examined Life*. **Donia Fahim and Jamie Bleiweiss**, directors of *Austism Friendly Spaces* share the story of their initiative to make entertainment and theatre more inclusive and accessible for those with autism. Finally, our **anonymous contributor** highlights the contradictions of successive governments' unemployment and disability policies.

We continue the debate through art: **Katie Reilly** imagines spaces that celebrate and integrate different ways of moving, through an *Architecture of Inclusion*. We showcase the paintings of **Bryan Charnley** and the work of graphic novelist, **Ellen Forney**. As always, the radical calendar offers next steps for if you want to think more about the ideas raised in the zine.

ReTheZine is published by a growing group of people who believe positive change is possible. Every quarter we publish a free (maga)zine on a different theme to explore new ideas and showcase those that work. Through ReTheZine we aim to create a community of people inspired to act. We'd love you to get involved - see the back page for more details.

Cover: Fish Schizophrenic by Bryan Charnley (see page 15)

Normal / Different / Disabled: Who gets to decide?

Lewis Turner and Portia Roelofs

We tell children that one of the great things about the world is that we're all different. Yet when those same kids grow up, they are increasingly confronted by a world in which people are labeled "ugly" if they don't look a certain way, "lazy" and "unproductive" if they can't produce what is demanded of them, and "weird" if they don't like the same things as everyone else. An acceptance of disability and difference fits uncomfortably into a world that is often judgemental of those who don't match up to our image of a "normal" person.

Yet if we were to take that message of diversity seriously, we might turn our attention away from whether individuals match our ideas about what people "should" be like, and turn our attention to the way the world has been built around an imagined idea of a "normal" person. This normal person has easy access to buildings and transport. Public spaces – from buses, to offices, to kitchens, to gyms, to schools – are perfectly designed for their bodies and abilities. The traditional working week matches the energy levels of this special normal person, taking account of their need to eat lunch around midday and have two days leisure at the end of it. Basically, the world fits the normal person very snugly, and the normal person fits comfortably into their space in the world.

However, most of us are not the normal person. We all exist on a spectrum of different needs and abilities. Whether you're affected by a physical condition or a mental illness, or are involved in caring for someone close to you, then the struggle to fit

is an uphill battle. So long as disability and sickness are seen as marginal issues, those who don't fit will continue to be excluded.

Discrimination against people on the grounds of disability isn't often thought about in the same way as sexism, racism or homophobia, which are typically seen as "political" issues. But there are crucial connections between them. Many different groups of people are excluded and discriminated against by the very same structures and ideas: the dominance of a rigid and rather inhuman idea of what is normal. This includes the stereotyping of people with visible disabilities, and the stigma that those with 'invisible' disabilities (those not immediately apparent) face for not meeting society's expectations of what disability 'looks like' (see www.butyoudontlooksick.com).

Yet so often people don't blame the system, they blame the people; they blame the very ones who the system makes "unproductive", "useless", "lazy" and "weird". In this issue we reject these labels and criticize the current government's political agenda of cuts and austerity that are severely threatening the ability of those with disabilities to life full independent lives.

We hope that this issue of Rethazine provokes new thoughts, conversations and debates about these important questions. Let's dare to dream what the world might look like if rather than asking us all to fit into the world as we find it, we were to refit the world around us. All of us.

NOBODY'S DONE THIS:



INSTEAD, I'VE ENCOUNTERED A RANGE LIKE THIS:



IT ALWAYS FEELS LIKE I'M DROPPING A BOMB TO SOME DEGREE, THOUGH.

Ellen Forney

marblesbyellenforney.com

Ellen Forney, a successful graphic artist, found out she was bipolar when she was thirty. *Marbles: Mania, Depression, Michael Angelo and Me* tells the story of her diagnosis and her journey to work out how her identity, artistic creativity and mental illness fit together. It's heart-wrenching, hilarious and dazzlingly drawn. Here she shares her experiences of telling her friends about her mental illness. Available from all good bookshops or online.

