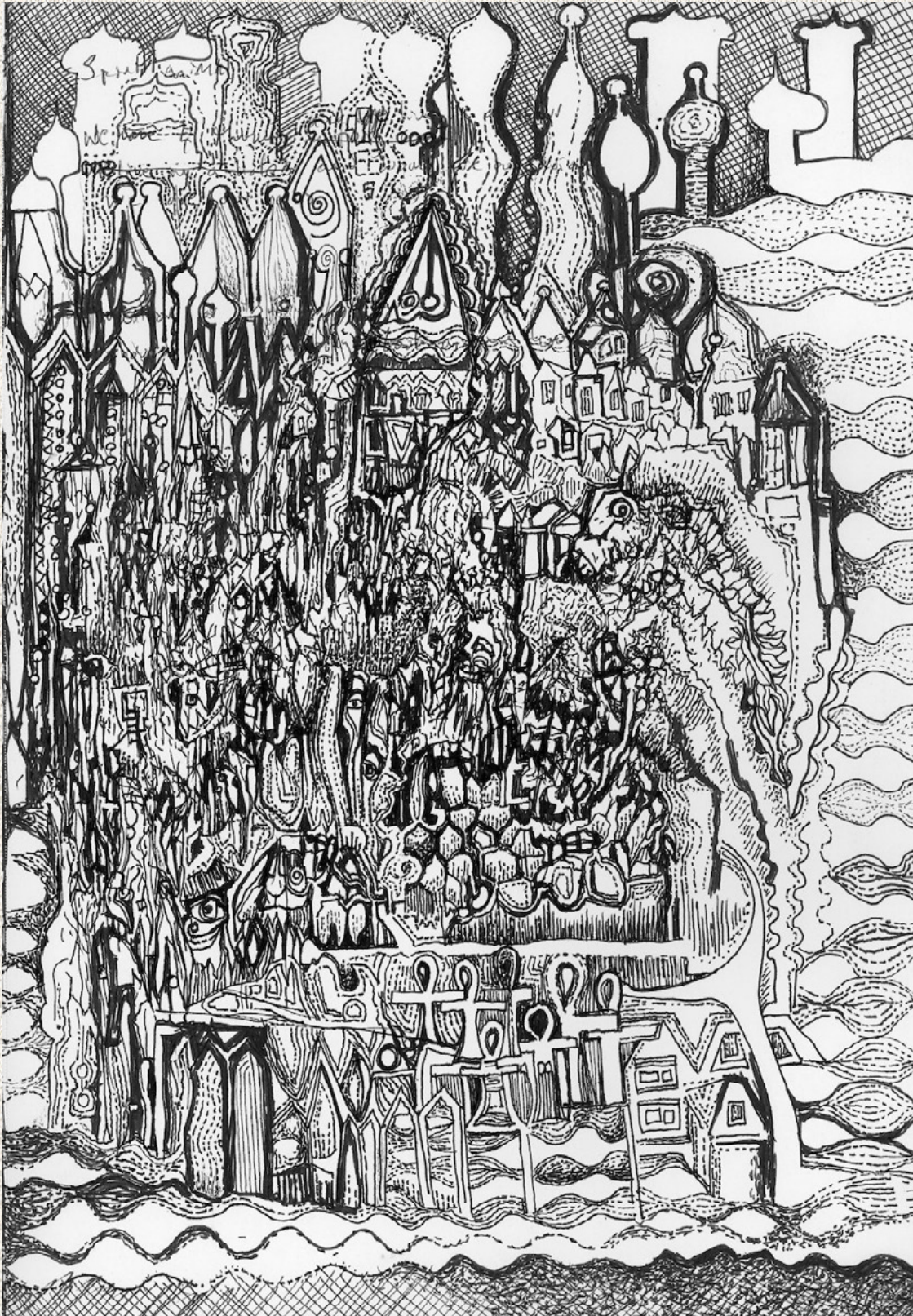


FUTURE PERFECT FUTURE IMPERFECT



EDITED BY Tanvir Bush, Esther Fox and Martin Levinson.

Cover Image ' Psychological Landscape' by Colin Hambrook

Designed by James Shaw, Volley Design

In memory of Sue Porter, and with gratitude for all her warmth, humour and energy.

Thank you to all the participants who have generously shared their observations, good and bad, and who have revealed the immensely rich and diverse range of life experiences disabled people understand today.

And in solidarity with friends and acquaintances who have suffered as a consequence of Covid 19, fallen on hard times, been victims of hate crime.

Finally, we would like to thank our funder, the AHRC (Arts and Humanities Research Council) for all the support and patience.

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Introduction

Running for five years, D4D was one of the final projects in the Connected Communities programme funded by the Arts and Humanities Research Council. Exploring the meanings of 'community' across different groups and the ways in which individuals participated in their communities, it had been rather surprising, given all the rich endeavour within that programme, that there had been no exploration in the first few years of the lived experience of disabled people. D4D sought to address that. A key principle lay in the belief that we should be capturing the stories of our participants, conducting research alongside them.

Intended as playful and subversive, the full project title - *Disability and Community: Dis/engagement, Dis/enfranchisement, Dis/parity and Dissent*, reflected the challenges: the sense of an uneven playing field in which some people were not only pushed to the margins but rendered invisible. Our team itself was a diverse group, who had come together through a 'sandpit' workshop in Sheffield. We were a ragtag assortment, who did not quite fit in with the other groups that were coalescing at that workshop. There was nothing that made us coherent. We had not known one another previously. Some of us were academics; some artists, writers and performers; some were activists. Some were disabled; others non-disabled.

Despite our differing experiences, we were all keen to build a project that would be challenging, disruptive, on occasion, playful, and at other times, with a hard edge. Some team

members had been active over a number of years in the Disability Rights movement. There was no collective vision emerging though our respective backgrounds, but we were agreed that, more often than not, 'inclusion' has always been partial, contingent on other factors. Some members of the group were sceptical of the very notion of a 'community' that includes people with a wide range of conditions. At a very early stage, it was decided that our project would involve individuals from across the 'disability' spectrum. It is difficult to represent the views of some who are proud to label themselves as 'disabled', and others who prefer to deny it. Nevertheless, disabled people should have the same right as any other group not to be homogenised.

Some of us were keen to dismantle the borders, believing that the world should not be divided into classifications of 'disabled' or 'non-disabled'. Ultimately, we are all 'human', part of a continuum. At the same time, some of us were concerned that arguing such a line could lead to the erosion of rights built up by the staunch efforts of pioneering campaigners.

While providing a sense of some of the work that went on, *Future Perfect – Future Imperfect?* was never intended as a book of the project. Featuring contributions from team members and others who have participated in the project, the central intention is to imagine future scenarios, speculating on possibilities while also foregrounding the shadows cast by the past. The first section, *Hidden Legacies; Recycled Dreams* is based on memory and experience.

There is a focus on the field of eugenics, which may appear to be part of history, but which remains pertinent in contemporary times, for example in the initial reaction to Covid 19 and speculation about 'herd immunity'. Still more, perhaps, it is to be encountered in the field of genomics. In the assumptions that underlie gene mapping and gene editing, there persist the values and thinking of the early Eugenics movement.

The second section, *Imagined Futures*, containing stories and images, shifts the focus to creative visions of what may be. While the overriding impression may still be more dystopian than utopian, that feels like an inevitable outcome of the difficult times in which we live, during which disabled people have often disproportionately suffered the brunt of policies of austerity and then the outcomes of a pandemic. However, an e-book such as this is an organic thing, and we will be delighted in the future if more optimistic times result in a glut of further contributions, illuminating brighter paths forward.

The final section of the book, *Fluid Identities / New Spaces*, includes a number of different elements, including the possibilities of new technologies, some of which were trialled during the D4D project. It is hoped that the section also contains seeds for a manifesto, a new call to arms.

Martin Levinson – September 2021



Hidden Legacies / Recycled Dreams

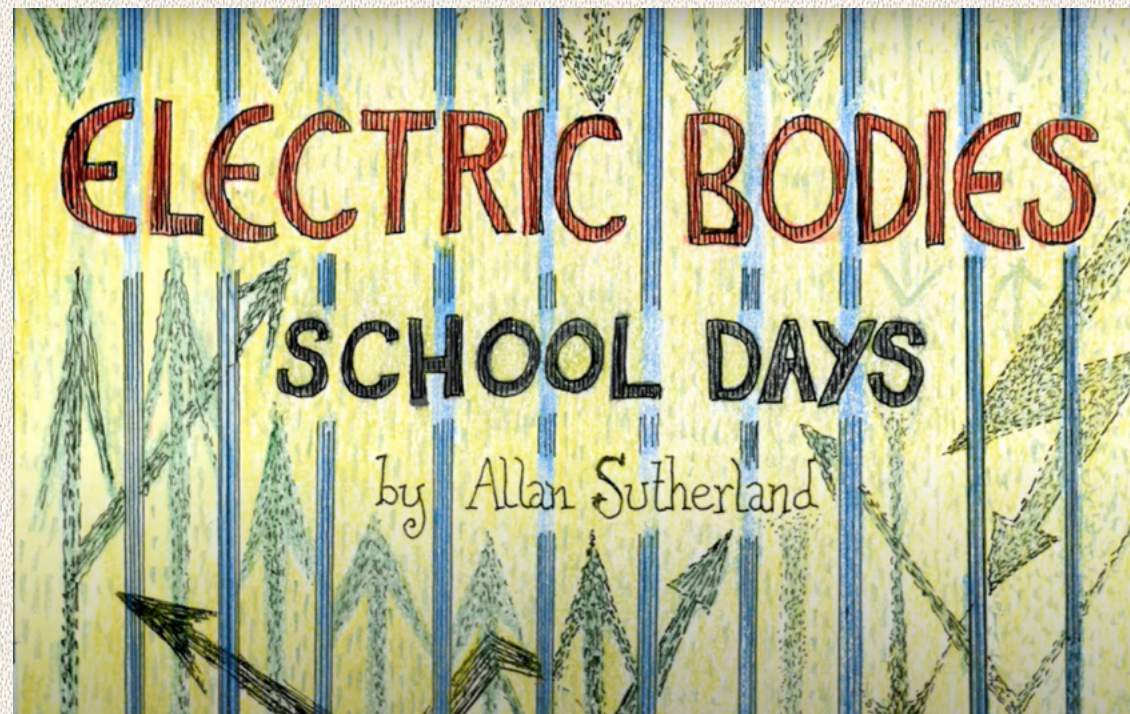


Sasha Saben Callaghan Collage

By Allan
Sutherland with
Illustrations by
Colin Hambrook
and animation by
Mark Hetherington

School Days - (From Electric Bodies)

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By Esther Fox

Evolution

Medical science subsumes all other views within its orbit, yet it is ill equipped to predict the wider sociological impacts which may occur with the reduction or abolition of genetic “abnormality”.

I believe socially engaged arts practice offers an opportunity to engage the wider public in the ethical issues relating to genetic screening that otherwise may be imagined too difficult to broach. To watch the Evolution workshop video [visit](#) the D4D website



By Esther Fox

New Eugenics; Acknowledging Troubling Legacies

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It is inevitable that genetic technology is quickly developing and we cannot turn away from the current trajectory. Now is the Zeitgeist of the genetic era. We have moved away from being merely flesh and blood and have instead become a code, a series of pre-programmed letters that must be deciphered and either discarded, because the spelling isn't correct, or amended, for the sake of creating decent prose.

So, if we cannot change this predicted widespread move towards screening, I am interested in what I and other disabled activists and researchers can do to at least problematise the pro screening debate.

I propose that genetic screening is indeed new eugenics. However, in order to make the arguments more palatable, screening is guised as entirely positive; offering choice in order to eliminate suffering, thus creating a Utopian world.

To understand the present and consider the future, I believe it is necessary to re-examine the past. The Wellcome Trust has a wealth of archive material that relates to the eugenics movement, and in particular Francis Galton the "Father of Eugenics". Reflecting on the origins of Eugenic theory enables an opportunity to interrogate how far we have really moved away from these early ideals which are now regarded as extreme and unacceptable.

Inspired by his half cousin, Charles Darwin and his theory of evolution, Galton believed that certain character traits ran in families and was interested in promoting what he believed to be "desirable" traits, while not allowing those people who



might "contaminate" wider society to breed. Galton goes on to describe what these more desirable human characteristics might be.

"A considerable list of qualities can easily be compiled that nearly everyone except "cranks" would take into account when picking out the best specimens of his class. It would include health, energy, ability, manliness and courteous disposition."¹

¹ *The American Journal of Sociology, July 1904, Volume X, Eugenics; Its Definition, Scope and Aims. Francis Galton.*

This may seem extreme by contemporary standards and this is perhaps in part, why a distinction is made between eugenics and genetic screening, but really how far have we departed from this eugenic logic? There is a hierarchy and some lives are deemed more valuable than others.

Although the language is somewhat outdated, what is not so dissimilar to contemporary pro-screening arguments are the traits that are considered positive relating to health, energy and ability. Importantly the notion that it would only be "cranks" that would oppose this logic resonates with current arguments, where women are encouraged to accept the screening of their pregnancy as part of being a responsible parent, because why wouldn't you and it would be irresponsible not to.

This thinking relating to disability as a deficit and therefore something that should be avoided at all costs, permeates contemporary values. However at the time of Galton he recognised that his thinking was ahead of his time and would



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require the wider public to come to terms with his radical ideas. Towards the end of his paper he draws the following conclusion.

“The first and main point, is to secure the general intellectual acceptance as a hopeful and most important study. Then let its principles work into the heart of a nation, which will gradually give practical effect to them in ways that we may not wholly foresee”.²

² *The American Journal of Sociology, July 1904, Volume X, Eugenics; Its Definition, Scope and Aims. Francis Galton.*

I would argue that we have reached that point where the principles have worked into the heart of a nation, indeed many nations. Eugenic logic in terms of medical impairments and to some extent age, has now been largely accepted and is barely even questioned. This was made particularly apparent during the Covid-19 pandemic where the safety of disabled and elderly people was not prioritised, instead they were seen as expendable collateral damage.

Problematizing Eugenics through Participatory Arts Practice

At the same time as pursuing this personal research, I had also begun to work with other disabled people to explore the ways in which we categorise, marginalise and make value judgements about people. At the heart of this exploration was utilising creative methods to enable free and authentic discussion about people's life experiences and thoughts around genetic



screening. The final aim was to produce an immersive piece of Virtual Reality that had been co-produced with disabled people's input.

I particularly aimed to attract participants who had a lived experience of a genetic condition as I wanted to give space to this particular perspective. I also wanted to explore with them the areas that they specifically wanted to foreground.

“The idea of collecting and collections I have found particularly interesting. The concept of what's kept and what's discarded is very interesting....The process of developing the VR has allowed me to consider how I might express these thoughts to others who may hold different opinions. It is a difficult thing to think of yourself in terms of being something that might be considered throwaway but allowing myself to think in these terms the question that really arose for me was: who is making the decision that one life is worthwhile and another is not? Who decides the terms and criteria D4D workshop participant?”

Evolution

Evolution is a piece of Virtual Reality which was created as a result of these participatory workshops with disabled people and research into the eugenics archive material. Stepping into the imagined study of Francis Galton, the viewer explores a VR world and fantasy collection of specimens. When asked to make their own selections they face uncomfortable questions about what we value and what we discard. Requiring the viewer to actively make choices, places the onus of responsibility on that individual. This is reflective of current day



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policies on genetic screening, where choice for that individual is only presented as being a positive thing. However, there is little public discussion about the pressures and difficulties that come with choice and having to make these life changing decisions. Did you make the “correct” choice? Evolution aims to show the viewer that trying to make any choices leads only to disappointment, as balance and diversity cannot be achieved. Evolution enables audiences to take a step back and reconsider contemporary ideas about classification and value.

