

a zine exploring disabled  
students' experience at university

## about

This zine is a compilation of work created by a group of disabled students reflecting on their experience at university. The works were created during a weekend retreat in summer 2017 consisting of discussion and collaborative writing sessions. All of the students who participated in this event, and Artemi Sakellariadis who facilitated it, have agreed for their writing to be included here. Through these sessions, we wished to articulate some aspects of what it is like for us to navigate the world – and institutions of higher education in particular – through differently-abled bodies/minds.

The group are part of the Getting Things Changed (Tackling Disabling Practices: Co-production and Change), a three-year research study funded by the ESRC (Economic and Social Research Council) in the UK. The project is based at the University of Bristol, Norah Fry Centre for Disability studies, and led by Val Williams. The disabled students' group forms one subsection of the larger project, and is led by Victoria Mason-Angelow.

zines are self-published booklets, often promoting social justice causes or distributing art and creative writing. zines grew out of a movement of people whose voices are marginalised distributing their work in a non-mainstream way.



twitter **@GTC\_SPS**  
**#GettingThingsChanged**  
email **gtc-sps@bristol.ac.uk**



all photos within are of the Ammerdown Centre garden, where our discussions concerning the barriers to inclusion faced by disabled students, and how to take them down, took place.

website: [www.bristol.ac.uk/sps/gettingthingschanged](http://www.bristol.ac.uk/sps/gettingthingschanged)

blog: [gettingthingschanged.wordpress.com](http://gettingthingschanged.wordpress.com)

read about another event from this group:

[storify.com/laurinegrmo/getting-things-changed-tackling-disabling-practice](http://storify.com/laurinegrmo/getting-things-changed-tackling-disabling-practice)

zine design by Lilit Movsisyan and Anni Movsisyan

illustrations and photos by Lilit Movsisyan

This work is dedicated to the memory of  
**Dr Sue Porter**  
whose perpetually energised and humorous  
creative spirit continues to inspire us.

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Please note that some members of the group have chosen for their works to remain anonymous.

## Me, you and the roles we play

Different  
Other  
Problematic  
Confusing  
Resource-requiring  
Not the norm  
Never-seen-before  
Not-what-we-usually-have

Person  
Female  
Mother  
Wife  
Friend  
Student

Pushy  
Helpless

Assertive  
Having power

If I play my role will you play yours?

What will you do if I step out...outside the box...off script...anything goes? Will you leave...stay...be outraged...inquisitive...does your thirst for knowledge extend to my experience... or others' experience and how we might experience you? Or does this kind of thing unsettle you...shake the boat...challenge the schemas you would rather not pick apart.

**I am here...**

**where are you?**

**Tara S**

## **Raw Air**

What is there to say  
to be seen to be saying the right thing  
when no-one will know  
but the person  
who has heard it all before?

The script is written  
not to be unwound.

Unwinding it  
from the wounds of history  
might set in motion  
tangential offshoots.

The wound would be  
unwound.

**Katrina Plumb**

## spontaneous unedited train of thought 1

No but seriously though why are you saying that kind of shit. You have literally just met me and you know nothing of me?

I think the worst is when they call me a role model sometimes, like I wouldn't want any kid to have my life, or have to develop my coping mechanisms. I swear to god if I could go back in time and not be a quiet compliant child who never says they're suffering, I would go and live my best life as a giant mess so people actually look. No one deserves to have to compensate the way I do, to make themselves small and tiny and invisible.

If I had one thing to say as a role model it would be to tell disabled kids and teens to make some fucking noise except I can't because sometimes you need to not make noise. Sometimes you need to play the game and play on yr weaknesses because if you show you have literally one ounce of agency the powerful people will go oh noesssss we can't have that. And it's legit super hard to know when to play the role of the poor disabled person who's a bit clueless you know, oh please come save me nondisabled saviour, or the role of the absolute badass motherfucker who will advocate like their life depends on it because guess what, my life actually depends on it.

I know you think it's a compliment when you call me a role model but you're saying this based on incomplete data. You're saying this based on thinking: reasonably well-kempt, can put some words together and make them sound fancy on a good day, oh look cute diploma bet you didn't get that printed at



Staples wow look it comes from a fancy ass university wow the ivory colour of this paper really matches your eyes.