Copyright for image: From *Marbles: Mania, Depression, Michelangelo, and Me*, by Ellen Forney ©2012

By Anonymous Square pegs in round holes

Disability, Unemployment and the Labour Market

I don't really know why my mum stopped working. She did work, for a long time. A tour guide, a caterer, a graphic design student, an archaeologist, a cleaner, a bar tender, a travel agent. But after I was 9, we lived off benefits, first off her jobseeker's, then incapacity. At some point in her life, she just didn't fit anymore. She became one of the long-term unemployed in the grey zone, shunted off

JSA onto incapacity because the hundreds of applications filled and useless 'trainings' completed did nothing to change the fact that she was a square peg that couldn't fit in any of the round holes available on the labour 'market'. Too overqualified for basic administrative jobs, too unfit for physically demanding for menial work, too indebted and lacking in self-confidence to be a go-it-alone

single mother entrepreneur, and too old and fat for everything else.

They're right, in some ways, Iain Duncan Smith and David Cameron. Living on benefits under this system isn't a life to live. Even apart from the myriad petty bureaucratic humiliations inflicted on the benefit recipient - either the 'job seeker' or the disabled - the logic of the market divides us into those who fit the round holes, and those who don't. The job seeking process pits us against each other; gruelling for even the fresh faced young graduate, for those who are psychologically vulnerable it is often an insurmountable challenge. Even to acquire a menial job now, applicants are in many cases required to navigate complex administrative processes, travel long distances, mobilise connections, demonstrate insider knowledge or use specialist terminology.

Then, at the end of the day, if they can tick the necessary boxes, many applicants will still fail, because there was someone younger or fitter or more experienced or whose jokes the employer liked more. And within a benefit system which is partly designed to be punitive - to stop people being too picky about what employment or pay or conditions they will accept - the amount of real support given to find employment is limited. Sue Townsend wrote in the 80s about the dehumanising treatment doled out by the benefit bureaucracy, and it was much the same when my mum was going through the job seeker mill in the early 2000s; at best job centre staff were often indifferent, at worst they actively shamed and bullied her. It's a destructive process for many, aggravating or creating debilitating mental health problems.

Yet all this degrading and punitive treatment is doubly meaningless: because the reality is

that for many of the long-term unemployed, there is no place for them in the labour market. Even for those considered fully able we are required to bend our lives and twist ourselves into uncomfortable shapes in order to meet our employers' requirements; in the most part jobs define us, rather than our skills, abilities or needs defining our jobs. The reality is that work the way it exists now actively excludes a section of the population. Those who are excluded are supported materially (if minimally) and survive; but they are not valued and much of what they could contribute to society in terms of skills and abilities is wasted. So they exist on the margins, a convenient political punching bag.

Most of us have a complex relationship with our jobs. Even those of us 'knowledge workers' who have been persuaded into believing we are in large part working to our own benefit and intellectual development, wish we could work less and earn more. Yet we also derive a large amount of self-worth and validation from our jobs, especially if we believe we are contributing to some greater goal. And it's hard for those of us fully integrated into the capitalist labour market, busy striving away, to understand how or why you can fail at working. We play the game and when we are winners we don't want to admit that the game's rules aren't fair.

I rage when I hear the political indignation and bluster against benefit cheats. Anyone who can cheat their benefits does. Mostly just by adding undeclared income; a bit of cash in hand work, renting a spare room. But why shouldn't you? You've been told you can't do what society values most, but the system's skewed against you. The game is rigged. I wouldn't be grateful either.



Spiderman and his biggest fan



Autism Friendly Spaces

Donia Fahim and Jamie Bleiweiss
Co-Founders & Executive Directors of AFS, Inc

The idea of Autism Friendly Spaces was conceived in an Upper East Side café over two black coffees in Spring 2011, by Jamie Bleiweiss a New Yorker, and Donia Fahim a Londoner now based in NYC. Both had worked in clinical practice and as university professors, specializing in autism spectrum disorders (ASD). An Autism Spectrum Disorder, more

commonly known as ASD is a broad term that describes a group of complex disorders of brain development. Autism can affect a person's ability to interact socially or to communicate with others.