Currently VR is relatively early on in its development in terms of it being an artform. I believe VR offers an exciting opportunity to merge futuristic visions, imagined spaces and arts practice. Consequently I’m interested in how through creating a VR experience I have been able to bring together the past and future ramifications of eugenics. We can travel in time, from the day of Galton through to imagined dystopian futures of perfection. VR has unique immersive properties that can disturb our understanding of what is real or imagined and instil a strong emotional sensation in the viewer. This capacity ensures that the VR experience is memorable. I intend for this piece of VR to disrupt and surprise the wider public, to begin a dialogue about what we choose to value and what we discard and to challenge medically driven perspectives of genetic screening being entirely positive. I hope to enable a conversation that challenges this deeply and historically routed privilege of the medical ideal being superior and leave the audience with a memorable experience that they will continue to reflect on and talk about, long after removing the headset.

With thanks to BRiGHTBLaCK for designing the VR programming.

By George Parker



Casual Eugenics

I’m sure when you talked about herd immunity you didn’t necessarily have me in mind.

I’m sure when the country was debating the fate of this nation

deciding which of the population had enough worth to be kept alive you didn’t specifically think of me or my disability.

Still, it hurt – watching you weigh up all the pros and cons, slamming protests, protecting statues of bronze and the economy while sacrificing thousands, casually.

You really didn’t think of me... or the other *others* who needed you.

These times of desperation
are not the finest of the nation.

They showed how many of us, when afraid
will begin a small flirtation with damnation,
saying, *It’s fine, God, let them die, just please, not me or my relations.*

We were the collateral damage for your pilgrimage to the beach, but even the corresponding peak in deaths didn’t teach you anything – another week and there’s another image:

you, like a thousand grains of sand;
you, jammed into bars like red, ripe fruit in a jar, pint in hand.

These times of desperation show ours to be a callous nation, brazen with determination to go on vacation, faces impatient as they yell,



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It's fine!

God! I deserve this occasion for me and my relations.

And I hasten to add, we paid the price
for you ignoring sage advice.
I'm not pointing fingers, but as someone who's disability
tends to wear a cloak of invisibility
I've heard it all. What you think of me. And others like me.

Or maybe it wasn't you I heard,
maybe you were one of those who stayed quiet,
compliant, complicit with the explicit plan
to let disabled people take the brunt of this pandemic.
Don't tell me that's not eugenics.

Eighty thousand of us lost a battle we were never meant to win
in a flutter of papers that prodded readers like cattle
into believing herd immunity was for the best,
with no thought of our community,
us who you deem unfit for page three, equality or society
anyway.

It's easy to shout
over those who couldn't even come out
of their homes and protest.
And perhaps that's best because I saw you there,
blaming protests for deaths, making scapegoats
of those who wanted to escape white supremacy and rape.
Protests didn't kill a hundred and thirty thousand;
sure, there was crowding
but people spouting this nonsense
just use it for their own astounding agenda, well, here's a fact:

Disabled people made up 60% of deaths in the pandemic,

You can't tell me that's not eugenics.

What killed them was a trident of a lack of compassion:
greed, ableism, capitalism –
wielded by the establishment.

It's indefensible –these deaths preventable,
but our government stood there and said its acceptable,
that we were expendable. And you just went along with it.

Society was never accessible but now
with eighty thousand of us dead to a battle we couldn't win,
you have a chance to begin again.
Include us.

These times of desperation could inspire the transformation of
this, our fractured nation.
We just need a new equation,
one without alienation or otherness,
with something more profound than tolerance,
and it starts with you, my audience.

Now's the time for innovation!
Equitable representation in politics would lead to unbiased
legislation, embracing all the variations
of the disabled population.

Give us invitations to places we can actually travel to
and accessible stations! Keep streaming shows to remote
locations!
Choose event destinations with consideration of integration.
And always, proper communication to enable education for all.

These adaptations are declarations of equality,
such simple affirmations of our belonging in society,
and with them, you'd see – we're just like you and your
relations, deserving of life and all the wonders of creation.



By Esther Fox &
Diane Carr

Genetic Screening

A discussion about games, VR and Esther Fox's work on genetic screening

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Introduction: Esther Fox is a visual artist, Head of Accentuate and a Community Co-Investigator on the D4D project as well as project manager. Diane Carr is a media and games researcher based at UCL. Diane is leading the Playful Bodies work-stream. What follows is an edited transcription of one of our working-discussions from summer 2018.

The discussion was structured a bit like an interview. Esther shared some notes prior to the meeting, and Diane used these as the basis for a series of questions. The recording was transcribed in January 2019. Diane edited the transcription, which Esther checked and approved. This transcription documents a particular stage in Esther's work on VR and games as a way to support public engagement in debates about genetic screening.

[Further Reading](#)



by Tanvir Bush

CULL and The Bushwick Book Club -

Alex has a problem. Categorized as one of the disabled, dole-scrounging underclass, she is finding it hard to make ends meet.

Now, in her part time placement at the local newspaper, she's stumbled onto a troubling link between the disappearance of several homeless people, the new government Care and Protect Bill and the sinister extension of the Grassybanks residential home for the disabled, elderly and vulnerable.

Can she afford the potential risk to herself and her wonderful guide dog Chris of further investigation?

Maggie Gee has written of this novel: 'Where is the satirist we need now, with the welfare state in chaos and politics a TV reality show? She is the fabulous, funny, sharp, outrageous Tanvir Bush, and Britain must read her. With a dauntless but sympathetic heroine, one of the best dog characters in literature and a disabled escort service called the Ladies' Defective Agency, this witty and all too believable novel is a 2017 inheritor of the satirical genius of Lindsay Anderson's Britannia Hospital and Anthony Burgess's Clockwork Orange.'

The Bushwick Book Club began in New York in January 2009 as a dare. Songwriter Susan Hwang dared Goodbye Blue Monday owner, Steve Timbali, to let her have a night of new songs inspired by literature. He said, 'Sure!'

They started with Kurt Vonegurt's Breakfast Of Champions and now meet monthly, employing the talents of local song-writers, artists and chefs to plumb the depths of a chosen literary gem to make that rare and beautiful thing- a new song (visual art, film, dance, food). These literature themed live shows have been inspired by everything from Raymond Carver to Charles Darwin to George RR Martin to the thesaurus.

By Andreas Hechler

In memory of Emilie Rau and of the other victims of Nazi 'euthanasia'

This week it's exactly eighty years since my great-grandmother, Emilie Rau, was murdered in a gas chamber built into the cellar of an asylum in Hadamar, a small town close to Frankfurt. She was forty-nine and had four children, of which my grandmother was the eldest.

On the most recent Holocaust Memorial Day, I was asked whether the Holocaust still casts a large shadow over people's lives. If you imagine a world where not only those people who were murdered were alive, but also their children and grandchildren had come into this world, our society would be very different. I write, but innumerable others do not because they were not born. Looking at history from this angle makes clear that the past is intrinsically linked to the present. We understand why this society is the way it is. It also links to the future by asking: do we want it to be different?

Nazi 'euthanasia'

The Nazi so called 'euthanasia' program began officially on 1 September 1939 – the same day that Germany invaded Poland. Parallel to the outward declaration of war, an inward war was declared. Those who claimed to be the 'master race' sought to enhance that race in order to demonstrate and justify their supremacy both at home and abroad. 'Cripples' and 'idiots' had no place in the master race.

The killing of disabled people began in January 1940 as part of what was called Aktion T4. There were six killing sites: Brandenburg, Bernburg, Hartheim, Pirna-Sonnenstein, Grafeneck and Hadamar – all of those sites were asylums recently equipped with gas chambers and crematoria. Aktion T4 officially came to an end in August 1941, meaning that it lasted a bit more than one and half years. About 70,000 people

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were killed in that phase, including, on the 21st of February, my great-grandmother.

However, the killing continued until the end of National Socialism, and in some clinics even until the late 1940s. This second phase of the program took place in a more decentralised way in a greater number of clinics. As the late Ernst Klee writes in his groundbreaking monograph "Euthanasie" im Dritten Reich. Die "Vernichtung lebensunwerten Lebens" ["Euthanasia" in the Third Reich. The "extermination of life unworthy of life"] The methods also changed, as patients were killed through intentional starvation and overdosing of administered medication and injections.

Over time, the circle of victims broadened. In this second phase, a further estimated 200,000 people were murdered. 5,000 children were murdered in specialised clinics and around 400,000 people were sterilised – among them not only disabled people, but also Romani people, sex workers, Afro-Germans and many other groups that faced multiple forms of discrimination.

All of the doctors who took part in the program did so voluntarily, and in most cases even enthusiastically. They were neither instrumentalised nor coerced by the Nazis. Not one of these doctors had their license to practice medicine revoked, not even those who were convicted or held criminally liable. Scientists continued to publish as experts and reviewers, often maintaining the positions they held before 8 May 1945, the day of Germany's surrender.

Links to the Holocaust

There was a direct link between Aktion T4 and the Holocaust,

as several members of the operational staff of Aktion T4 were relocated to the killing centres in the East to carry out the 'final solution to the Jewish question'. They were accustomed to murder, knew the procedures and had shown themselves to be 'clean', efficient and discrete. What began as the first industrial mass murder perpetrated by the Nazis in the six killing centres in Germany found its personal, conceptual and institutional continuation and expansion on the extermination camps in the East. The mass killing began, then, in the heart of Germany and Austria, and not at the geographical margins. Here, the method of killing with gas was tried out and even some of its apparatus was directly transported to the East.

There are many intersections between Nazi 'euthanasia' and the Holocaust which there is no scope to discuss here, but I will touch upon one aspect. If you were 'Aryan' and disabled you might have gotten a red 'plus' in your case notes – which meant you would be killed – or a blue 'minus' – which meant you would be spared. If you were Jewish or Roma and disabled, you would definitely get a plus.

Romani people use the word Porajmos for the genocide on their people, while the words Holocaust and Shoah are commonly reserved to Jewish victims. Consequently, we don't have a word for the victims of Nazi 'euthanasia'.

While Holocaust deniers are sadly numerous, there are no Aktion T4 deniers that I'm aware of, except for the neo-Nazi Horst Jürgen Schöfer, a denier of Hadamar. This may be because the gas chambers in German psychiatric institutions never rose to the level of general awareness that the killing centres in the East achieved. It's almost as though denial was not even necessary, since knowledge is so scant and its recognition does not seem to pose a challenge to German identity.

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The murder of the people that Nazis called 'useless eaters' was not only advocated during the Third Reich, but it was also not regarded as a crime for a long time in post-war West Germany. Although the Allied Control Council abrogated all the laws that it believed to be infused with National Socialist ideology, the Law for the Prevention of Hereditarily Diseased Offspring was not one of them. In fact, it is one of approximately seventy Nazi laws that are still not declared null and void in contemporary German law. As Jürgen Schreiber documents in an article entitled *Schuld ohne Sühne* ['guilt without expiation'], out of 438 criminal proceedings carried out until 1999 concerning Nazi 'euthanasia', only 6.8 per cent resulted in verdicts, including numerous acquittals that were greeted by the public with applause. In the rulings well into the 1970s, even when the cases reached the German Supreme Court, the murders were partially justified as morally defensible.

The continuities are countless. I'll just cite one more example that I find particularly repulsive: a male nurse convicted of being an accessory to the murder of patients in Hadamar was, after his release from prison, employed again in a psychiatric facility at Hadamar. And, yes, those same killing centres continue to operate as psychiatric institutions. Imagine yourself being a patient there.

Airbrushed out of existence

To the extent that people know about Nazi 'euthanasia' at all, they usually reduce it to Aktion T4. This is a problem, as it is vitally important to speak about the second phase, and the so-called 'child-euthanasia,' as well as not forget those who were forcibly sterilised. There are survivors, and hardly

anything is known about them. My friend Christoph Schneider just published a book about the survivors of Nazi 'euthanasia'. I believe it to be the first book of its kind.

Some of those who got forcibly sterilized are still alive today. Their number by now is approximately 100. Since they got sterilized, they do not have children to testify their lives and they were shamed so much by German society that they usually do not speak about what was done to them. Almost all of them live without rehabilitation and without any financial compensation for the injustice done to them.

As we all know, survivors and their narratives are important aspects of teaching and learning about National Socialism and the processes of memorial politics. Survivors of Nazi 'euthanasia' usually had no access to cultural techniques such as writing or publishing memoirs, or otherwise going public as survivors, because of poverty, impairment or other social deprivation – not to mention the lack of public awareness or interest. The dearth of reports from survivors impedes learning about, identifying and remembering those who were hunted and murdered for being 'unworthy of life'.

The vast majority of descendants of those exterminated, like myself, have tended to avoid commemorating the lives of their murdered relatives. The perceived danger of one's own potential stigmatisation as 'disabled' leads to processes of avoidance including denial of relatives, a particular fear and special caution regarding possible disabilities and so-called 'mental illnesses' in later generations, transgenerational trauma, etc. A conscious recognition and acceptance of history in general and family history in particular remains incomplete as a result.

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Additionally, up until two years ago apparatus of Holocaust archiving in Germany forbade the use of the full names of Nazi 'euthanasia' victims, as was also the case for those persecuted for being homosexual or 'asocial.' The non-publication of names cements the covering up, the hiding, and the taboos surrounding people murdered as 'unworthy of life'. Those people who were wilfully stripped of their personalities, made into numbers, gassed, and burned often have no grave and are even today officially airbrushed out of existence. There are cemeteries all over Germany where victims of Nazi 'euthanasia' are buried without a mention of the fact that they were victims of Nazism. This is not only in contrast to the many other National Socialist victims' groups, where the names of those murdered are searchable on the internet as a matter of course, but it also counteracts the efforts to restore dignity to those murdered, to give back their individuality and their humanity, and to create a visible space in history and in collective memory.

The scandalous rehabilitation of the perpetrators and the multifarious continuities stand in contrast to the continued humiliation, emotional injury and social ostracism of the survivors and their families. In 1987 the 'Federation of People Aggrieved by 'Euthanasia' and Forced Sterilisation' commented: Our efforts to be recognized as people aggrieved by National Socialism and to seek reasonable restitution have not been respected, and moreover denied with injurious and insulting arguments that at times resembled the notions and justifications of the National Socialists themselves.

The struggle against these ideas and regimes of power is not

only to be fought in the name of the historical record, but also of contemporary society. I not only look back into the past to remember my great-grandmother, but also to build a better present and an even better future – a future that is not ableist.



Image: Emilie Listmann before her wedding with Christian Rau
Overland is a not-for-profit magazine with a proud history of supporting writers, and publishing ideas and voices often excluded from other places.

If you like this piece, or support Overland's work in general, please subscribe or donate.

Andreas Hechler lives in Berlin. He works on medical violence and other topics and is on the advisory board of the Organisation Intersex International (OII) Germany. He has written about Nazi 'euthanasia' for Disability Studies Quarterly and welcomes contact with other descendants of the victims and survivors of the program through his website andreashechler.com

More by Andreas Hechler

By Lindsay
Sedgewick

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A call for Kindness by L J Sedgewick

In her 80s, my mother deliberately chooses to slow down as she crosses roads. When I try to speed her up she says, "They wouldn't hit an old woman".

I'm less sure.

My neighbours are elderly. Have been for years. I'm watching them age, quite suddenly it seems, and dread their passing. In bed at night, when I can't sleep, I imagine a wish list I should write in case I become incapable of speaking for myself.

'Remember I hate creases in the pillow against my cheek. They cause me a sort of physical pain. That I hate bright lights and plugged in devices that flash and flicker and make the night bright. I need darkness to sleep. I like warmth on my belly and under my lower back, if possible and I'll need something under my left knee and ankle or they will ache. I'd love you to read to me the books I never got around to reading.'

One of my neighbours has Parkinsons. We have nicknamed her walking frame Speedy Gonzales so that when she goes out, she can say Gonzales is taking her for a spin. A good friend has cancer. She's not the first but may be the dearest so far.

My step son is severely autistic. He can stand for hours on one leg, quite happily. Our Pelican Boy. Pillars make him stop, dead, in his tracks. He dances a step or two around it, each side, and nips back to his place behind it. I think the view looks different depending which side you pass the pillar on and this is why he cannot decide.

Sometimes a synapse goes off in his brain in the middle of the night and he laughs uproariously. At other times he is so frustrated that he bites himself.