And like I actually want them to see me as capable so I'll say that wow yeah look I've done all that stuff and more but I'd disappear into a hole before I let you see me on a bad day. I can joke around all I want on tumblr about "that feel when your body gives up and executive dysfunction schmucktion look I don't have any executive function ah ah I can't even make some toast even though I'm super hungry" but that won't give me some toast.

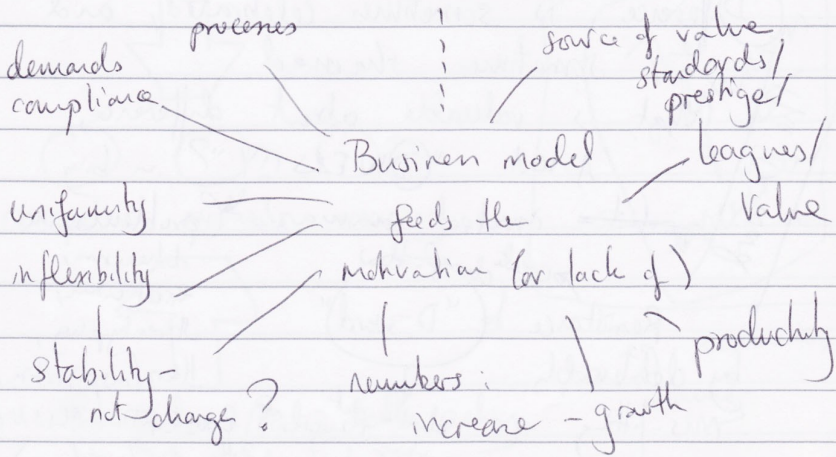
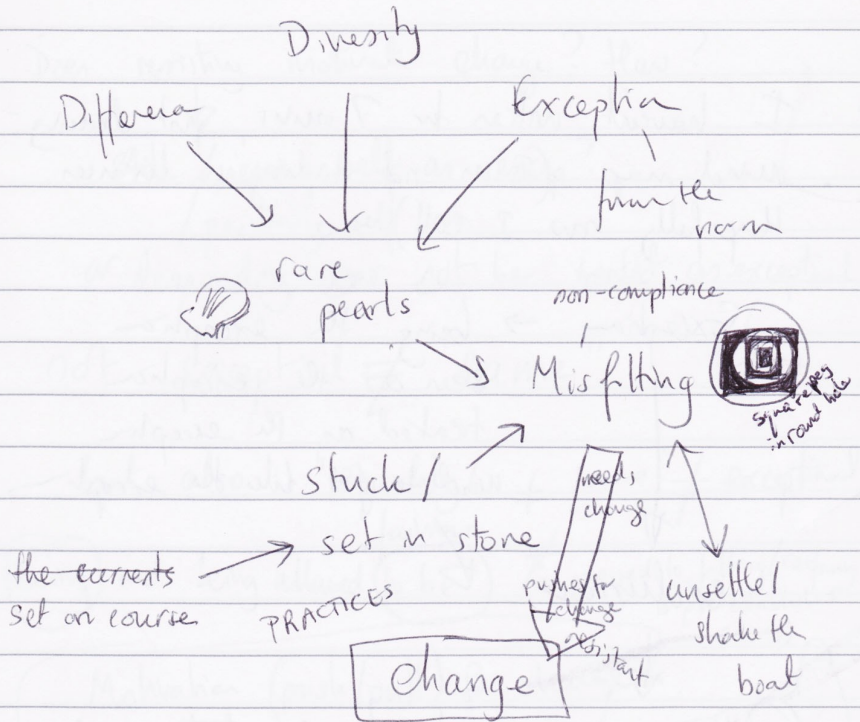
And I can do the seemingly complicated thing like wow look this is a 4k words essay of me trying to come to grasp with Foucault, ok I haven't really come to grasp with Foucault tbh but I still enjoy him sometimes because having Discipline and Punish in my bathroom when I was 18 made me feel like a really fancy scholar, anyways I wrote the essay ok and I did my best and it's actually ok, so you think I can make toast well no I can't make the toast DON'T YOU THINK I WOULD RATHER GET UP AND MAKE THE EFFING TOAST RATHER THAN ARGUE WITH YOU FOR 10 MINUTES ABOUT WHY I CANT MAKE THE TOAST, IT IS LITERALLY MORE ENERGY THAN I HAVE. Wait why would I ask someone at uni to make me toast, well no I'm not asking for my teacher to make me toast I wouldn't do that I've learnt a couple of social skills although my friend did borrow bananas from their PhD supervisor but I think that's because he's actually nice. I don't think my PhD supervisor would give me fruit because he doesn't even give me kudos ever.