Donia and Jamie had seen a growing need for everyday community spaces to become

accessible, accepting, and welcoming to the ASD community. Time and time again they would speak to parents of children with ASDs and professionals who would share their frustrations about the numerous challenges they frequently encountered when trying to complete everyday routines or participate in enjoyable recreational activities outside of the home.

Imagine an accommodating world where parents of children with autism didn't have to explain their child's behaviour to everyone, where they don't feel chastised by people staring and misjudging their 'poor parenting skills'. What if there was a place where personnel received training on ASD and could readily assist individuals or families experiencing difficulties? Where going through airport security was made slightly simpler and more straightforward. Where attending a Broadway show could be enjoyed by all the family, without planning a quick exit in case their child started behaving in a way that isn't typically seen as acceptable in a theatre.

Thinking of the powerful impact this could have for so many families touched by autism and rising to the challenge, the AFS team knew they needed to directly approach, museums, theatres, restaurants and zoos, in fact any place an individual with ASD would want to go to. Not starting by any means small, the first project the AFS team took on was to collaborate with the Theatre Development Fund (TDF) on the first ever Broadway autism friendly performance of Disney's the Lion King. On October 2, 2011, history was made when over 1600 individuals in the autism community attended a special performance of Disney's The Lion King. The changes and supports made are research based and copyrighted by Jamie Blewies and Donia Fahim, and included the house lights on by 30-40%, ensuring the audio was not louder than 80db, training the ushers and cast to understand the needs of an audience with ASD, having family friendly bathrooms and providing areas for breaks. In addition the show was evaluated and minor modifications were made that did not

change the theatrical experience or integrity of the show. For example the exploding steam from one scene was removed.

AFS has played an instrumental role in the successful execution of additional autism friendly performances of other hit Broadway shows, including Disney's Mary Poppins, Elf The Musical, Spiderman: Turn Off the Dark and Bello Mania at the famous children's theatre, New Victory Theater. Within the last first two and a half years, Autism Friendly Spaces has generated a proven track record of opening doors for the autism community, working with an array of businesses and service providers, as well as with prominent cultural institutions such as The Metropolitan Museum of Art, the Intrepid Sea, Air, and Space Museum, the Fraunces Tavern Museum and Union County Performing Arts Center. No space is too small or too big to become Autism Friendly!

A final word from the Executive Directors: "When we make spaces more accessible and accommodating for individuals with ASD

Stacey, parent of adult with ASD:

"When I saw they were having an Autism Friendly performance of The Lion King I thought it was a watershed moment. When I arrived with my husband, Emily our daughter and our son I knew I was right. My husband and I were in tears to see all the autistic kids and parents just like us. Emily was encouraged to sing Hakuna Matatta. Everyone was making noise no one cared, I was with my people as was my daughter Emily. I love that AFS's symbol is a key, the key is not to unlock the secrets of ASD but to unlock the door that locks the autistic person from acceptance into the community."



Specially trained ushers at autism friendly performance of Disney's the Lion King

by slightly adjusting the environment and adding supports to help them succeed, we are essentially unlocking doors and making the seemingly impossible, possible. The logo representing the organisation and a space that has become autism friendly is a key. Autism is typically depicted as a puzzle. AFS believes that nothing about autism needs to be solved, there is no puzzle. Instead, minds and spaces in wider society need to be unlocked

to support meaningful inclusion of those with ASDs. It is only then that we will move beyond awareness to acceptance, accommodation and appreciation".

If you would like additional information about Autism Friendly Spaces, Inc, such as the services we provide or the clients we collaborate with, please check out our website:

<http://autismfriendlyspaces.org>

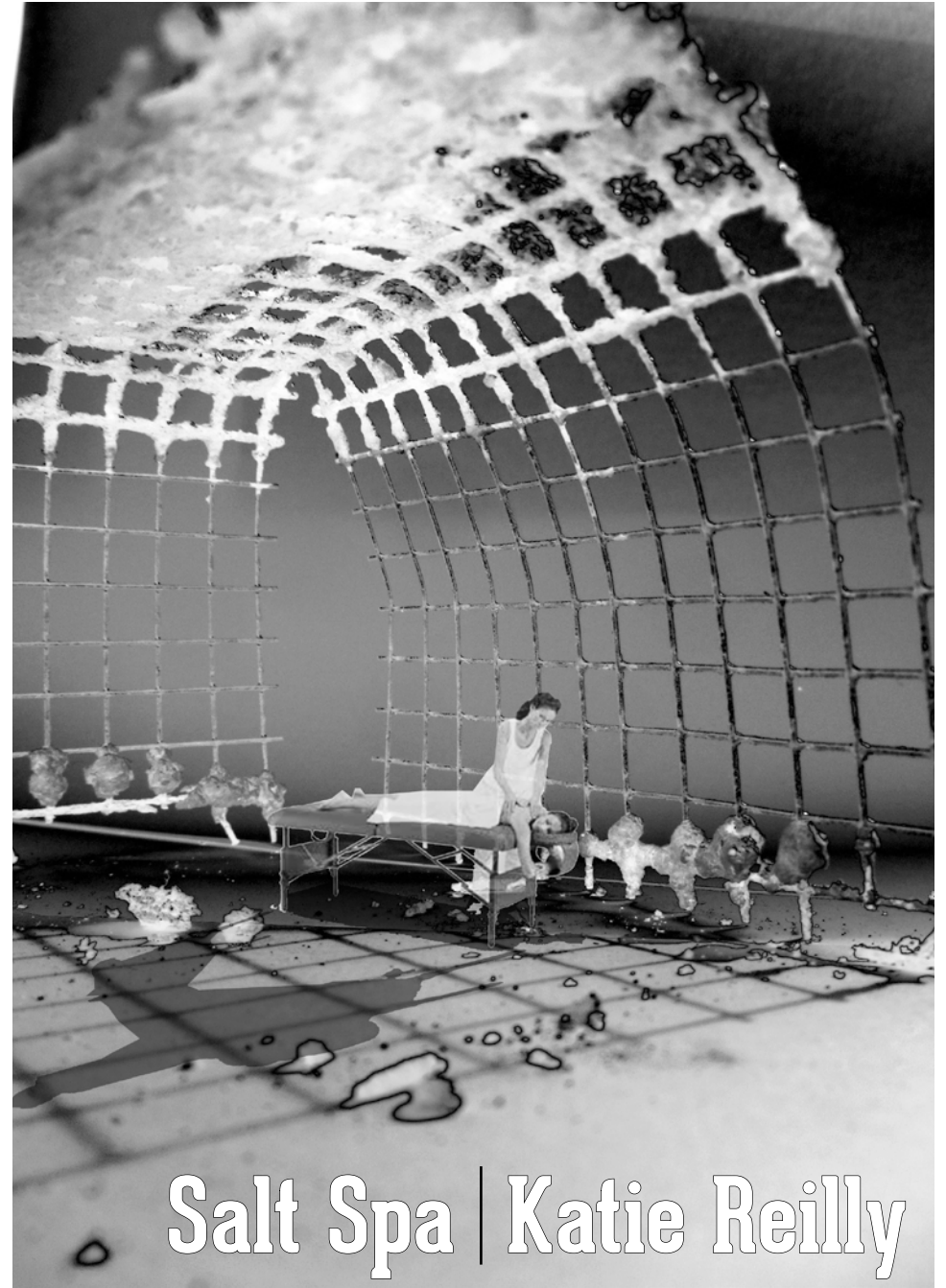