In the series I created, the main character, Punky, has special needs. The actress, who had Down's syndrome herself, identified strongly with the character she played. She said once on a radio show, "Sometimes I think you invented me". They did a test, in the UK I think. Blue-eyed children were told not to play with brown-eyed ones. Within days, there was a two tier system of friendship and power. In New York, for a prank, a chalk line was drawn down a pavement. One side was for people moving fast, the other slow. Within half an hour people were policing themselves.

I always wanted to meet a man with brown eyes. I got a blue-eyed one instead.

I have chronic osteoarthritis, diagnosed in my late 40s. After 20 minutes either my leg or my back or my shoulder will hurt. I don't only walk short distances because I am lazy.

I could not outrun a cull.

I do not know what this list is. A cry for the diverse. For the underneath of us. The person behind, below, within whatever it is that distresses or appals or amuses you. For the unknown to be known and heard and seen.

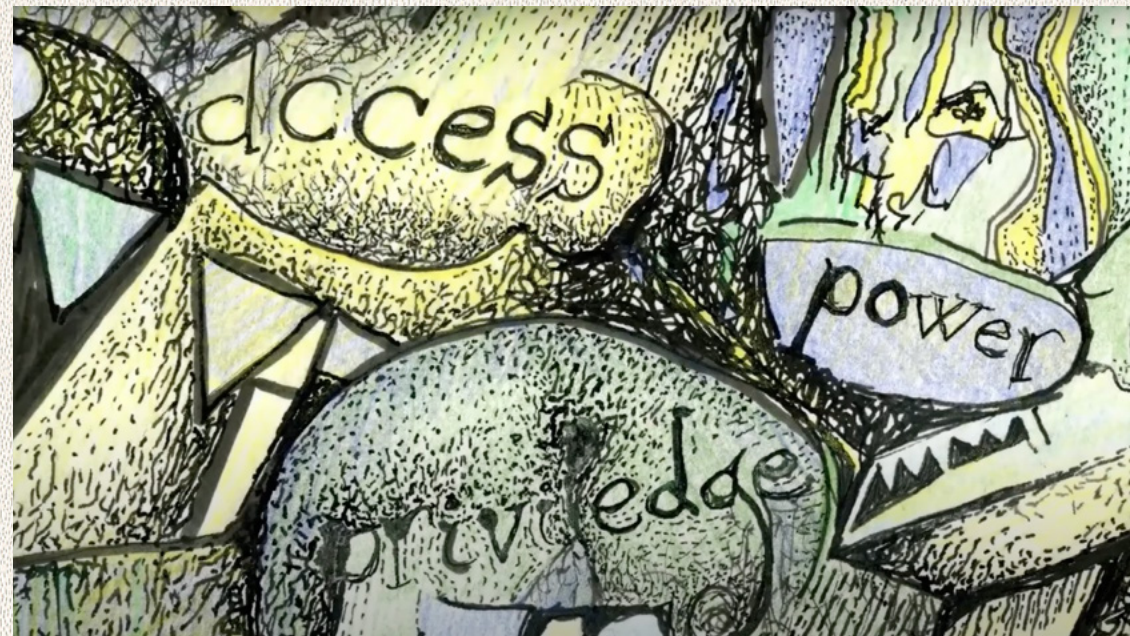
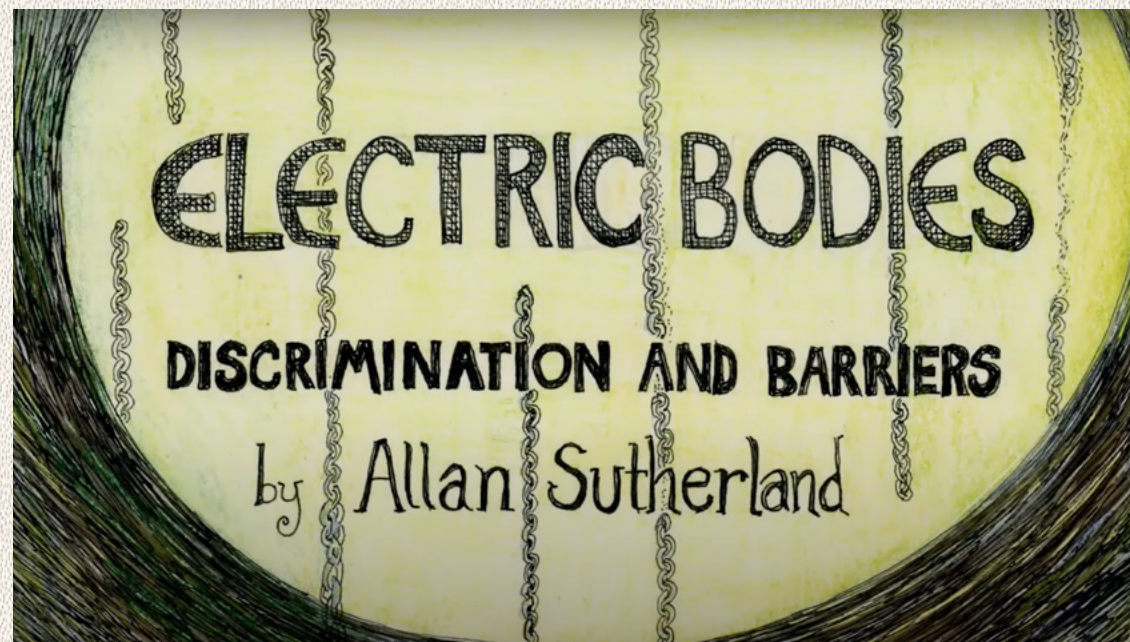
I imagine a world in which attitudes are given heft and weight and physical form. Intolerance would be a shoulder ache, a couldn't-lie-on-that-side, can't-sleep-with-comfort ache like torn muscle. Racist thoughts would be stabs between the shoulder blades. Enough, just enough to make you bend over, more with each one until your back was bent in two. Hateful thoughts would wrench you in the stomach, cruelty would make the bones rub in your feet so that you could not stand... Kind thoughts, reaching out to know another, to hear another's story, would be the balm.

By Allan
Sutherland

Discrimination and Barriers

Discrimination and Barriers contains lines taken from multiple poems within several of the poetry cycles, taken from the words of Katherine Araniello, Robin Surgeoner, Tony Heaton, Jess Thom, Mat Fraser and Colin Hambrook.

To watch Electric Bodies, Discrimination and Barriers animation [visit the D4D Youtube](#)





Imagined Futures



Sasha Saben Callaghan Collage

By Sarah L Bell

Sketching Lines of more-than-human Interdependence

It's March 2020. I am on Day 10 of the new daily 'normal' of social distancing in a bid to halt the spread of the COVID-19 coronavirus pandemic. I live in a small top floor flat with my partner, in a Cornish 'city'. No outdoor space but we're lucky to have big Velux roof windows, with early spring sunshine streaming in, warming my hands as I type. I squint through the screen glare but can't quite bring myself to close the blinds, increasingly treasuring these moments of warmth; a probable lifeline as the days go on and 'social distancing' turns to 'lock down'. Last week, I stepped away from my computer screen when I could, pausing the new 'Zoom' meeting regime to wander along quiet lanes, relishing the opportunity for movement; my own but also that of the world outside, the breeze, the mizzle, the birds, the gathering momentum of spring.

This is not the piece I thought I'd write for this collection. I'm an academic (ish) with research and applied interests in the health and wellbeing impacts of time spent with nature; human and otherwise. I've spent the last few years exploring this in close collaboration with people with sight impairment, stemming from a research project called 'Sensing Nature' (www.sensing-nature.com). In recent days, the words of my research participants have been running through my head in many different ways. Reminding me to tune into daily moments of light, warmth, the breeze and bird song as the world seemingly unravels around us. Reminding me to notice the kindness unfolding in its wake, and to find ways to adjust to the ever-changing concept of 'normal' that each day brings. Finding patience when frustration takes hold, and gratitude for everyone working so hard in health and social care, across food supply

chains, cleaning, running deliveries and more – those who don't have the luxury to sit and type a 'think piece' while basking in the sun.

With everything happening at present, I can't help but reflect on the salient calls of disability activist and scholar, Alison Kafer, to rethink human-nature relationships and counter notions of the 'independent' self in nature; to recognise 'common structures of bone, flesh, oxygen and air' (2017: 229). In recent days, our more-than-human interdependence has never been more apparent. Indeed, the health and wellbeing of individuals across the planet rests more than ever on collective cooperation; a contingency that brings interdependence very much to the centre of more-than-human life. The COVID-19 coronavirus needs human-human interaction to thrive, and humans more explicitly need each other to survive; for care, for food supplies, for continued access to water and energy, and for emotional support. To chat, to listen, to bring a sense of normality in small but treasured ways, to find and share humour at times when anxieties threaten to overwhelm.

Yet, the illusion of independence continues to frame many people's responses to COVID-19. The idea that stockpiling groceries and so forth will see oneself and perhaps immediate family through the pandemic. That open spaces will provide immunity regardless of the widespread presence of other human bodies therein. That continuing as if nothing has changed is acceptable if young, fit and healthy. There is a strange tension in these responses. People are clinging to ideals of independence yet struggling to socially (or physically) distance from each other. Indeed, one might wonder why social distancing is proving so challenging and undesirable for so many people if we are such independent creatures.


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By Sarah L Bell

Sketching Lines of more-than-human Interdependence

And why are people flocking to big open spaces to move, to socialise, to hear birds and breathe in the scents of fresh spring flowers if we are also independent from nonhuman nature? This plethora of responses indicate a collective plea to be – or at least to feel – connected in some way at a time when, paradoxically, physical distance is key to each other's survival.

So why am I writing this for a piece about disability futures? Many people in the disability community are acutely aware of our more-than-human interdependence, including the pleasures and challenges that come with this. For a long time, disability activists have countered ableist rhetoric and widespread valorisation of human independence, calling for human limitations and interconnection to be recognised as integral, not marginal or extra-ordinary, conditions of everyday life. As COVID-19 develops, people all round the world are seeking new ways of remote working, new ways of connecting socially without physical proximity, new forms of daily pleasure, and new ways of existing in a world they no longer fully know or trust. Many of the digital adjustments and innovations coming into play are initiatives long called for by disability activists. Many of the challenges of isolation and physical distance being experienced are challenges routinely negotiated within diverse disability communities. With more nuanced disability awareness, this critical global juncture could provide a valuable opportunity for people to 'take disability experiences seriously, as sites of knowledge production' (Kafer, 2017: 233), not solely as 'vulnerabilities' to 'cater for'.

This shift in awareness is a step change that we have tried to highlight through the Sensing Nature project, albeit in a different context. Through the project, and in collaboration with fantastic organisations such as the Royal Society for the Protection of Birds, the Wildfowl and Wetland Trust, VocalEyes and fantastic visually impaired facilitator and sensory explorer, Andy Shipley, we have been foregrounding opportunities to reframe disability as a site for rich sensory knowledges and creativity in varied nature settings, rather than an access 'need'. What kind of disability futures do we hope for through such efforts? We hope for more widespread awareness and respect for more-than-human interdependence. We hope for disability justice, that disabled individuals come to be recognised, not as people to make changes for, but as people to make changes with; making space for a wider range of values, priorities and embodiments in contemporary society, both within and beyond decisions pertaining to the rich and varied nature encounters all around us. And we hope these messages continue to resonate beyond the time of COVID-19, that people remember these individual and collective feelings and channel them into social inclusion. For a long time, we have celebrated biodiversity (though whether that extends to biodiversity in the coronavirus family I'm not so sure). Perhaps the transformations unfolding in society today could act to reconfigure our values around human diversity too?

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By Mik Scarlet
2020

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Welcome to the world of tomorrow - What Will It Mean To Be Disabled In The Future

I often think “what will being disabled be like in the future?” How will it feel? Who will be ‘disabled’? Will it even be a thing people consider other people to be? The key to really unpacking what sort of future we could hope for our community ahead is to answer three questions. “What does it mean to be disabled?” “What will it mean to be disabled tomorrow?” and “what can we do now to ensure a positive outcome for future disabled people?”

I grew up disabled from birth and was raised to believe that the Medical Model of Disability describes what it means to be disabled. I was broken. A lesser version of what I could have been if I hadn’t been born with cancer, that left me paralysed. I strived to not be that broken kid, to be the best I could be and even to be better than the non-disabled kids, that at the time I still called able bodied. I was lucky to have been born at precisely the right time. My cancer treatment was at an experimental stage with doctors seeking test subjects, and that treatment worked. Before then most kids with my cancer died. The call for test subjects went out the week before I was rushed to hospital, near to death. A week earlier, or a week later and I might easily have died. I started school when the laws in the UK changed and local education authorities could allow disabled children to attend mainstream schools, so I had a good education throughout my childhood. Meaning I mixed with non-disabled kids and learned that we weren’t so different.

As a teenager I had a disabled pop star to look up to, Ian Dury, and developed my style during Punk and Goth, where being different was all anyone in our gang wanted. I started singing in bands. I was spotted by a TV producer at one of these gigs

and became a TV presenter known all over the world. At work I met other disabled people, including one amazing campaigner, Vicki Waddington, who taught me about the Social Model of Disability. This changed my life in ways I don’t have enough words to explain here. I met my wife in a nightclub, when I caught sight of her at the bar, as she stood under a spotlight, and fell in love there and then.

I feel each one of these events was down to luck, and these are just the key lucky moments, too. As I grew older, I realised that not every disabled person has this much luck. In fact, to become disabled for many disabled people can feel like a total lack of luck. With my work on TV, and later in campaigning around disability issues, I met so many disabled people who faced circumstances that stopped them ever having the chances I had had. I saw in them the real truth of the Social Model. It’s not about ramps, lifts and big toilets. It’s about being in a society that gives you the chance to live your best life, to shine to the best of your ability and be able to dream for a better tomorrow. For too many disabled people in the developed world those aspirations are out of reach, let alone poorer countries where the lives of disabled people are often horrific. People like myself and so many others all over the globe are working tirelessly to change that situation today. But what of prospects for the future? I suppose it could get much worse. It could go down a dark road, as it did in the 20th century in Nazi Germany, just with more spaceships and flying cars. For this article I want to look to the future with positivity. I want to explore my hopes for tomorrow.



By Mik Scarlet
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It is important to remember that many impairments that might lead us to be disabled people today may not exist in the future. I know that what led me to join the disabled club, the cancer and the spinal cord injury it caused and both of which will probably be curable in the near future. I've met scientists in prosthetics who expect their robotic limbs to become so amazing that amputee Paralympic athletes will soon be able to beat their non-disabled Olympic counterparts easily. Bionic eyes and ears, artificial memory dumps to solve illnesses like Alzheimer's and brain injuries are all far closer than we grasp. While there is much debate around genetics, I am sure that modifying the human genome will eradicate many of the life limiting impairments we now live with. This isn't saying the future will eradicate disabled people, just that the concept of what makes someone disabled will change.

Of course, just because you no longer have people who we consider disabled today, who knows what being disabled might mean tomorrow? Talking to people in cybernetics, they all say they can see a day when prosthetics are so amazing and give the people who use them such an advantage that non-disabled people may begin augmenting their bodies to become more than human, superhuman – trying to emulate the advantage that some disabled people have been given through the use of advanced equipment and aids. It could lead to a situation where the non-disabled become the disabled of tomorrow. Even if that "Mik has been reading WAY too much science fiction" future possibility doesn't come to pass, there will still be illness and injury. There will still be people who are not physically or mentally the 'norm'. Will the future see a time when this doesn't



matter? If I'm truthful I really hope the concept of disability itself may disappear.

I am proudly disabled. I know that being disabled has made me the person I am and I am very happy to be that person. I would never wish away my impairment or the wonderful disabled community I am part of today. When I look to the future and wonder if 'being disabled' will fade from our public psyche, I mean that the concept of being disabled will vanish. If the Social Model were adopted by humanity as fact, leading to societies that knock down the barriers that disable people. This ideal could become reality. We aren't cured away, just the concept of being us has changed so much that it's something disabled people today could only dream of. That a future could happen that celebrates difference, embraces it and allows all to flourish. That's the future I hope will happen. Sure, I fully expect some dead ends and societies going backwards along the way, but I am thinking of the long game, of a world that finally becomes enlightened. Great Mik, all very nice, but how the hell is that going to happen?