## An open letter to the captain of the cruise ship

Dear Captain

I've been hearing this morning from four people who have been passengers on your ship for a brief while. They have been telling me about their rich knowledge of the waters you are sailing in, and I think you will be interested to hear from them. You see, they know how successful your cruise ship is, how its reputation alone keeps passengers flocking in, and they understand that you do not need to change a thing for your cruise ship to carry on being as popular as it has always been. And yet, they tell me that by sailing at high speeds you and your crew – and your passengers – may be missing out on some rare beauties that lie in the sea beneath you. One of them mentioned a rare substance that grows inside some kind of clams at the bottom of the seabed – all I remember is that they called it a name that rhymes with 'earl' – I'm sure your distinguished guests would like that. And someone mentioned a medieval shipwreck not far from the lighthouse – there is a legend that a trunkful of gold coins is lying in the seabed with it. A little further down, close to the sandy bay to the east of the large port you usually drop anchor in, there is a natural spring with water they tell me has healing powers. To experience all of these things, however, you would have to slow your pace or even take a little detour. What do you say? Would you like to let these people show you around, in the waters you habitually cruise through?

**Artemi Sakellariadis**



## spontaneous unedited train of thought 2

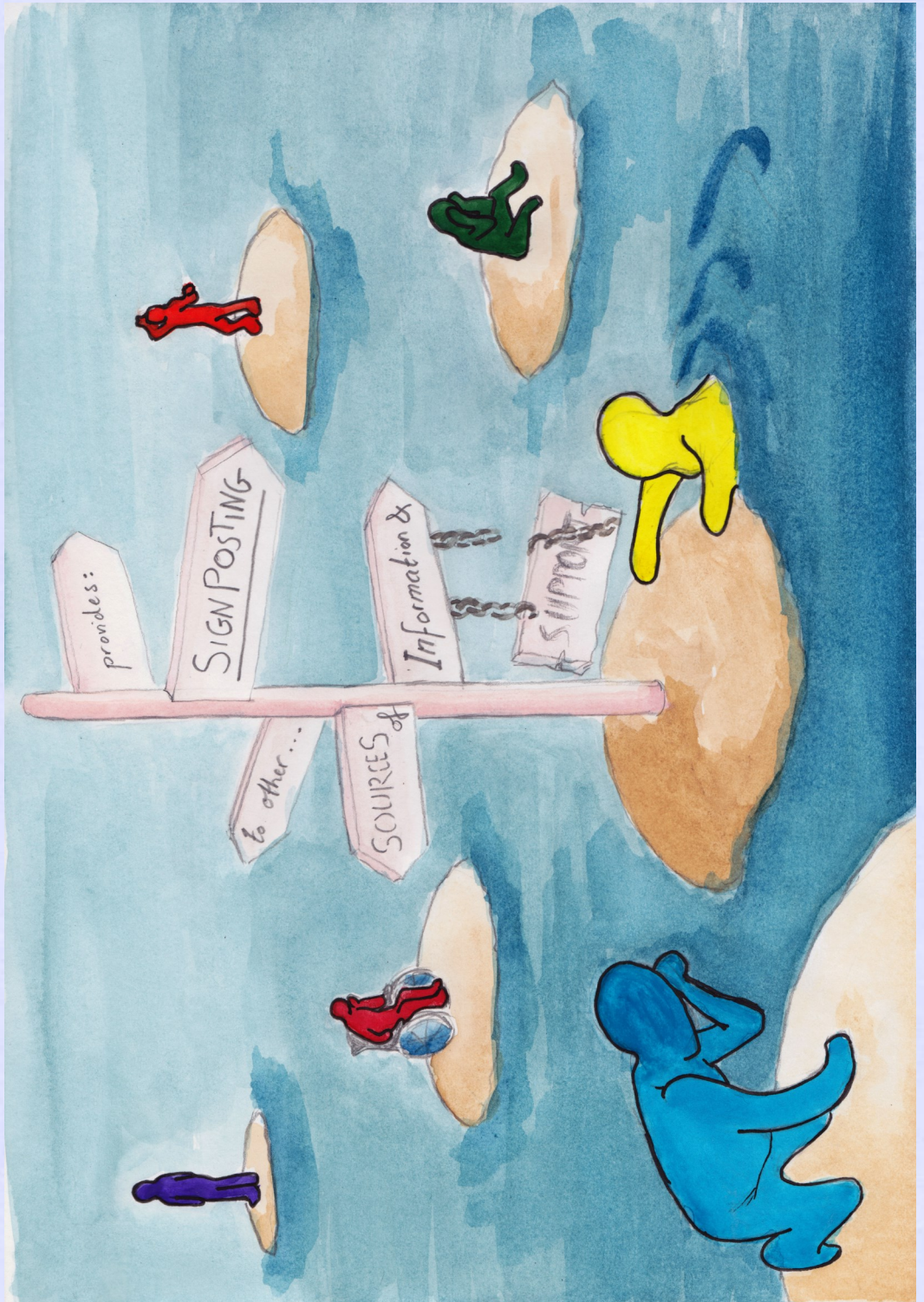
Wilful ignorance is when I tell you things suck a lot and you try to convince me they don't. Like okay there are some good things and I don't want to be some ungrateful disabled person, except I also don't want to give you cookies for not being an asshole.