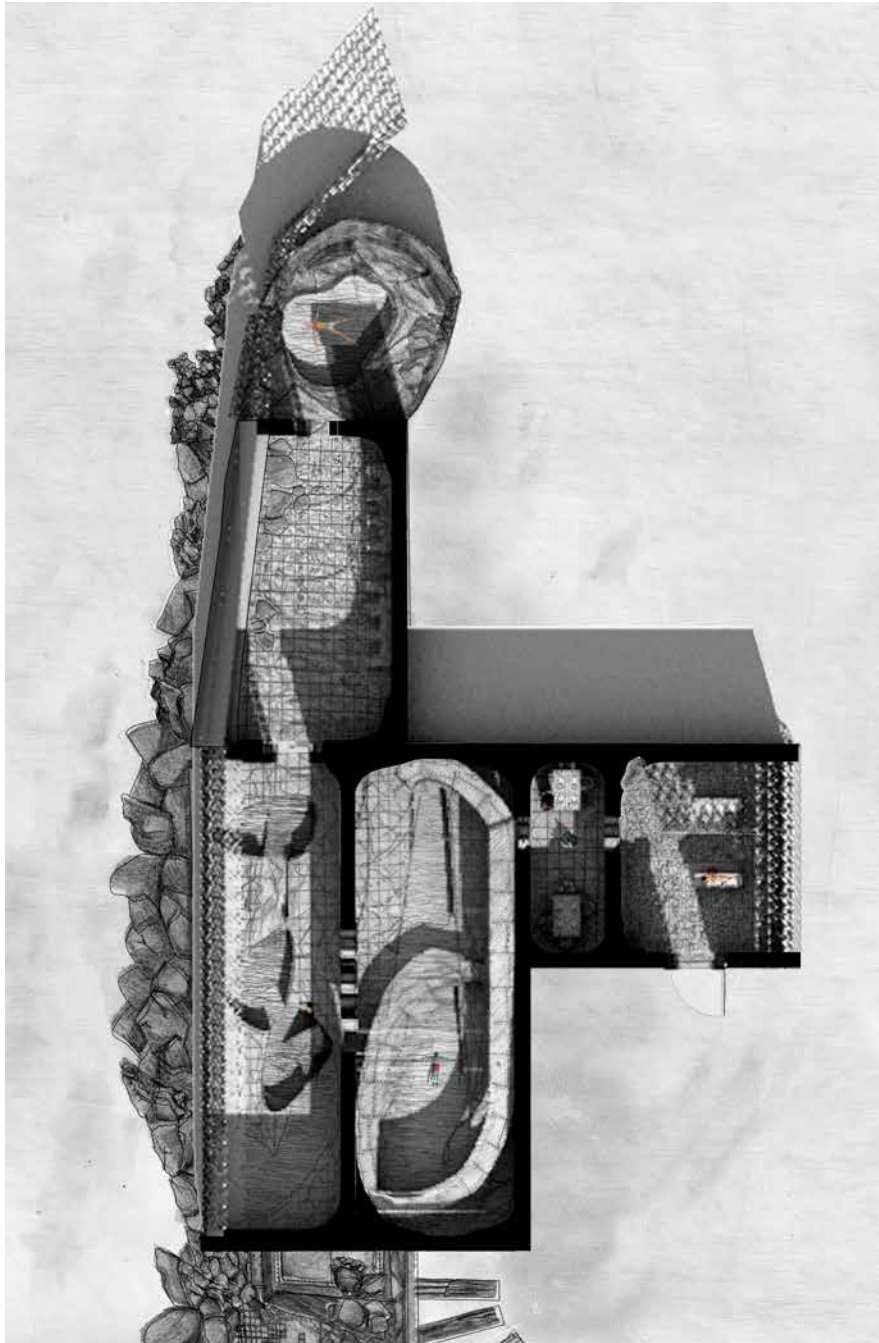
Salt Spa by Katie Reilly [over page]