Typically it's going to be down to disabled people to keep fighting, to never give up, and to work together. We've come so far, let's not forget that, celebrate it and use it to build on for tomorrow. Recently the globe has been struggling to battle its way through the Coronavirus pandemic, and as I type this the UK is still in the grip of it with high death tolls and hundreds of thousands of confirmed cases. As the crisis grew and the attempts to find a way to open up our economy again were rolled out, my belief that if our society had just embraced the inclusive concepts disabled people have been campaigning for over decades, the whole situation could have been a lot better.

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A society that follows inclusive design principles would have been able to develop processes to avoid a pandemic and would have systems in place to ensure the economy wasn't as badly hit as it was by lockdown. A lockdown that also might not have been necessary if our society had been designed to be more inclusive. The space and access requirements that disabled people champion as making the world better for them, make a society better prepared for new illnesses like Covid 19. They also lead to ways of living that allow people to stay at home and remain able to play a role in the economy. The need to make huge changes to implement social distancing disappears in an inclusively designed society as everything is already in place. As the world adjusts and tries to shape this 'new normal' we keep hearing about disabled people struggling to ensure their safety. Without wanting to sound too "I told you so", we need to say "I told you so."

Something that I have noticed since the lockdown is that disabled people are splitting into factions again. We must avoid this. We must not focus only on what 'We' need, each impairment group shouting for themselves. If we maintain our collective voice that's how we come out of the crisis stronger, and society will listen.

Everything we have achieved so far has been from us working together, so we must maintain our shared objectives. Then we have to just keep pushing. Many people will be coming out of having Covid-19 with newly acquired impairments and we must be there for them. We must support them and be their champions. You don't have to shout loudly. All that matters is you know you're worthy of being listened to, of having a better



tomorrow. If you can shout loudly, do so, if you can't please still shout. If we add all those voices together they will grow to a roar that can't be ignored. If we do this we will be paving the road with a lovely smooth rolling surface to a better tomorrow – to use a typical wheelchair users analogy. Us older disabled people must support the next generation. We must embrace the intersectionality of our community. Not only the mixture of impairments but the other identities that lay within our community.

We really are the only minority that anyone can join. Let's make that our best feature. Let's show non-disabled people the beauty and wonder in difference and prove that perfection is a myth. If we keep dreaming of a better tomorrow and do our utmost to work towards it – which I know is a tough ask at times – we will reach a tomorrow where 'disabled' is just a word, a description of a cultural group. It might even become a section in a history book, where children are taught of a time where humankind divided itself into groups defined by a concept of ability and function. The children will sit there and try to imagine it, just as I remember doing when I was taught about the history of the Tudors. We might look into the future and we would see disabled and non-disabled kids studying together in a society in which they couldn't imagine what we thought made them so different.

All I know is I spend my days, mostly working around improving the access and inclusion for today's disabled community, knowing that I will have succeeded when people doing my job are no longer needed. Society will be inclusive and accessible and a future version of Mik will never need to put so much effort into trying to make the world around him be a better version of itself.

By Susan Shapiro

Have a nice day!

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I stood in front of the whiteboard, dry erase marker in hand, looking out over a sea of virtual students. Even though all the students were projected with wide-eyed enthusiasm, I knew some of them were snoozing while others were eating dinner or playing the latest game on their handhelds. It was an easy hack to look involved in the virtual classroom. For a few credits, your avatar would look more studious and involved than any real student could be. As I asked the question, several hands shot up in an effort to make their voice heard or just make sure that they received the prized “green thumbs up” for their participation.

“Dr. Swartz, could another issue be Tourette syndrome?”

I paused and wrote ‘Touretet’ on the board, the whiteboard flicked and reversed the E and the T. I tried not to look flustered as I continued the lesson. This was my 6th-semester an introduction to my disability.

“I am dyslexic”, I would declare proudly; ” I reverse letters and numbers. and I’ll let you in on a little secret, my strategy for dealing with my issue is to write illegibly so you can’t see my mistakes.”

I found it a great class opener. We would go around the class of graduate education students and share our little secrets and learn about our private struggles. It humanized what we were studying. Gave it context.

But now when children wore earpieces to correct mispronunciations, stutters and ticks and machines could project a walking avatar for those who couldn’t as their human counterparts sat hidden away, I wondered if my students could even relate to anything as mundane as “imperfection” anymore. We were all “perfect”, or at least we could mimic the new ideal, and those who weren’t were rarely, if ever, seen at all.

As the students logged out, they quickly submitted their review on my classroom performance. I did the same as their avatars flashed on my computer screen. Green for a good review, yellow passable and red for poor. Insta-Instruct the buttons read, “Instant feedback, a valuable tool for students and professors alike.” It made me queasy as I tried not to think too deeply about any of it. I hoped they hadn’t seen my slip. The whiteboard was efficient, but what if it wasn’t fast enough? Last week after a very passionate discussion on the dangers of Avatars one of my colleges had become Insta-fired based on a 70% red review. I had tried to ignore the worry that came when I called to offer my condolences and I couldn’t get through. I tried to push down the panic that came when I realized his number was gone, email disconnected like he had never existed. I vowed to myself to keep my secret and silently thanked the whiteboard and the tech that kept it hidden. I knew, if not for the whiteboard, these students would never have agreed to have been taught by such an imperfect professor, I was lucky to have any job and to be left alone.



By Bill Moody

This will suit everyone!

Luna looked at the Huform suit in front of her.

“Wow, these things really are a step up on the previous models.”

It better bloody well had be as well. It had cost her enough. She leaned forward from her chair and felt the skin. It was eerily human and eerily lifeless.

Blondie was at the bar as per usual. He was leaning forward onto the counter casually chatting with his entourage. Easy. Gesturing. Laughing. Luna eyed him openly, her head tilted to one side like a Crow eyes a worm. His three-tone-glitter spandex trousers were so tight that she could hardly breath. She laughed inwardly at the joke. He didn't look at her. Not even a glance. He never did.

Luna thinned the wheelchair forward some more and found the almost imperceptibly fine split into which she would gain access into the Huform suit. They were called Cinderella suits because after 12 hours they could suffocate the person wearing them. So entwined was the user once inside that the suit became them, took them over. Refused to let go. Many had died. But it was worth it. Luna didn't care. 34 years in a chair gave her a licence to not care sometimes. To live life if not exactly on the edge, then certainly well-off centre. Time to get inside she thought eventually pulling off the 'warning' tag after three attempts with her weak hands. She hated this bit. But it was worth it. She hooked a hand under her mostly inactive leg and moved it forward out of her chair. Then Luna did the same with her 'not so inactive as her other leg', leg. With some metronomic moves she lurched forward and found herself face down on the back of the suit. She found the opening and began to nose herself in.

With Tessa in the loo Luna was alone and made her move. She was using Blondie's behind as her focus and zoning in she thinned her chair to move forward, and yet, she was not thinking at all. What was she doing? What was she going to say? She had to move quickly before logic overtook her. People leaned out of her way as she gathered speed, as they usually did, a sea of waists flashed by. Too fast. Oops. She stopped alright, just after she'd hit the back of Blondie's legs.

“What the...”

He turned, didn't see anyone and then looked down. He reared back slightly. Luna kind of knew that it wasn't due to her beauty. His gaggle giggled.

“Hey, crazy driver, mind where you're going. Think before you stop,” he said tapping his forehead with an index finger whilst eyeing his friends for approval.

Luna looked up at him. He looked down at her with unconcealed discomfort. She was drooling which wasn't due to uncontrolled saliva as per normal. No. She was drooling over him.

It was like being inside a duvet cover, a duvet cover where the duvet was still inside it. Luna wriggled her way to get her head into position, squirming until she was aware of a cavity. She pushed the back of her head into place and felt the grip of the suit tighten around her. She waited until the thrum and vibration started. A few minutes and then she'd have control of this thing. Luna had no vision yet and was pressed in firmly on all sides. It could have been considered claustrophobic, but Luna was used to restricted movement and a limited view of the world, so she waited contentedly. Her mind drifted to the previous Huform suit called Molly, and her attempts to use it.

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By Bill Moody

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It was hotter inside the suit than she'd imagined. But she at least was walking now, she hadn't hit a table thus far and for once she was drawing looks of admiration rather than pity. Even so, leaning at the bar was easier than having to keep thinking to control her suit to stay standing up. Luna had named herself 'Molly' in this guise. It felt an innocent yet dirty name to her. She sucked some Vod-Gin up through an animation straw with dancing unicorns on it and was glad that no one could see the drink exit her real mouth inside the suit, her capacity for liquid was not high. Blondie was to her left. He'd been there for two hours. She'd been shooting coy and vampy looks at him for 120 minutes and yes, he was looking at her but not how she'd imagined. She felt like he was eyeing her as that last slice of cake on the plate whilst knowing that he'd already eaten too much. Nice to look at but no appetite for tasting. She gave him another lip glossed beamer. He pulled back and turned to talk to another woman who was dowdy compared to Molly's plumage. She stuck her rear outwards ramrod fashion towards him brushing his leg slightly. He seemed appreciative but not enough. She was worried. All people knew about Huform suits and whilst their use for attraction was well known, lots of people did not want to be caught out by actually getting off with one. Perhaps he was a Huform suit hater? Maybe the suit she was wearing wasn't good enough. There were much better models than this one. Luna knew she'd have to step up her game. She turned down a lewd offer from a guy at the bar and then think steered her way towards the door, disabling many men's brains as she passed by.

Luna at last felt as one with the suit. No longer was it like being cocooned inside an armchair. She stood up. Ungainly. She think-walked to the mirror. She held both arms out straight, then wiggled her fingers 1 to 10, 10 back to 1, to make sure she had control, as per the advice in the manual. Same with her toes. Then she bent over and touched her toes easily sending blood rushing to her head, all systems were go. She looked at her reflection. Amazing. She jumped up and down and enjoyed both the sensation and view of her bouncing self. Nothing bounced on her own body. Jumping was for other people. She moved her hands up and down her skin and curves. This suit was so much more real than Molly had been. She looked again into the mirror. Her eyes stared back from someone else's face. Luna looked so real. What did that mean? Real? Surely she was already real? She looked again and wasn't sure where she ended and Matilda (her name for 'it') began. Like this she could attempt being real and normal for 12 hours or die trying. But wasn't her world real? Surely her state of being was the norm for her. Real. Wasn't it? Guilt formed in her mind. What was she doing? Having achieved this condition of super humanity Luna felt as if she'd let herself down. The game had gone too far. It had made the gap wider, made her conform, hid her real self away. Normal? She sat down on her bed. Tears bubbled into life in each eye.

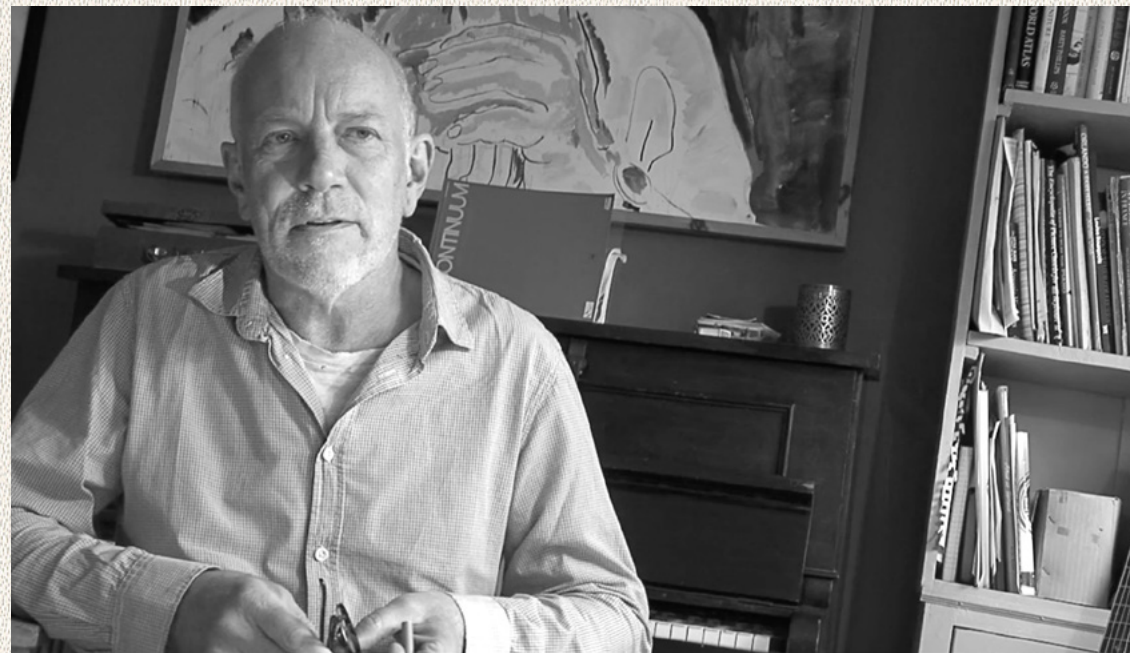
"Fuck Blondie," she said without irony.

By Paul Leyland

Journey to an Alien Planet with an ill fitting space suit

Paul Leyland gives a short introduction to a planned project working with stroke survivors following his own stroke 2 years ago. To watch Journey to an alien planet visit [the D4D website](#)

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Started ten years ago on a dare in New York, the Bushwick

By Martin Levinson

Timed Out



There was enough oxygen. He had made careful calculations. Just enough time to leave the craft and make his way across the planet below to the dome. He would be able to accomplish the mission and return to the safety of his capsule.

By Martin Levinson

Timed Out

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It was not a trip he wanted to make. It was daunting. How long did a day last on this planet? He was not sure. One day here might be just a couple of hours. Would it get dark before he returned? The thought of a journey back in the dusk was quite scary. The stars looked unfamiliar from here. The sky was huge and seemed to push up close against him, making him feel as if he might tumble into a giant screen. Would he even be able to navigate his way back to his capsule?

But it had to be done. The data had to be inputted. His controller had said there would be repercussions if it did not get completed.

He did not like the planet. The inhabitants were not friendly. They stared at him now as if he were some strange, alien life form. He lumbered slowly across the surface, listening to the unnaturally loud sound of his heartbeat.

He imagined their eyes boring into him as he entered the dome and made his way to the booth. But when he stared around, it seemed that no one had noticed him, as if he had suddenly become invisible. He logged into the screen and downloaded the forms, trying to concentrate and reading the section, carefully:

HELP USING THIS PDF FORM.

This form will only save if:

- the form is saved on your computer and
- opened in a recent version of Adobe Reader.

The form will not save in versions of Acrobat Reader older than version MCXI.

Already it was confusing. What exactly was Adobe Reader? Was it the same or different from Acrobat Reader? Was the latter something that entailed doing somersaults? He wondered which version of Acrobat Reader he had. Probably the one that fell over when it tried to do somersaults.

And how old was his version? Was it older than MCXI?

He tried to think what MCXI might mean. Mushy carrots incorporated? Mental cases identified? The X was a problem. There were so few words that began with the letter X. Was it something to do with X-rays? That did not seem to fit in with either of his ideas.

The he noticed something at the bottom of the first page:

If you are having technical difficulties:

- downloading the form
- navigating around the form
- printing the form

Please contact the online help desk

It gave a number. It was always soothing to listen to people, calmly, explaining what he needed to do. Taking out his phone, he tried dialling it. It was an automated message.

You are in a queue. You are number 22. Please hold the line. Your call is valued.



By Martin Levinson

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There was some music, then a pause before the message was repeated. After he had heard the message half a dozen times, he decided that there was little point in waiting any longer. After all, twenty-one people ahead of him sounded quite a lot. He might have to wait a very long time. Unless it was like Bingo, where a number was called out and maybe you got lucky. Number 22 might be next.

It wasn't.

Putting down the phone, he returned to the form.

If you would like this questionnaire in Braille, large print, audio or Welsh, please call Jobcentre Interstellar on 0800 169 0310 or textphone 0800 169 0314 and tell us which you need. He tried to recollect what Braille was. He was sure he had heard the word once. Was it something to do with the sound that donkeys made? But why in Welsh? Perhaps, the donkeys had been on the beach there. He had seen some once, many years ago in Bangor. He imagined one now, wearing headphones and asking him the questions in a singsong eeyore.