The thing is no one is given some sort of manual when you're born disabled or you become disabled, or you're born disabled but it takes you a while to learn about it or any other configuration. When you're disabled and people know, they might interact with you a certain way, and what people don't realise is that colours your interactions with other people too.

I mean ok what you said wasn't that bad and on most days I won't bother even mentioning it, but also what you said is kind of bad but it's not actually my job to educate you all the time. But also if I say something, like will I make it all worse because you'll think hey I was just trying to be kinda nice here, I was just trying to make conversation, I was just. Ok you were just, but I also was just, I was just trying to exist in your vicinity.

And now you've just noticed me you're relying on me to tell you what to do, like by virtue of being disabled I have all this knowledge. And I do have all this knowledge but guess what it's not by virtue of being disabled actually I worked really hard for what I know and I talked a lot and I read a lot and you're treating what I know as some sort of internal magical pieces of information I was given by the disability fairy.

You like draining me for knowledge but that's also conditional, like if I try to have agency a little too hard or challenge you a little much you just sort of freak out, because that's not what you signed up for. Or if I am a little bit too angry in your direction you'll go wowowow, not all nondisabled people, don't be so ungrateful, don't be so angry, but there is a place for anger and it is within me.



## A meeting with the captain

I knock on the door and wait.

“Come in!” his confident voice booms. Maybe I imagined it, but it feels as though his voice carries an air of superiority – he greets me with his typical welcome smile which, to me, makes me feel as though he is used to looking down on others entering His Space.

He offers me a brandy, which I politely decline – I’ve got to keep my whits about me here. He pours himself a glass, sits back and asks “So what can I do for you?”

“Well, thank you for reading my letter and inviting me to discuss it”, I begin. I am painfully aware he has invited me, the author of the letter admittedly, but not any of the people my letter suggested he may want to hear from. This hierarchy in this institution probably makes him think his time is better spent hearing it second-hand.

“My pleasure!” he says. “So what about these hidden treasures you mentioned?”

His directness unsettles me. Is he only interested in what can be of tangible benefit to him and, by implication, his cruise ship?

“Well, you see”, I improvise on the spot, “I am not so sure that knowing about them will be of value to you.” What I mean is that there are different ways of knowing and my second-hand narrative may not be the best way for him to find out. He needs to hear directly.

“And how would you know what is of value to me?”

I see an opportunity and grab it.

“Well, perhaps I don’t. Why don’t you tell me about your values, and those of your cruise ship?”

“It’s quite simple really”, he says gesturing towards the wall display behind him. “Equality and respect for diversity are of the utmost importance to us here.”

I can see what he is doing. Most cruise ships follow this mantra, and dish out similar values with similar certainty.

“What about money and profit?” I say. “It looks as though that is hugely valued on this ship.”



“Ah, now, we mustn’t confuse values with being realistic” he says, without a hint of apology in his voice. “You and I know that we have to be realistic, and that without passengers this cruise ship would not go anywhere. That is taken for granted. But if you want to talk about our values, about what we believe in...”

“I don’t actually”, I interrupt. “What interests me is not so much which values you subscribe to, as to which are the values that shape your practice.”

“As I was saying...”

**Artemi Sakellariadis**

Exception → being the exception  
seen as the exception  
treated as the exception  
wants to feel like the exception

↓  
exclusion ↙

↓

① Difference is sometimes celebrated, and  
sometimes shamed.

↳  
D-word

What is valuable about difference,  
A.K.A. "DIVERSITY"?