Reilly's designs envision a salt spa to be located in Rosia Bay, Gibraltar, that will be accessible to all. She set out to redefine the architect's approach to 'accessible architecture' by embracing disability as the 'norm' and an integral part to design and not just an addition.

Her design proposes a place of healing through salt, for those with both visible and invisible disabilities. Ramps dictate the user's journey through warm and cold saline pools and into the variety of healing spaces. The tread of the wheelchair leave their memories engraved into the salt floors, as they move between the pools which leads to the salt massage space.

The absence of stairs is not a cause for concern, and the presence of a winding ramp not a reminder that disabled people might use this building. Instead, these are a celebration of the traditional ramp as it is integrated into the journey through the spaces; and the disabled people who will use this building. She believes that architecture should be a reflection of social diversity, and further a celebration of our mental and physical differences, not just social opinions.

Katie Reilly is a 3rd year Architecture Student at Oxford Brookes University. See more at: katie93.tumblr.com/



Salt Spa | Katie Reilly

Review ●●● Luke Roelofs

Sunaura Taylor and Judith Butler take a walk

In a clip from Astra Taylor's documentary *The Examined Life*, philosopher Judith Butler and artist and disability activist Sunaura Taylor talk about disability and what it means to 'take a walk'.

Luke Roelofs discusses the issues raised.

In its very first lines, this clip confronts us with two meanings of 'walk'. In one obvious sense, Taylor in her wheelchair is not walking. Yet she insists that she is on a walk, and goes for walks often. In this sense, 'walk' means 'that thing which people do to get places or relax' – that familiar, relatable, normal piece of human life. By laying claim to the word, Taylor lays claim to normality.

One might object that this is wilful denial of reality. Surely, for someone who's not normal to pretend they're normal is as foolish as for someone to pretend their hat is a pencil? But when Taylor lays claim to normality, she doesn't mean to deny any facts about her body. Instead she means to challenge the labelling of some bodies as 'normal' and others (hers for example) as 'abnormal'.

This requires understanding the social model of disability that Taylor discusses in the clip. This is often contrast with the medical model, according to which being disabled is an intrinsic feature of certain individuals, one which they have in themselves regardless of how people around them act. By contrast, the social model treats disability as resulting from a relation between an individual with an intrinsic impairment and a society which

erects barriers to them. To be disabled, on this model, is for other people to exclude you.

It's easy to look at this and say 'Barriers? Who's putting up barriers? Nobody's actively stopping disabled people doing things. If I construct a building on land I own and install only stairs, if I broadcast a show with speech but no subtitles, if I cut disability benefits, all I'm doing is not helping certain people – not erecting barriers in their path.'

Taken to its logical conclusion, the objection says that all anyone else is responsible for is not making you worse off than you would be 'naturally', if you lived on your own in complete isolation from others. Anything beyond that is just icing on the cake, and it's ungrateful for people with 'special needs' to decry a failure to help them as 'oppression'.

But this is exactly the viewpoint that Taylor and Butler are trying to undermine. We can't start from the idea of independent individuals, islands free of obligations, they say, because vulnerability and dependence are woven into our nature as human beings. If we base our moral reasoning on leaving each of us alone with what we naturally have, we'll go wrong because we don't naturally have anything.

For instance: to read this you need someone to have taught you to read, and someone before that to have taught you to speak; you need someone to have invented the computer, and other people to have done



Image: Youtube

the menial work that allowed inventors the leisure to invent. And all those people needed to be nurtured as infants – indeed, one of the most distinctive features of humans as a species is how long our young need to be cared for.

If we do start from human dependence, not human independence, then it must seem a direct and serious harm to exclude someone from the forms of care and assistance that humans have collectively built for other humans. That's why it's oppression to someone to not let them eat at your restaurant on account of their race or their lifestyle: the social recognition you cut them off from is like air to humans.

Isn't there still a difference between Taylor and Butler? Sure: one can walk, one can't. But we could equally take Butler and a pigeon, and note that one can fly and one can't. Butler's inability to fly, her 'flying

impairment', isn't a disability because she doesn't live in – isn't essentially dependent on – a society that normalises flying, where stairs, lifts and elevators were never invented and flying was the expected route from floor to floor. What differentiates Taylor's inability to walk from Butler's inability to fly is that we have taken one type of body as the right sort, ignored all the ways that people with that sort of body are dependent on others, and categorised all other bodies as uniquely wrong and the people with those bodies as uniquely dependent. Everyone is dependent, and humane politics would start from this assumption.

Zeitgeist Films, Written and directed by Astra Taylor. Official film website: zeitgeistfilms.com/examinedlife/

(clip available on youtube: <http://www.youtube.com/watch?v=kOHZaPkF6qE>).



Fish Schizophrene [cover] and Fish Schizophrene Detail, 1986, oil on canvas, from the series Bondaged Heads.

Bryan Charnley 1986

Copyright: Terence James Charnley.