He continued reading the instructions.
What you need to do

Please fill in this questionnaire and send it back to the Health Assessment Advisory Service by the date on the letter that it came with. The Health Assessment Advisory Service will use the information you provide to decide if you need to come for a face-to-face assessment or not. We will use this information to give you the best support we can and pay you the right amount of benefit.

He noted that the form had to be returned by a certain date, and that all the questions had to be answered in full. He had to type in CAPITAL LETTERS. Taking out a pen and notebook from his pocket, he scribbled down these important instructions and placed them close to the computer to make sure he did not forget. Having the instructions in front of him helped master his anxiety.

Looking down the form, he frowned. There were so many questions. Would he be able to finish them in time? He noticed another message:

If you need help filling in the questionnaire, you can call Jobcentre Interstellar on 0800 169 0310 to arrange for a trained advisor to talk you through the questions over the phone. Please do not go into your local Jobcentre Interstellar. There was a warning that his allowance payments might be stopped if he did not fill in the questionnaire and send it to the Health Assessment Advisory Service by the date requested. He phoned the number. There was another automated message.

Time was passing and still he had not filled in anything. He turned his attention to the form.

Surname.
That was easy.

Other names.
He could do that, too.
Address and Date of Birth.
Oh, this was quite easy. He breathed a sigh of relief.



By Martin Levinson

National Insurance Number.

He was not sure what that was. He would just have to leave it blank. It could not matter that much whatever it was. After all, he had got the other answers right.

But then, maybe, he should put down something. The instruction had been that all questions must be answered. Better to get one wrong than not answer it at all.

He had a brainwave. He had been given the number on the phone. They had already told him the answer.

He wrote it down.

NUMBER 22.

He could do this!

He worked through the other questions. Had he been in hospital for over 28 days in the last month? Had he served in HM forces? Had he been released from prison in the last six months? Was he pregnant?

Maybe the correct answer was NO to everything.

Only his controller had told him that NO was a rather negative word. Maybe he should write down YES to one of them to show that he was not a negative person.

He went back a couple of questions.

He decided he had served in HM Forces, ticking the box Royal

Navy/Marines.

He liked the sea.

The next section asked for the names and addresses of his doctor and Health Care Professionals. This was a little more difficult. He never really seemed to see the same doctor more than once. The names of the others he forgot. There was one doctor whose surname had begun with the letter K. It had been quite an unusual name.

DOCTOR K – he now wrote. It would be easier for them to find out who that was and add in the complete name.

He scrolled down the form, hoping that outside it was not getting dark.

Please tell us what your disabilities, illnesses or health conditions are / how they affect you / when they started / if you think any of your conditions are linked to drugs or alcohol. There seemed to be a lot of questions here, only they were not actually questions. It was so much easier to answer simply, Yes or No.

He now put in capital letters YES after this section.

Please tell us about / any aids you use, such as a wheelchair or hearing aid / anything else you think we should know about your disabilities, illnesses or health conditions. Again, after this section he wrote YES.

He reached a new section all about how his conditions affected him.

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Part 1 is about physical health problems Part 2 is about mental health, cognitive and intellectual problems. By cognitive we mean problems you may have with thinking, learning, understanding or remembering things. Part 3 is about eating and drinking.

He ticked a box to say that he could use steps without difficulty. This was not altogether accurate, as he was rather clumsy and sometimes stumbled, but what if one of those jobs came up cleaning spaceship windows, where you had to use a ladder. He did not want to be precluded because he had given the wrong answer.

After this question it told him to go to question 2 on the next page. But there were other questions in between. Did they not want him to bother answering those questions?

That was good. It meant that he would not need to answer all the questions in between because he had provided the right answers

He considered the next question.

Please tick this box if you can reach up with either of your arms without difficulty.

He put his arms in the air.

Can you lift at least one of your arms high enough to put something in the top pocket of a coat or jacket while you are wearing it?

Holding one of his arms in the air, he now picked up a pen that was on the desk, putting it into his pocket.

YES, he typed.

Can you pick up and move a half-litre (one pint) carton full of liquid using your upper body and either arm?

This was ridiculous. If they wanted to ask a question like this, why did they not leave a carton on the desk for him to attempt this? Unsure about the right answer, he decided on

another YES.

Can you pick up and move a litre (two pint) carton full of liquid using your upper body and either arm?

Wasn't this the same question? Were they trying to catch him out?

YES, he typed again.

Can you pick up and move a large, light object like an empty cardboard box?

Can you use either hand to: press a button, such as a telephone keypad / turn the pages of a book / pick up a £1 coin / use a pen or pencil / use a suitable keyboard or mouse?

In each case, he typed in YES.

The next section was about communication. The instructions emphasized that this was not about communicating in another language. He read the first question:



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Can you communicate a simple message to other people such as the presence of something dangerous?

He wondered whether he had typed in the word YES too many times. But NO was not a good word. In the past his controller had also told him off for being monosyllabic and not engaging properly with people. He thought about it.

What if he showed them that he understood the question and was able to give an example? He considered things that frightened him: loud sounds; angry people; someone arriving at his door, unexpectedly.

THERE IS SOMETHING COMING THROUGH YOUR LETTERBOX, he typed.

He thought about it. It could be post. Post was not dangerous. IT IS A... PYTHON, he decided after a few moments. After all, pythons were dangerous. You would not want one coming through your letterbox.

He read on.

Can you understand simple messages from other people by hearing or lip reading without the help of another person? This was difficult. He could hear people when they spoke to him but he had never learned to lip-read. You could not put YES and NO as an answer.

SOMETIMES, he typed.

Time was passing. He tried to progress through the form as quickly as possible. There followed a series of questions that veered confusingly between topics. Could he safely get round a place he had not been to before without help? That

was something he always avoided. He typed NO. Could he control his bowels and bladder? YES, he typed. Could he stay conscious while awake?

Was that another trick question?

Next he was asked about epileptic seizures and diabetic hypos. He was not entirely sure what these things were. He had heard about an illness called 'diabetes' but did not know that it was a problem for hippos.

Was the form now testing his general knowledge? It had seemed quite easy at the start but was getting increasingly difficult.

He had come to a new section.

In this part we ask how your mental health, cognitive or intellectual problems affect how you can do things on a daily basis. By this we mean problems you may have from mental illnesses like schizophrenia, depression and anxiety, or conditions like autism, learning difficulties, the effects of head injuries and brain or neurological conditions.

This was getting complicated. Now he was being invited to send additional information from his doctor, community psychiatric nurse, occupational therapist, counsellor, psychotherapist, cognitive therapist, social worker, support worker or carer. Only send us copies of medical or other information if you already have them.

How could you send them information you did not have? He was instructed to send his National Insurance number with each piece of information. Well, at least that was easy. He typed out 22 again in case they had forgotten.



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There followed some odd questions about alarm clocks and washing machines and going to places and meeting people you didn't know. There was a request for examples of ways in which his behaviour upset other people. And was he able to chew or swallow food without being prompted by other people?

He thought about this. Were there people then who would put, say, a spoon of mashed potato in their mouths and then forget it was there? Would such people be filling out a form like this, and if so, would they be sitting at a computer with their mouths full of mash? It seemed a bit strange to think that they would be expected to work through such a long series of difficult questions when they could not remember to swallow their mash. It was hard to imagine that they would even be filling out this form, so why even ask the question?

Fortunately, he was near the end, though he was not sure whether he was meant to respond to the last section about face-to-face assessment. He read through the section three times to make sure that there were no YES/NO questions he had missed.

All that remained was the DECLARATION section at the end of the form. There was a slightly frightening line that reminded him that he could be liable to prosecution or face a financial penalty. He was not sure that he followed what it meant when the form told him he had to inform the authorities about a change of circumstances. He had found a stray cat recently, which had started to come to visit him each day for milk? Did this entail a change of circumstances? Should he have informed someone? He just hoped he had got all the answers right and that they did not find out about the cat.

There was a second form to be filled in, but that would have

to wait for another day. With an immense sense of relief, he clicked the SUBMIT button.

Nothing happened, and then an error message flashed on the screen: SESSION TIMED OUT.

As he feared, it was by now dark outside. His oxygen levels were getting low. He hoped there would be enough to get back. He had reached the steps, and attached his line, carefully. Perhaps, he was in too much of a hurry, fraught after such a difficult day. He had almost reached the entrance to his craft when he stumbled and the line seemed to snap.

He was floating. It was frightening but strangely beautiful. The silence enveloped him. A tear formed in the corner of his eye, billowing into a bubble. Without gravity, there was nowhere for it to fall.

He could answer the questions on the form differently now.

Can you safely get around a place that you haven't been to before without help?

He had never been to this place, but here he was, without help and no longer afraid.

Every so often something drifted past, bits and pieces from broken up space ships, a spanner, a cat! Not his cat, of course. This one was inside the re-entry capsule of an ancient spaceship, part of a Sputnik, perhaps. Then something came close. He reached out, instinctively.

It was a phone. He put it to his ear. It had not run out of charge. He tried re-dialling the last number. A voice spoke back to him. A human voice – the most beautiful sound in the Universe.

Please hold the line. Your call is valued.



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Illustrations for 'Timed Out' by Colin Hambrook

By Eilís Ó
Muircheartaigh

Of Bodies Changed - An odyssey in pain

Not long after those eternal flames first licked my rosy cheeks and made them forever florid, I became the White Witch of Narnia, a trail of ice glittering in the wake throughout this new world where I am fated to dwell. During the course of one arctic February night I plunged deep into the waters of Lethe and awoke in a strange new world consumed by never-ending fire, just like Jadis who also leapt into her own world of ice from that pool in the Wood between the Worlds. Here, in the ice-white firelight of my own parallel universe, friendships cool then wither black as frost-burnt blossom for despite the livid flames that make a lantern of my face, it is always a bleak mid-winter here, without ever any hope of Christmas.

As the wintertime of endless ice and fire drew on, a great gulf opened up between ourselves and the outside world too wide to bridge, so instead I gladly fled from the gaudy display of everyday hopes and dreams, that great flash-back flood tide of every possible bodily desire, the inescapable fact of this world's here and now. Such material greed is unbearable to witness when if like myself your one sole desire — to once again rest your cheek against a pillow's crisp cool whiteness— cannot neither be bought or traded.

At long last, I found a kind of asylum at the bottom of the electronic Underworld where we latter-day shades descend; in that special part of the Hadean inferno where flesh burns bright for eternity. Upon arrival each lost soul's first act is to vent the pangs of heartache into the cavernous void, and listen to their cries echo back to them crackling like fusillades in the smouldering darkness. Here confined with me are Debra from Las Vegas, Maria from Manresa, Hekla from Álfanes and many others from all around that netherworld.

By Eilis O
Muirchertaigh

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We stand all together here, united by our great suffering— the Sisterhood of Erythromelalgia, more intimately connected with each other than with our own flesh and blood, and seek out the kindness of strangers.

‘My husband, he does not think my pain can be so bad, even though I weep all night, he don’t listen. He say, “Hey, make some chilli, woman!” so I get up and cook it even though the my feet are on fire— my eyes too if I forget not to touch them. He make me eat it too, even though eating chilli feels like pouring petrol on hot coals in my mouth.’

‘My boyfriend’s okay, but he just doesn’t get it somehow. Every weekend he drags me on long hikes up to the glacier, then he complains I can’t keep up. Afterwards, I have to lie in bed with my feet sticking out of the covers under the open window!’

‘My partner is really caring but it’s just impossible to make love any more now. I can’t hear her burning breath against my face or neck, I just have to push her away before she sets off a flare!’ ‘Just hang in there!’, sings the chorus in unison. ‘Hun, I’m gonna pray for you!’ whispers a voice in contrary motion to the others.

There is little for us left to do now but share our woeful stories of living with blazing pain while waiting for a cure. Soon I gain regard as the wise sage of our hexed sorority; translator in chief of that alien tongue, neuroscience, with all its baffling jargon and diagrams like cabalistic puzzles. Others seek their own news of cures elsewhere, within the pages of those electronic rags that flutter in the digital gutter.

‘Look at this — “Scientists unlock pain secret!” Can you explain it to me, Eilís?’



But the words are overblown nonsense, mere click-bait to harvest the hopes of the sick like fishes for the sake of a healthy profit—somewhere in another world, five Wistar rats partially recovery from a massed scientific assault upon the left personal nerve of each; new nerve tissue grafted to ganglia now allows them to flee the murderous hands of white-coated keepers as they plot their funereal dissections. I should have paused before answering her; found some kinder way to explain all the overlooked imponderables.

‘It’s just hype,’ I say angrily, ‘an isolated case report, it’s far too early yet to be tried out in humans. And even if it worked, there wouldn’t be enough neurosurgeons in the world to free all of us from this eternal burning.’

‘I hate you,’ comes the reply, red hot from her fiery fingertips, ‘All you do is kill our hope!’

‘I don’t care if it is all bullshit, I need to hear stuff like this otherwise I just wanna kill myself!’

‘Don’t listen to her,’ purrs our preacher, ‘she’s just a toxic person hun, overflowing with negative energy, cos she don’t have faith in nothing ! You just hang in there, I’m gonna pray to our father in Heaven, Jesus Christ, ‘coz I no u’r gonna get the cure you deserve sister!’

With tears in my eyes click Leave this group?’ then slip away alone again into the stygian darkness.



By Tanvir Bush

You're POINTLESS!

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Stage set up in way that resembles a cross between a Monopoly board and an obstacle course.

SFX: Bright lights flashing and canned applause as smarmy Host enters: .

HOST: Welcome to YOU'RE POINTLESS!

SFX: Canned applause. Cuts off.

HOST: The game that brings the 'party' into 'payments! The rules are simple – but no one knows where they are!

SFX: Canned laughter. Cuts out

HOST: Here are our plucky, 'you're pointless' participants lining up eagerly for the first obstacle!

SFX: Canned muttering, spattering applause.

10 people a mix of actors and audience volunteers, stand looking confused and scared in a taped off square with only five chairs placed in front of boxes that resemble computers.

HOST: But before we begin – we mustn't forget, your favourites and mine...The Heavies!

SFX: Smoke and loud ominous music (need Jaw' theme or some nasty rock i/e/ 'Welcome to the Jungle' by Aerosmith)

SFX: Rowdy applause and cheering.

Two ominous burly minders emerge through the smoke with batons and Iain Duncan Smith masks on both sides of their heads They walk threateningly towards the audience smacking their coshes in their palms and hissing. Villains. The crowd loves it!

HOST: Right, no time to waste – (aside to audience) these people have wasted far too much of all our time already (SFX: canned laughter) Let's get to the first obstacle!

SFX: Benny hill music begins and the 10 participants panic trying to find a seat and a 'computer'.

HOST: Oh yes the first thing is to find a seat and filling in the forms before the computer at your local library times out.

SFX: Music suddenly cuts out and everyone dashes for the chairs. 5 make it . the others fall or crouch down looking terrified as the HEAVIES music begins and the HEAVIES stride over and drag and push the losers off the stage.

HOST: Well done you five! You have managed to get through part one of the form.

SFX: A loud buzzer sounds. A spotlight lights up one person still



By Tanvir Bush

You're POINTLESS!

desperately looking for a chair. They have their hands out in front of them,- are they blind?

HOST: : Oh dear – looks like you haven't got the right paperwork with you.

SFX: HEAVIES music; The HEAVIES close in. The participant looks terrified tries to get away. The HEAVIES push him around for a bit and literally kick the person off stage.

SFX: Audience cheering.

HOST: Oh boo-hoo my guide-dog ate my home work!

SFX: Canned laughter.

HOST: Right, let's see who we still have for the next stage of You're pointless' Remember NO points means payment!

SFX: Benny Hill music again. The five competitors kicked, wheeled and pushed into the next square. A large screen drops down.

HOST: Number one, who are you are you and what's your disability?