~~gated~~ invited ~~commas~~. (problems inc.  
theism,  
exotism,  
stereotyping,  
Hero/inspirator,

↳ create change? How  
Resistance to "D-word"

by delectably  
mis-fitting  
(examples?)

↓  
what aspect  
are we resisting?

& EXCEPTIONALISING  
(with pre/-vedy)

Does resisting motivate change? How?



still / viewing self as excep?  
/ positioning self as

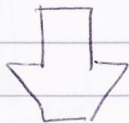
or demanding ~~one~~ not be treated as exceptional

not exceptional ≠ "same" ↓

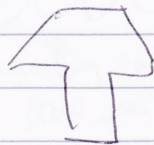
but also "equality/ <sup>fairness</sup> ≠ same" ≠ exceptional

(Being) and being allowed (to be) <sup>fairness</sup> ≠ (as opposed to fitting/conforming to pre-established norms)

Motivation (push/pull) for change



competence materials meaning



Other factors (independently acting on the elements)

The ordinariness of the exceptional

→ eg. economics, meaning

**N. I. C. E. :**

**Normal Institute of Clichéd Expectation**

Investment in ignorance seems innate  
conned by conditioning.

Collective values support

matters of maturity,

materialise,

matted with standards:

provisos promoting the status

quo-ntity, qualified by questionnaires

automated to set autonomy

into a selection of 'oughts',

prescribed prejudicially by pressure

precluding presence.

Absence is advocated,

investing in ignorance.

I'm an image  
immunised against immaturity.  
I'm aged.  
I could be an imago  
imminently flying;  
some stages of  
our species  
ago.

Original organs  
are now an orifice.  
Or is it organisations'  
objective?  
Ostentation dictates  
all manner of states  
when statistics stick fingers  
in ignorance.

**Katrina Plumb**

## key messages

### BEING THE EXCEPTION / SHAME CULTURE

The unusual shouldn't carry stigma.

Being allowed to be *is not the same* as conforming to pre-established norms.

Medical labelling gets in the way of people's abilities.

The need for labels creates an excuse for stigma and for being treated as an exception.

### ROLES / CAPTAIN

There needs to be communication between different levels of hierarchy.

Creating an inclusive institution is a collective responsibility: it's up to everybody. Not 'somebody else'.

Don't let power imbalance dictate expectations of disabled students -

*"Don't make me perform what you think a disabled person should be like".*

### WAYS OF KNOWING / IGNORANCE

You have to engage with the 'Other' to understand Their Experience.

You need to do the hard work of unlearning your ignorance.

Different experiences lead to different ways of viewing the world, and different ways of knowing.

## VALUES / STANDARDS

Paying lip service to values such as equality and inclusion: in practice, institutional practices are often guided by “other values” such as prestige, standards... Efforts to create more inclusive environments are often met with bureaucratic barriers.

## PATRONISING INSTITUTIONAL MESSAGE / STRUCTURES

Being kind *does not* mean being patronising. Your statements may appear kind, but if you look down on people it *is* patronising.

Being patronising is *not necessarily* to be mean or malicious. You can be patronising without intending to be malicious.

Injustice can persist without any individual's malicious intent. It's the structures that need to change for inclusion to prevail; otherwise, things stay just the way they are, because that's how it's always been done.

## acknowledgements

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Thank you also to the following institutions: the University of Bristol, Norah Fry Research Centre, the ESRC, and the Ammerdown Conference and Retreat Centre, for hosting us comfortably and accessibly.







## Letter to my child (about going to University)

You asked me 'why are you doing this?'....

Yes, you're right, it's really hard work...I could be doing something else...easier, that doesn't end up leaving me exhausted, in pain, exasperated at times. Somewhere where difference and diversity are not simply terms on paper, sitting next to tick boxes. I could stick to places where I can manage physically, like home, hospital and places set up for people 'like me'. But that's not the point...why shouldn't I go there? Why shouldn't I do that?

You may not want to do what I have done in the future, but I want you to know that you can...to know that there's a path there and to be able to find a path, a well-trodden path, signposted and dotted about with people, who will journey alongside you, if you want or need that.

If nobody walks on a path then it can become overgrown, easy to be ignored, untended. I want there to be a path there, so that you and others know that there's a path there...whether you choose that path or another path, it will be up to you...I just want you to know that it's there...as part of a wider network of paths that you could take, because others have walked there before.

**Tara S**