Bryan Charnley (1949-1991) was an artist whose work vividly portrays the effects of schizophrenia.

The image of a head, blindfolded and gagged, with the mind exposed stands as a powerful metaphor for schizophrenia.

The sufferer is without a voice and what he sees is disturbingly affected by his own mind. This experience is very difficult

to communicate, the emotional and conceptual upheavals are invisible to the outside observer.

The bondaged head makes this point while at the same time attempting, by imaginative imagery to speak for those who have no voice and show what cannot be seen.

<http://www.bryancharnley.info/>

Excerpt: Interview with Comedian Francesca Martinez

"Francesca Martinez's victim is squirming. Trapped under the scrutiny of the comedian and fellow members of the audience at her show in Edinburgh, he is clearly wishing for the proverbial hole to open up. "What are you bad at?" asks Martinez. "Football," comes the sheepish reply. "Were you born like that?" she enquires, head tilted in sympathy, "Couldn't your mum have had a test when she was pregnant?" Turning to the man's girlfriend, she simpers: "You are so brave. Well done... Does it mean he can't have sex?"

Martinez's humour bears a political sting. As one of a tiny number of disabled performers who have made it into the mainstream, she is not about to waste opportunities to ram home a message. Born with cerebral palsy, the 31-year-old refuses to accept the label of her condition, preferring to describe herself as "wobbly".

"I get asked a lot why I talk so much about the issue of disability and I always say I'm just a woman who talks about her life," she explains with exasperation. "It's not about issues. No one says 'oh, that Jimmy Carr, he's always talking about being middle class and male' - or 'Johnny Vegas, he's always talking about liking cars and drinking'. But because I'm different from the norm, if I talk about being different, suddenly I'm talking about the issue of disability. I never talk about any other kind of disability. I just talk about my life and my views, some of which happen to contain my experience with CP. I'm not doing anything different from anyone else."

From an interview with Francesca Martinez by Emily Dugan for the Independent 08 November 2009.

<http://www.independent.co.uk/news/people/profiles/francesca-martinez-a-wobbly-girls-battle-against-the-last-taboo-1816861.html>

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Radical Calendar

A guide to free and nearly free events across London through the next few months. Listing does not imply endorsement, only curiosity.

Un-box: Future Cities - A Discussion

22 May 2014, 6.00pm: Sunley Pavillion at Royal Festival Hall, Southbank
Discussion about the future of our cities with participants and mentors from UnBox Labs 2014: providing a space for experts from the fields of design, architecture, data visualisation and interactive arts to exchange ideas and develop new prototypes that challenge the way we use our urban spaces. Free but booking required.

Southbank Centre Book Club

28 May, 6.30pm: Come along to explore Rabindranath Tagore's *The Home and the World* / 11 June, 6.30pm: A discussion on Jean Rhys's pithy and devastating novel *After Leaving Mr Mackenzie*.

Both in Foyer Spaces, Southbank Centre. Free but booking required.

B.S.L. interpreted tour of Medicine Man exhibition

Thursday 29 May 2014, 6.00pm: Wellcome Collection
Join this free British Sign Language (BSL) interpreted tour of 'Medicine Man'. One of our knowledgeable Visitor Services Assistants will lead you through the gallery, drawing out the hidden stories and significance of some of the objects. BSL users wishing to reserve places should book by emailing access@wellcomecollection.org or by calling +44(0)20 7611 2222.

On making a difference and choosing a career

3 June, 6.30pm: Wolfson Theatre, New Academic Building, LSE
Should I work for a non-profit organisation in Africa? Or should I go into the City, and try to earn as much as I can to donate to good causes? Dr William MacAskill, president of 80,000 hours, talks about choosing an ethical career.

Thrive: the power of evidence-based psychological therapies

10 July, 6.30pm: Old Theatre, Old Building, LSE
This event marks the launch of David Clark and Richard Layard's new book, *Thrive*, which argues that mental health problems are pervasive. They have massive social impacts and huge economic costs. They can be effectively treated by evidence-based psychological therapies, but these are not widely available. They should be.

Things can change, so please check with the organisers before attending.

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