BILL: Hi ...(voice frail)

HOST: Louder please -even parasites need to entertain!
SFX: canned laughter)

BILL: Hello...my name is Bill Nash and I have Parkinson's Disease

HOST: Oh a good one! A contender after all! . Is that you nodding Billy or is that your sickness?

SFX: canned laughter

Host: Number two!

GILL: Hello, I am Gillian Tower and I have terminal cancer.

HOST: We better hurry up with the show then right Gilly, tick tock!

SFX: canned laughter

HOST: Number three?

TOBIAS: Hello, my name is Tobias Green and I have complex physical.....

HOST: Tobias, Tobias, Tobias. , Please, no! . We don't do complex here! Now come along. Don't make this boring! Give us a simple sickness! He leads the crowd in chorus
!

SFX: CROWD: ' give us a simple sickness! give us a simple sickness!'

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By Tanvir Bush

You're POINTLESS!

TOBIAS: Well, it's not a sickness as such – I am a double amputee and...

SFX: Silence. Then the HEAVIES music starts. Heavies move forward.

TOBIAS: (terrified) Okay, okay I am simply sick with... loss of limbs

SFX: Audience cheer The heavies back away disappointed.

HOST Number 4. What's your name and what is wrong with you? Apart from your face!

SFX: canned laughter

The deaf woman starts to sign her name.

HOST: No idea. Get her off.

SFX: HEAVIES music: Heavies drag her away.

HOST: Right you the last one, Out with it.

MOLLIE: Hi I'm Mollie James and I have ..do I have to say it out loud?

SFx: AUDIENCE: Give us a sickness give us a sickness

MOLLIE: I have chronic depression and extreme anxiety and agoraphobia. (bursts into tears)

HOST: Good one, Mollie! A bit of a drama queen eh?
Right you lot. The quick fire rounds. All multiple-choice just to make it easier for you (makes whirring sign with finger at head and gurns at the audience)

SFX: On the large screen comes the question and multi-choice answers. The HOST reads out the questions and answers but gives no time for any responses.

Q. While you are standing or sitting (or a combination of the two) how long can you stay in one place and be pain free without the help of another person?

1 minute

10 minutes

2 hours

Q. Can you lift at least one of your arms high enough to put something in the top pocket of a coat or jacket while you are wearing it?

Yes

no

I never wear a coat or jacket

Q. How far can you walk (with aids)

Less than 20 metres

Between 20 and 50 metres

26 miles



By Tanvir Bush

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Q Do you use a wheelchair or similar device to move around safely, reliably and repeated and in a reasonable time period?

Yes

No

Sometimes

Q Can you pick up and move a half litre carton (pint) of liquid using your upper body and either arm?

Yes

No

I drink out of the toilet.

Q. Can you press a button?

Yes

No

Sometimes

SFX: Buzzers and lights flash. The terrified participants call out in fear 'I don't have a buzzer' 'I didn't do that' etc.

HOST: and your time is over! Let's see the results!

Ah, Gillie with your cancer and Mollie with your misery – you were able to do all the physical tasks and have accrued 5 points each. You are fit for work.

SFX: Audience boos and hisses.

HOST: Tobias, you with the phantom limbs also scored high and that means – you cheating son of a bitch, You are fit for work! Get out of our sight! All of you!

SFX: HEAVIES music. The Heavies descend on the terrified participants and the audience goes wild booing hissing and whistling. Calls of Scrounger! scrounger! .

HOST: Bill – you can't even push a button. Pathetic. You are absolutely POINTLESS!

SFX: wild canned cheering.

HOST: You are our winner. For now. We expect to see you back in six months for a review and to play again the game: YOU'RE POINTLESS!!"

SFX: Music applause and cheering!

Bill weeps.

Black





Fluid Identities / New Spaces



Sasha Saben Callaghan Collage

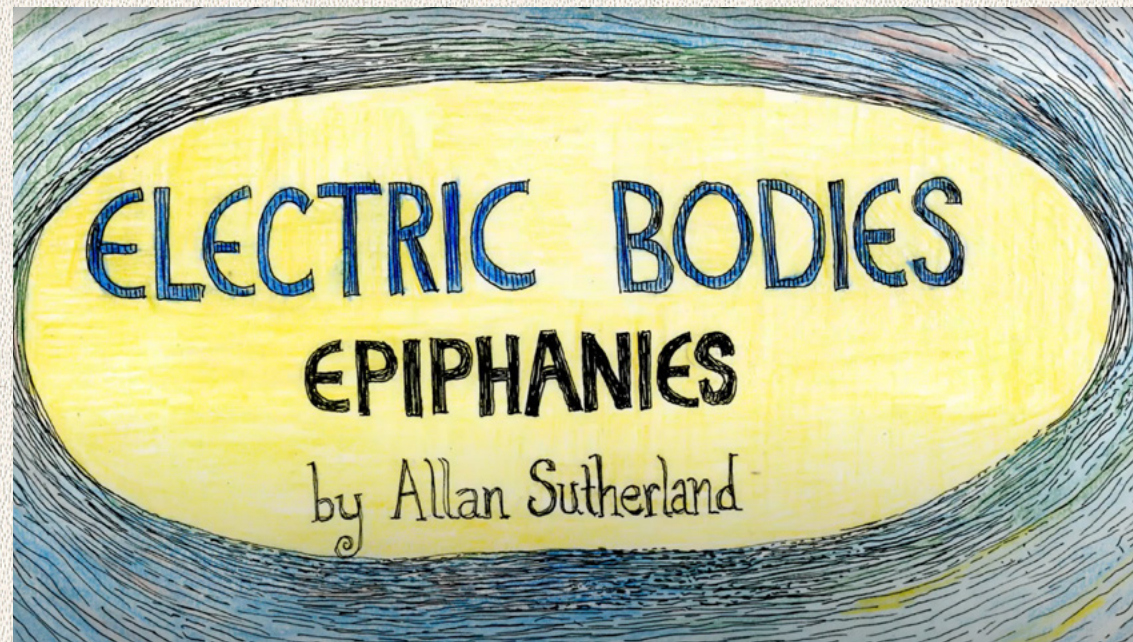
By Katherine Araniello, Robin Surgeoner, Tony Heaton, Jess Thom, Mat Fraser and Colin Hambrook

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Epiphanies

Electric Bodies is a series of eight poetry cycles by Allan Sutherland taken from the transcripts of oral history interviews with practitioners from within the Disability Arts Movement. Within the context of the D4D project *Electric Bodies* aims to examine aspects of disabled artists lives that give voice to some of the main concerns of disability arts as a movement and genre.

Epiphanies contains lines taken from multiple poems within several of the poetry cycles; taken from the words of Robin Surgeoner, Katherine Araniello, Jess Thom, Mat Fraser and Colin Hambrook. To watch *Electric Bodies* [visit the D4D website](#)



By Misfits Theatre

Misfits Theatre Company Explore the Meaning of 'Community'.

Misfits Theatre Company Explore the Meaning of 'Community'. Misfits Theatre Company; we are a theatre and social group that brings creativity and inspiration to people with learning difficulties. In 2020, several of us took part in a sensory photography and poetry film project exploring the meaning of 'community' – what do we feel about our community? Who is in our community? Do we feel safe, scared, happy, adventurous, bonded, included, excluded? The photography project was led by Tanvir Bush and Penney Ellis with the lead researcher Aggie Bezzina. Below are a selection of our photographs!



Friendship - Photograph by Debbie Curwen

By Misfits Theatre

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Blocked up - Photograph by Caroline Hall



No 10 Downing Street - Photograph by Rachael Hillier

By Misfits Theatre



Fairy Power - Photograph by Caroline Hall



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New Beginnings Disco - Photograph by Tim Knight



Fun-loving Man - Photograph by Debbie Curwen



Hot-Pink Nails - Photograph by Hayley Marsden

By Misfits Theatre

Poetry Films

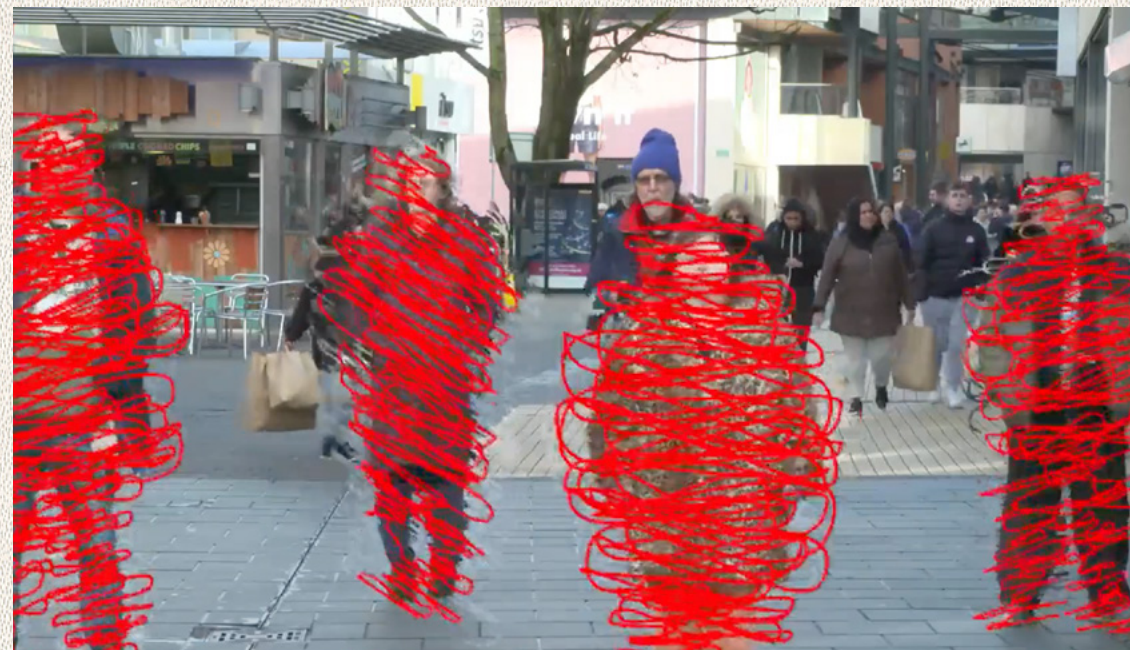
[Click here](#) or images below to watch Where do I feel safe



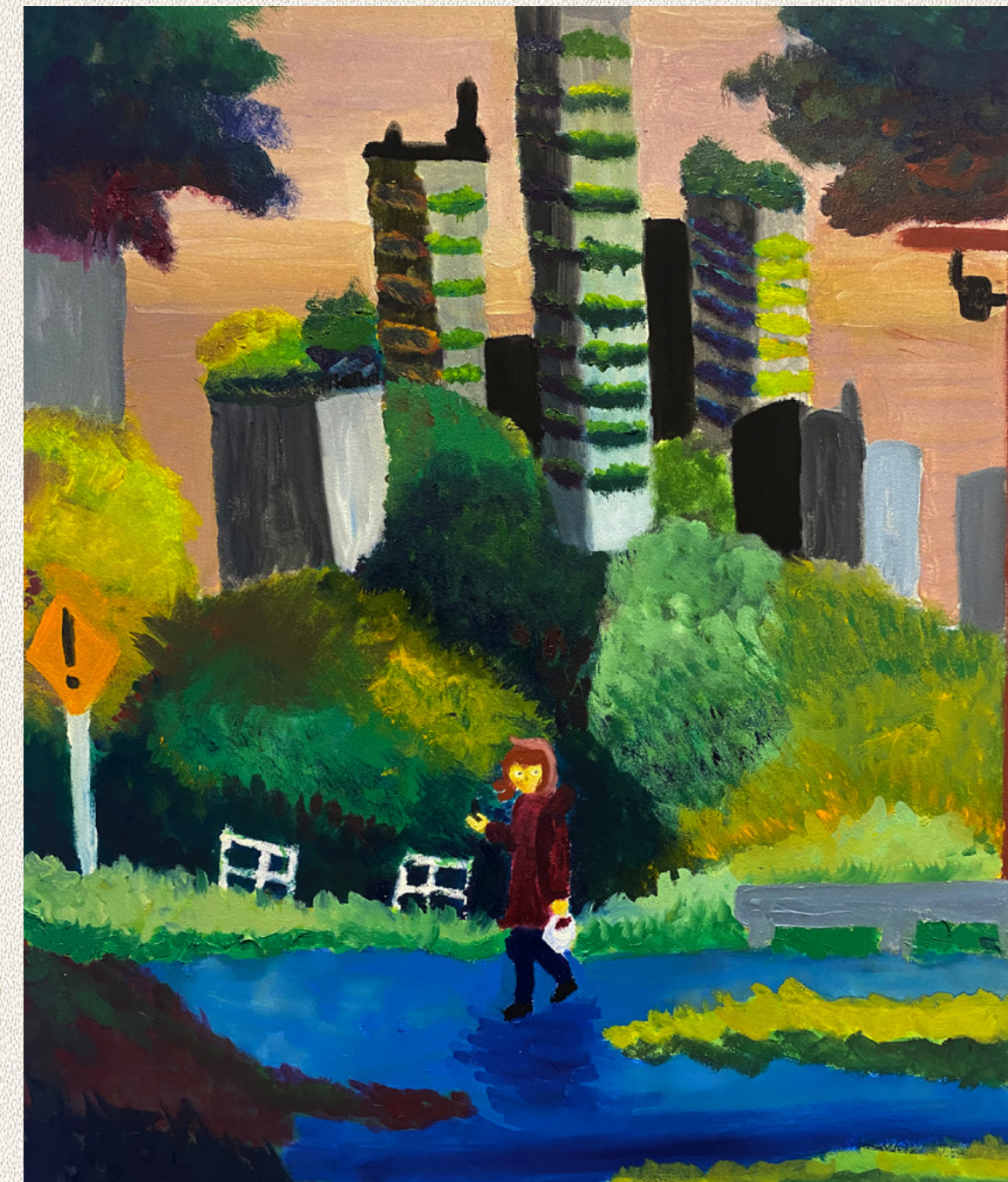
By Gary Turner

To watch 'Will there be disabled people in the future [visit the D4D Vimeo](#)

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City of Trees by Gary Turner



By Stuart Read &
Anne Parfitt

Can I park my car here

Introduction: Misfitting in spaces

A disabled car parking space may seem benign and something not worth focusing attention on, particularly for non-disabled people. However, what the above haikus emphasise is that the often-inconspicuous nature of car parking spaces hides in plain sight many issues of inaccessibility that disabled people routinely have to think about and navigate. In this chapter, we use Rosemarie Garland-Thomson's theory of 'misfitting' (2011) as a frame to discuss disabled people's current access to disabled car parking, and what this means for the development of future spaces.

Rosemarie Garland-Thomson (2011) discussed that how we see and experience our lived environments and spaces can be theorised through the extent to which we 'fit' or 'misfit'. She described how 'fitting' versus 'misfitting' emerges from the interaction between the disabled person and the environment we are navigating. Specifically, disabled people experience fitting when the environment is built to effectively support our bodies and needs (both in attitudinal and structural ways), and misfitting when it is not. There are myriad elements that can contribute to disabled people's experiences of fitting and misfitting. Particular examples may include, but are not limited to, the accessibility of buildings, other individuals who are around us, or for the purposes of this chapter, the design and use of disabled car parking spaces. Each of these examples can directly shape how we experience of particular situations, and therefore the degree to which we fit or misfit. Experiences of fit and misfit are highly flexible and situationally-specific – or as Garland-Thomson (2011, p. 597) described, "[a]ny of us can



fit here today and misfit there tomorrow."



1. Unsettled spaces, in future a no car land in spite of the now



2. Park up get comfortable ask if the signage is working for anyone

By Stuart Read &
Anne Parfitt

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3. misfitting at best or imposterism even, I took up the space

By Praminda
Caleb Solly &
Esther Fox

Leaky Robots - We the Curious-Robot Double

Praminda Caleb-Solly is Co Investigator on the Catch Me If You Can project and team leader for assisted living in the Bristol Robotics Laboratory at UWE. For Catch Me If You Can she has been developing a series of events called Leaky Robots – these events are exploring ways a Robot Double can support access to culture for disabled people as well as the role new technologies play in giving disabled people greater independence. The Robot Double Device is designed to give agency and autonomy through a remote connection.

This short film documents Esther Fox's remote engagement through the Robot Doubledevice with an event in August 2019 at We the Curious on Bristol's harbourside – a space that exists to remove boundaries between science, art, people and ideas, providing opportunities to interact with exhibits and take part in experiments. To watch the Robot Double [visit the D4D website](#)



By Praminda
Caleb-Solly

Wizzybugs a go-go!

Robotics Engineer Praminda Caleb-Solly on her D4D project
Catch Me If You Can

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An expert in designing practical, technical tools for disabled people, Caleb-Solly is a team leader for assisted living at the Bristol Robotics Laboratory at the University of the West of England. Natasha Sutton-Williams spoke to her about D4D project 'Catch Me If You Can'.

To watch catch me if you can [visit the D4D website](#)



Catch Me If You Can explores how technological interventions can positively impact on the lives of very young disabled children. Through practical and investigative research, Caleb-Solly and her team have analysed how technology can support children. Research has gone into understanding disabled childrens' experience of play, and how they can enhance their experience of social belonging in communities.

"In 2016 when we first started to formulate our D4D project, I was working for a not-for-profit enterprise called Designability who make assistive products for disabled people," says Caleb-Solly. "One of their products is called a Wizzybug, which is an innovative mobility device for early years children. Essentially, it's a fun electric wheelchair for kids! In the UK, kids under five don't get access to wheelchairs, so we designed one. It's available as part of a loan scheme, and it's actually free to parents. Going into the D4D project, I could see an opportunity for the children and families who use the Wizzybug to participate in our study so we could better understand how the Wizzybug was changing their experience of day-to-day life."

More [here](#)



By Diane Carr

Disability, assessment and able bodies in games and science fiction

Diane Carr is a reader in Media and Cultural Studies at University College London (UCL's) Institute of Education, where she teaches courses including 'Digital Games and Play'. For the D4D project Carr has been leading the work-stream Playful Bodies, Technology and Community. Natasha Sutton Williams spoke to Carr about her work with videogames and players, and collaborations with Esther Fox and DAO.

One of the challenges Carr faced early on in her D4D project was the myriad assumptions surrounding disability and video games.

"First, there was the assumption that if I'm talking about games and disability, I'm going to focus on accessibility," says Carr. "Accessibility is important, obviously, but that was not my focus. Second, it was assumed that I'm working on simulations of impairment for the sake of educating able-identified people: No, I'm not. Third, there's the assumption that if my topic is 'games and disability' then I'm going to focus on therapy or games as a way to 'help' disabled people. That's not what I'm doing either."

[Further Reading](#)

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Photo Caption 1



Photo Caption 2

By Milo Griffiths

Disability Pride!

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There have been many styles of thought and action to explain disability pride. It would be hopeless to try to outline them here in order to determine any conflicting perspectives or offer a general theory. What is important is to recognise the significance of pride in challenging how society is established and social change becomes a viable option. We should not conflate disability pride with an acceptance of the barriers that we experience, nor should we articulate pride as a dismissal of the external factors that influence the way we perceive ourselves. Having pride is to be resilient, it offers a mechanism to endure substantial pressure to conform and become passive. I am not proud because I am disabled, I am proud because I reject normality.

To be proud of ourselves, in this context, is to recognise the historical and contemporary representations of disabled people. We have been medicalised, it is assumed that we require professionals and treatment interventions to relieve us of continuous suffering. It is insisted that we are separated, institutionalised, protected for our own benefit, promised and offered cures and rehabilitation - those with substantial power declare or imply that we are disabled because of our bodies. Of course, there is resistance - we have the social model of disability¹ and the independent living philosophy². Our social movements, allies and user led organisations, articulate disability as a social condition, emerging as a consequence of the way the social world is produced. Yet, the reality necessitates the desperate need for disability pride.

Our resistance is continuously attacked and dismantled; many of us are killed or we die because the right level of support to exist is never provided. We are murdered across the globe and the dominant narratives state it was a product of mercy killing,



we are exposed to hate crime and told it was an administrative or bureaucratic error to ever allow the person to be near us, we are informed that prenatal screening and genetic modification makes sense because we exist as a fate worse than death. Disability pride is part of the foundation to challenge the systematic discrimination, exploitation and marginalisation. Disability pride is a recognition of the unjust world that we are part of, it is a recognition of the dialogue that implies social justice is conditional and dependent upon political and economic events. To have pride means I must be angry.

How does the social world develop and exist? This was the first question I had to answer in order to have any sense of pride. I am an unwavering supporter of the social model of disability, although - like the independent living definitions - I believe they have been hijacked and no longer work as a device to oppose discrimination and marginalisation³. Demanding better access, suggesting better policies or challenging attitudes, merely perpetuates the ideals and actions offered by those that have colonised the expectations of the future. There is substantial power within our social world, it resides with the corporate agendas, the consumerist culture and the cascade of events that shape our economic and political activities; our tactics, tools and vision should not just resist current practices - they must revolutionise our thinking.

The world and its contents are not rigid, stable entities - what exists is in constant fluctuation and permanently affected by our relationship to each other and the materials surrounding us. By stating that everything is relational and contextual, continuously affected by a multitude of factors, it gives hope and possibility that all of us can affect the world⁴. This means disability pride

By Milo Griffiths

Disability Pride!

is an expressive composition of our ability to recognise struggle and demand change.

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One might ask what value there is in explaining pride through a lens that does not express specific and detailed examples of feeling proud or demonstrating confidence. Indeed, many would dismiss my understanding as too abstract, incompatible with the daily realities of a complex society but my focus is to highlight how pride can disrupt the sense of normality. Currently, there is an overwhelming desire to “fit in”, be “part of the mainstream”, appear “like everybody else” - essentially, be normal. Why should we belong to a world that continues to produce systematic violence and oppression in order to protect the current ways of working? Why should we have better access to services just for the professionals and services to objectify our bodies, and categorise us according to prescribed labels and terminologies? Why should we accept or tweak current policy and practice that, ultimately, attempts to diminish our social position and status? Dominant narratives perceive difference as a threat, as a resistance to conform; many of us navigate the social world by adapting our environment, challenging our surroundings and critiquing assumptions and expectations - we demonstrate that change is possible and preferable.

This is uncomfortable for those who wish to maintain current levels of oppression but is exactly why disability pride is essential. It forces us to acknowledge that marginalisation and exclusion is a choice, it is a product of the contemporary



relationships. For those intrigued by my perspective, I would suggest exploring the extensive literature associated with anarchism⁵. As a libertarian socialist, I argue that our social inclusion is dependent upon establishing disabled people's assemblies, organisational councils and have localised control of the systems and structures that can provide the assistance to address our access needs.

If we reject the illegitimate authority that dictates how we should live, then we must establish relationships with those that can assist us to dismantle centralised structures of oppression. In doing so, we must demonstrate our passion to create change - not by asking to be let in, but by demonstrating how our sense of pride serves as inspiration for creating a different world.

¹ <https://www.youtube.com/watch?v=mXuiP-n1h8s>

² <http://enil.eu/independent-living/definitions/>

³ http://eprints.whiterose.ac.uk/83173/3/Social_Model_as_an_Oppositional_Device%5B1%5D.pdf

⁴ https://www.researchgate.net/publication/309380129_Sociology_and_the_New_Materialism

⁵ <https://chomsky.info/state01/>

By Lindsay
Sedgewick

Punky

P.

‘Punky’ came to me fully formed in a short film script called ‘Bookcraft’. A little girl who had a different way of understanding and negotiating with the world, and she happened to have Down’s syndrome.

When the first series was launched, we discovered that it was the first mainstream animation series in the world in which the central character had special needs.

U.

Unintentionally ground-breaking in 2011, it was still ground-breaking when the second series came out in 2014. It shouldn’t have been. By then ‘Punky’ was available in more than 100 countries and had won several international awards all over the world. Surely there should have been more series in development featuring children who had different intellectual or physical abilities?

Instead, I have found myself recently being expected to applaud that a mainstream series has a character in a wheelchair, that a series featuring animals showcases physical diversity or mental health issues or that there is a pair of mums as parents incidentally included into another.

It wasn’t that we had pitched ‘Punky’ as one that featured special needs. We pitched it as a mainstream series in which a character happened to have special needs. That’s what seems to still be lacking. You can dig deep and find reflections of different needs, but they don’t tend to be – as far as I can tell – central characters. You feel a lot of what we see is so broadcasters or networks can tick boxes to say they are doing their bit.



N.

Networks and broadcasters need to be pushed to go farther, especially when it comes to mainstream children’s shows. There seems to be slightly more diversity in mainstream shows, or at least on the indie channels but this is mostly to represent gender or racial diversity, which should have been done decades ago. They are still far from representing the communities in which we live.

Not long after ‘Punky’, there were shows developed that featured children with autism. But they were primarily educational shows, albeit done in an engaging way. I know some fell by the wayside. I developed one myself, but again it was a mainstream pre-school series in which the central character happened to have autism. We didn’t get funding. It was as if there was a perception that one series dealing with autism was enough. As with Down’s. I think that attitude still prevails.

There are certainly a few more characters who happen to have Down’s on the screen. The dialogue around mental health issues has opened considerably – but still not enough – and there seem to be more stories that feature such issues.

As for mainstream lead or central characters who happen to have physical or intellectual challenges? I could be wrong, but there still seems to be a dearth. In children’s animation, issues seem to primarily dealt anthropomorphically, by using characters for animals. Again, that the issues are there, however lightly handled, is good.

By Lindsay
Sedgewick

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But these characters need to be people.

We all need to see characters on fictional shows with whom we can identify. We also need to see people with different challenges. If we are engaged by their stories, which would include challenges faced as a result of their being 'different' to us, we will no longer see them as different from us. We remove the ignorance and the preconceptions that lead to prejudice, fear and hate.

K.

Kids respond to stories. We won't change public opinion by preaching to our audiences and we all know this. We do it by entertaining, through story, which means through characters with whom we want to spend time. And these stories need to be across all streams, but especially in the mainstream where the largest possible audiences are. So, if 'K' also stands for a grand, ie money, let's build audiences they can't ignore. Let's create demand for the stories that we want to see. A representative of one of the world's largest network and broadcaster of children's material was quoted, off the record, as saying they didn't 'do sickness'; singularly the most damning phrase I've ever heard. (It was their reason to reject the pitch for Punky.) Yet Punky had an audience, a global audience waiting for it. And animation audiences 're-grow' every five years if the series has legs.



Imagine what you could do with the power of a major network behind you?

Imagine what we could do if those large networks who dominate our industry could be persuaded to show a little imagination and invest in the future.

Y.

Yes, we can make a difference. If our stories are compelling, whatever message we want to spread about the celebration and acceptance of difference can be imbibed subliminally. It can become part of the new 'normal'. If we can't get them on screen, let's get them out there as books or plays or pamphlets or web-series and build the network around them so that producers and broadcasters pay attention. Let's get stories out in whatever medium we can find.

Let's make them irresistible.

One very well known British broadcaster turned Punky down apparently because it didn't fit into their disability slot. Because it was mainstream. Because while test audiences loved it, only one child asked what Down's syndrome was. For us that meant it was a success. For them it meant it didn't 'fit'.

We still have a long way to go.

By Bogsey, 2018

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The Genie Genie

When bits of you start to break down
 don't worry, the Gene Genie is in town.
 Your chromosomes can be dissected,
 Your X and Y can be corrected.
 A snip here will sort that sticky out ear,
 A snip there will give you a fuller head of hair.
 Your body and mind can be improved,
 Every fault and flaw can be removed.

When our body parts age and wear,
 don't worry, we can grow a spare.
 And if your genes are beyond repair, don't despair!
 They can take your own skin cells,
 Treat them with proteins and chemicals and shit,
 And here's the clever bit -
 Turn them back into stem cells,
 You know, the ones that haven't decided yet
 what they want to be,
 And they can grow them for people like me,
 Into retinal cells that can help me see,
 Or maybe a hand, a heart or a knee.
 So yes Mr Austin, perhaps we can rebuild you
 And wipe out the disease that would otherwise have killed you.



But are we foolish or misguided if we doubt
 The power of this technology to weed out the weak?
 At what point will the way we are
 Stray too far from normal?
 Who'll be accepted?
 Who won't fit the mould?
 Too weak, too fat,
 sts unlock pain secret!" Can you explain it to me Eilís?

Too disabled, too old.
 And now we have the power to dissect the very essence of life,
 Who do we trust to hold the knife?
 The scientists? Clinicians? Judges?
 Or god help us the politicians?
 And when they're deciding how our grandchildren's
 DNA should be treated,
 allowed to live or be deleted,
 What's the model what's the template they'll be working to?

It won't be me, will it be you?

By Martin Levinson

Invasion of the Benefit Snatchers

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The anthropological sections of traditional British museums have become in themselves fascinating artefacts, not least for the manner in which they demonstrate how a particular group can construct a single-lensed, linear view of human history which conveniently places itself at the apex of cultural evolution. Our Victorian ancestors were particularly adept at categorisations of other groups that did not merely serve to justify colonialist policies but actively demanded them. A purported window into the worlds of others was still more a reflection of self, a series of frozen tableaux that allowed for no paradigmatic leaps that might cloud issues of privilege.

The classification of others within certain frameworks served as proof of our own society's superior identity, and for the axis to remain fixed, there was the need for regular input, further 'evidence' showing the inferiority of those others. In particular, it was important to show their child-like and primitive nature, rendering acceptable the appropriation of land and resources that did not belong to us.

Even without the ways in which Galton developed Darwinian thinking in a certain direction, there is a logical point whereby the notion of some inherent supremacy demands protection that can only ensue from some degree of separation. While a small number of primitives in our midst might have been exotic, the idea of any influx was viewed with consternation. In that sense, it might be argued that the British Empire was less inclusive than its Roman forebear to which it likened itself.



The sense of innate superiority over other groups risked being undermined by the presence of undesirable groups within – the poor, vagabonds, tramps and beggars, the 'idle', 'deviants', and a host of people who were identified as 'handicapped' or 'feeble-minded', and included all kinds of people, labelled as 'freaks', 'cripples', 'defectives', 'incurables', 'ineducables', 'lunatics', 'idiots', 'imbeciles', etc. This was not a suitable brand image for a mighty empire, and for that reason alone, there was a need for such people to be segregated, beings who existed within the body of the nation but were not really part of it. For the process of segregation to be accepted, it was imperative that such people were othered.

It would be unfair to ignore the relative enlightenment of many of those involved in charitable initiatives; nevertheless, those who belonged to the *Guild of Brave Poor Things* were, in the final analysis, 'things', not part of the 'nation' and extrinsic to the main body. When it came to those with mental illness, it should not be forgotten that early psychiatrists were referred to as 'alienists'.

In the classic sci-fi film, *Invasion of the Body Snatchers*, conceived against the backcloth of paranoid McCarthyism 'in the USA during the 1950s', there is a particularly iconic scene in an abandoned cave, in which the protagonist returns to discover that the woman he loves has fallen asleep to reawaken as a one of the 'pod people', a loveless alien, the husk of her former human self. The film encapsulates the fear of the Other who has burrowed into the fabric of our world and now lies hidden amongst us.

By Martin Levinson

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When this D4D team first came together the world was a different place. Covid 19 was (possibly) lurking in some dark corner of another cave in Yunnan, South China, populated by bats harbouring an unknown virus that would kill millions. Donald Trump was a self-aggrandising businessman and TV personality, little known by the general public on this side of the Atlantic. Over here, Nick Clegg had only recently lifted the covers to snuggle up in bed with David Cameron, and while ‘austerity’ policies were being devised, the notion of ‘austerity’ remained, something nasty that had probably happened in the 1930s. Nigel Farage was an English eccentric with outmoded views, a character who might have toppled out of *Wind in the Willows*, and who would doubtless just vanish like other crazes of the decade, such as planking, twerking, Tamagotchi, Harlem Shakes, Mannequin challenges, side shaves, Pepe the Frog, Honey Boo Boo and ice-bucket challenges. Dominic Cummings was unheard of, a gleam in Michael Gove’s eye, burrowing away in some clandestine stock cupboard in the education department. Alexander Boris de Pfeffel Johnson was a Worzel Gummidge lookalike in London, who we in the provinces occasionally spotted on *Have I Got News For You*. We knew he had an important job in the capital: Running a cycle shop or something along those lines.

In those days if someone had enunciated the word ‘Brexit’, you might have guessed they were misremembering the word for an old breakfast cereal, and may have even pictured Jon Pertwee, another Worzel, the time-travelling prime minister we never got, voicing the advert – Readybrexit, “Central heating for kids”;

“This is the way to glow to school”.

In an altogether more innocent world, in which social distancing was a concept we might have associated with polar bears, latter-day Carthusians and *Herman’s Hermits*, the original members of the D4D team were locked away in a Stalinist hotel conference room in Sheffield, plotting a future project. The team wanted the project to go beyond exploration around its central theme of exclusion that threaded across its diverse workstreams; we hoped to evolve new ways of investigating issues around disability. We hoped to help show that the Other was only another form of Us.

The dominant perceptions of disability were beginning to veer between ‘sponger’ and ‘hero’, the former fuelled by the recession and the latter by the 2012 London Paralympics. It was as if a race of superhuman scroungers had selected the UK as their new home, and, having travelled from some distant planet, were now hurrying in hordes on their high-speed, prosthetic legs in the direction of the nearest Benefit Office.

With their carbon fibre reinforced polymer prosthetics, they were at significant advantage alongside our indigenous breed of decent, hard-working, non-disabled, unemployed citizens, who had to rely on standard limbs to get to the Benefit Office. Meanwhile, other indigenous (non-disabled) citizens, who had managed to hold on to their jobs through the recession, were now having to work twice as hard just to feed these blood-sucking monsters from outer space.



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In our D4D team we had hoped to contribute to a third image: ordinary people, neither heroes nor scroungers, some in work, some out of work, generally, doing their best in an inequitable and often hostile world. The project team sought to explore their experiences alongside them, presenting them in a realistic way with no media distortion.

It was already too late. George Osborne and IDS were by now hacking away at the benefit system. Cameron was, complacently, committing himself to a referendum. Meanwhile, grown in dark caves, the Dr Moreau laboratories at Eton and other such institutions, strange things had been lurking in the shadows, waiting for their moment.

Depressingly, the world seems a still more unequal, unfair and dangerous place than it was when we began our project. For disabled people, this has resulted in the dismantling of support, the reduction of benefits, the movement away from ideas of inclusion back to those of separation.

To justify this, narratives around disability needed to change. Tabloids such as the *Daily Mail* and the *Sun* were only too happy to oblige. Soon it was clear that ordinary citizens were fighting for its survival, hapless victims of the *Invasion of the Benefit Snatchers*.

This process happened remarkably quickly. In the midst of the austerity drive it was possible to identify a significant shift

between press stories about disability between 2004-5 and 2010-11. Not only was there a significant increase in stories about disability; the language, tone and content darkened. Positive stories about disabled people and stories of real life experience decreased. Instead, there was a focus on fraudulence and cheating. The Victorian notion of the *Deserving* (and therefore, *Underserving*) Poor was revived. It was during this period that a close friend with MS recounted his experience of being summoned for a 'Fitness for Work Assessment'.

My friend, Steve, had been working for nearly forty years as a teacher in Nottingham, during which time he had missed one day at school through illness, despite all the difficulties with mobility. His condition had become more intense, and by the time of the assessment, he had been retired for about a year - with his movement reduced to a little mobility in one hand.

"Just try a few steps," said the assessor.

"I'm in a wheelchair," said Steve, "and can't get up without help."

"Well, just try and get up, and just take a few steps towards us," came the reply. "I'm sure you can manage just a few steps." In such a situation it is not permissible to seek even a polite way of saying, 'Fuck off, you half-wit'. The disabled person can only earn the right to identify as such through crashing to the ground. And even then, you might be faking it.

It was not just policy directives that resulted in such callous behaviour. It was a shift in perceptions driven by the repetition



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of certain types of stories in the printed media and online. There is a link between such a narrative and the growth of hate crime. Police recorded hate crime figures moved from 39,130 to 105,090 between 2013 and 2020. One of the fastest rising areas was in disability hate crimes. Back in 2012, 1,676 crimes were recorded by police; by 2020, the figure had risen to 8,469. Such statistics, of course, represent only the visible tip of the iceberg, with only a small proportion of incidents reported. Meanwhile, disability hate crimes led to the smallest percentage of prosecutions, 1.6% of those reported ended up with perpetrators being charged.

A culture of apathy towards this ensues from the internalisation of othering processes. How much easier it is to ignore such crimes when the recipients can be viewed as a tribe of layabouts and parasites! Transcending prejudice, this is also about identities; in a Hegelian sense, a strong sense of the 'other' is critical to the perception of 'self'. While the Nation was rooting out European from the sense of collective self, it was also extracting other undesirable associations.

The pandemic saw the revival of Galtonian eugenics in the initial Covid reaction. The statements made in March 2020 already seem as if they belong to another era. Rather than referring to lockdowns, the talk was of 'herd immunity'; in effect, there was no plan to protect those who were most vulnerable to the pandemic. Meanwhile, plans for a 'Test and Trace' programme were afoot, which would cost £37 billion over two years - for negligible outcomes in the view of a Parliamentary committee.

We live in a society in which it is quite acceptable to squander billions of pounds on contracts to political cronies and companies with government connections, but where we cannot afford to spend far less to protect the dignity of ordinary people. I'm all for eugenic logic – and propose it on the basis that we are prepared to shed all those who lack compassion, humanity, basic decency. They are the real 'pod people'.

And if we in the D4D team fell short in our endeavours, it was not through a lack of idealism. Even in the darkest of caves, penetrated only by tiny glimmers of light, we must hold onto our hope that we can build something better. It is what makes us human.

In memory of Steve Arnett, one of the first victims of Covid 19, who outlived MS for many decades with dignity, wit - and a rich hinterland with borders protected by music.

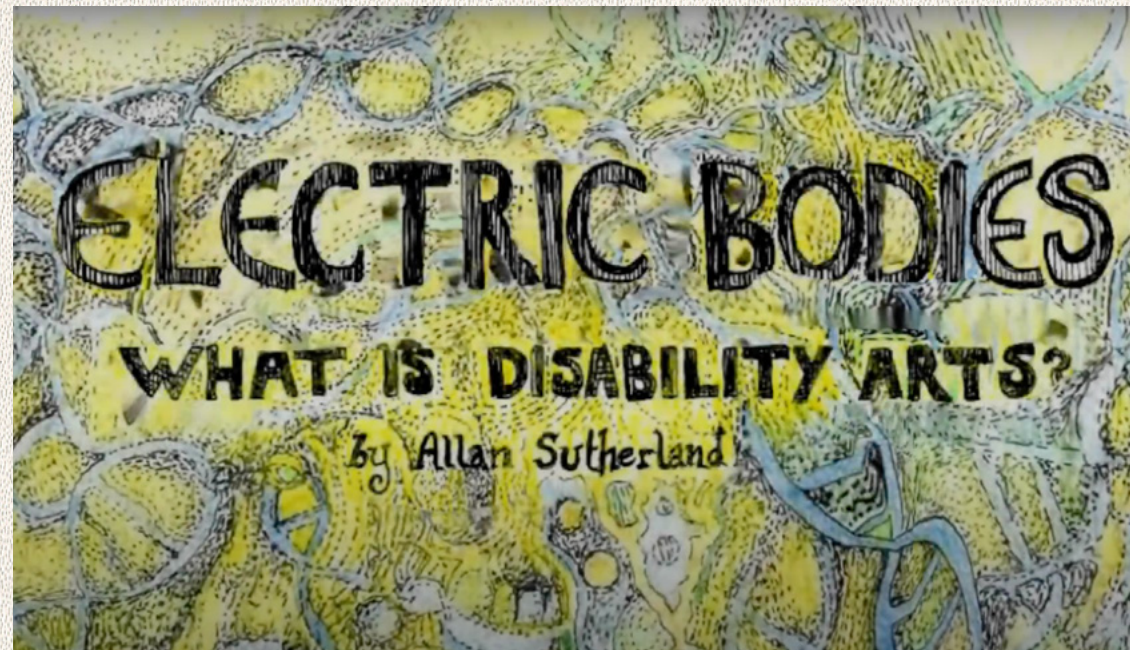
The views expressed here are entirely personal, and in no way should be taken to represent those of my colleagues on the D4D project.



By Electric Bodies

What is Disability Art?

What is Disability Art? contains lines taken from multiple poems, taken from the words of Robin Surgeoner, Vici Wreford-Sinnot, Tony Heaton, Jess Thom, Katherine Araniello and Colin Hambrook. To watch Electric Bodies, What is Disability Arts [visit the D4D website.](#)

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By Colin Hambrook

A Question Born of Love

We've entered this new universe; looks just like the old one; small group in the pub sitting around cool and inane as it ever was. Lamps are lit; bohemian frills, loud techno, a life size white porcelain hound sitting up, attention alert, a white hard hat poised for action on its head. A stage is filled with debris waiting for a band to play; piles of wood and forest litter arranged beneath a microphone on a stand ready to add their rustle to the proceedings. Yet something is wildly amiss; this flutter in my heart ... is this love? This will to carry on, ignore all the threats? Is this love, this will to move through darkness despite the danger? Or maybe the danger makes the need to fulfil a creative need all the more profound? We are determined creatures in the face of disaster. We will push on through even as our fellow humans fall. We will ignore their loss and push on through to extract something precious from the moment, a smile, a laugh, a story of resilience. In the face of it all we will not accept defeat.

And yet we ignore the voices of our ancestors as we assert our privilege; leave their shadows in empty anonymity to pursue our folly. We dress in love this will to forge a way through disaster by burying our heads. After all what can we do? We resign our lives to selective attention even as the bush burns, cliffs of ice fall, the biosphere billows with carbon carrying the tortured screams of our children and our grandchildren. And we refuse to listen. Is not this denial of imminent suffering a form of self-hatred? Are they not us... those born and unborn in the shadows of tomorrows longings? Why do we ignore the suffocating heart of life in all its richness sliding off the curve of this planet? This is a question born of love, sitting here in this new universe watching the hubbub of human interaction breathing to the beat of each moment... here. The lamps are lit; bohemian frills, cool customers sitting around, cool and inane as it ever was.

By Tanvir Bush

Tanvir Bush - Afterword

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I joined D4D in March 2018 as an Associate Research Fellow. I had recently had a novel published, a satire exploring the idea of the state sponsored euthanasia of disabled people. The novel was titled CULL.

Things had been incredibly tough for disabled folk; austerity dovetailed with the grotesque, humiliating, Kafka-esque benefit system, the work capability tests, the sanctions, the inadequate employment and education support, the lack of social care. Luckily, working with the D4D team gave me renewed hope as well as an income and I was completely engaged in all the various research projects, creative endeavours, publications and activism.

And then came Covid 19.

On March 23rd 2020, I blogged about the new state of lockdown. I wrote

Last Monday I was on the bus trying not to touch anything with my hands--which is tricky if you are visually impaired, bus lurching, Mitzie sliding helplessly into the aisle.

Back then, hundreds of long hours ago, when we were still living in that other England, a gaggle of pensioners were braving it out in the backseats, muttering, squeaking and giggling like teenagers bunking off school. Across from Mitzie and I, a baby in a pram coughed snottily and both me and the kid's anxious mother, flinched. When we got to the bus station, there was a sound of much squelching and the sharp, sweet, palate-cleansing stink of hand sanitiser flooded the bus as almost everyone squirted and rubbed.

A week later and I wouldn't risk the bus again. Few would. Going to the Co-Op is a dangerous idea. In the last couple of days, I have seen an x-ray of a mucus encrusted lung and heard the statistics. This morning I played 'Un Bel Di Vedremo' from Madame Butterfly sung by Renee Fleming at full volume, followed by 'The End of the world As We Know it' by REM. 'Alexa, play music for the apocalypse, please'.

Schools closed last Friday. The death count in UK is 303 as of this evening – doctors and nurses still don't have the right safety gear and freelancers, the self-employed, are still waiting to hear their financial fate. And there is another black hole emerging – potentially, under the Coronavirus Bill being read in Parliament as I type, the rights of disabled adults and children will be binned. More on that anon. I am tired.

Then the death count was 303.

Now it is September 2021 and the death count is 158,664 and over 60% of them were disabled people. The government has 'done all it can' and – post the vaccination campaign- sent everyone back to work, school and left anyone vulnerable to decide for themselves what to do. Masks and kindness optional. The vaccinations have saved millions. I have been double jabbed along with many of the people I know, but most of the rest of the world couldn't afford to stockpile vaccinations and therein lies the rub. The pandemic will continue until all have vaccinations.

There is an emptiness in me now too, a realisation that disabled people really are disposable. I mean I had an idea we were lurching that way, had even written a novel about exactly that but I had hoped compassion would out in the end ...the pandemic has squashed that hope flat.

By Tanvir Bush

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There is nothing we can do BUT take action. Quite literally for disabled people, along with those in poverty, we must fight for our lives. I truly believe that, given everyone will be disabled at one time or other – we cannot avoid the four tenants of our humanity: birth, sickness, aging and death - that we must stop the medieval and insane ‘othering’ of disabled and chronically ill people. We are the actual reality of being human- we are at every intersection of humanity, every tribe, every religion, every school, every community- we are there. 20% of the population and rising. It is time, before the next pandemic, before the climate crisis deepens, for humans to acknowledge that disability is part of living. All our lives depend on it.

They started with Kurt Vonnegut’s Breakfast of Champions and now meet monthly employing the talents of local songwriters, artists and chefs who plumb the depths of a chosen literary gem to create that rare and beautiful thing – a new song (or visual art, dance, film or snack). These literature-themed live shows have been inspired by everything from Raymond Carver to Charles Darwin to George R.R. Martin to the thesaurus.

The Bushwick Book Club now has several branches all over the world, including Portland, Los Angeles, Seattle, Santa Barbara, New Orleans, Greenville, London and Malmö, Sweden.

By Esther Fox

Esther Fox - Afterword

I have been with D4D since the beginning, when I was selected to take part in a 3-day long meeting in Sheffield with a mix of academics and community partners, as part of the AHRC’s connecting community programme. I didn’t quite know what to expect as a non-academic, but I was hoping my thinking would be expanded, my networks broadened and my resolve to work positively for disabled people strengthened. I still strongly believe there is a space and a need for academics and non-academics to come together. I believe with the rigor of research, alongside valuing lived experience, we have the potential to be more persuasive about the changes that are needed in our society for people to have equity and access to opportunities.

My role has been as Project Manager and Co-Investigator, this has enabled me to work across project streams with different academics, as well as delivering my own participatory workshops with D/deaf and disabled people. My research interests were the ethical dilemmas surrounding genetic screening and the potential impact this will have on disabled communities. During this research I became more confronted by the troubling legacy of eugenics. The idea that some lives are more valuable than others, has always lurked not very deeply under the surface of society, particularly in relation to disabled people. However, I didn’t think I would ever see it quite so obviously play out in the way we have seen during the Covid 19 pandemic. My colleagues and other contributors to this book have highlighted just what a desperate position disabled people have found themselves in over the last 18months, and it has been even more emphasised as we enter winter, with little or no consideration given to those most at risk of the virus. Therefore, suffice to say, I wholeheartedly agree with the predominantly dystopian view that this book proffers.

By Esther Fox

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However, as I am forever the optimist, I hope that hearing the real voices of disabled people sharing their fears and their life experiences, will provide further evidence that we can't be ignored. I have also found a sense of community and solidarity with other disabled people during this period, which I have not experienced so strongly before. Therefore, if we can harness this anger and shared sense of purpose, perhaps we can drive forward a movement to demand to be treated equitably and not be forgotten. Now perhaps is the time for change. We have seen the pandemic require people to rethink working practices and provide more widespread digital engagement in ways that we perhaps only dreamt of. So, let's not revert to old exclusionary ways, but strive for a future of equity and opportunity, where disabled people are valued, not overlooked, and not left behind.

