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Special Issue: Interrogating Disability, Part One

Edited by The Interrogating Disability Collective

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Inside...

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- The disability benefits system

Clinical Psychology Forum

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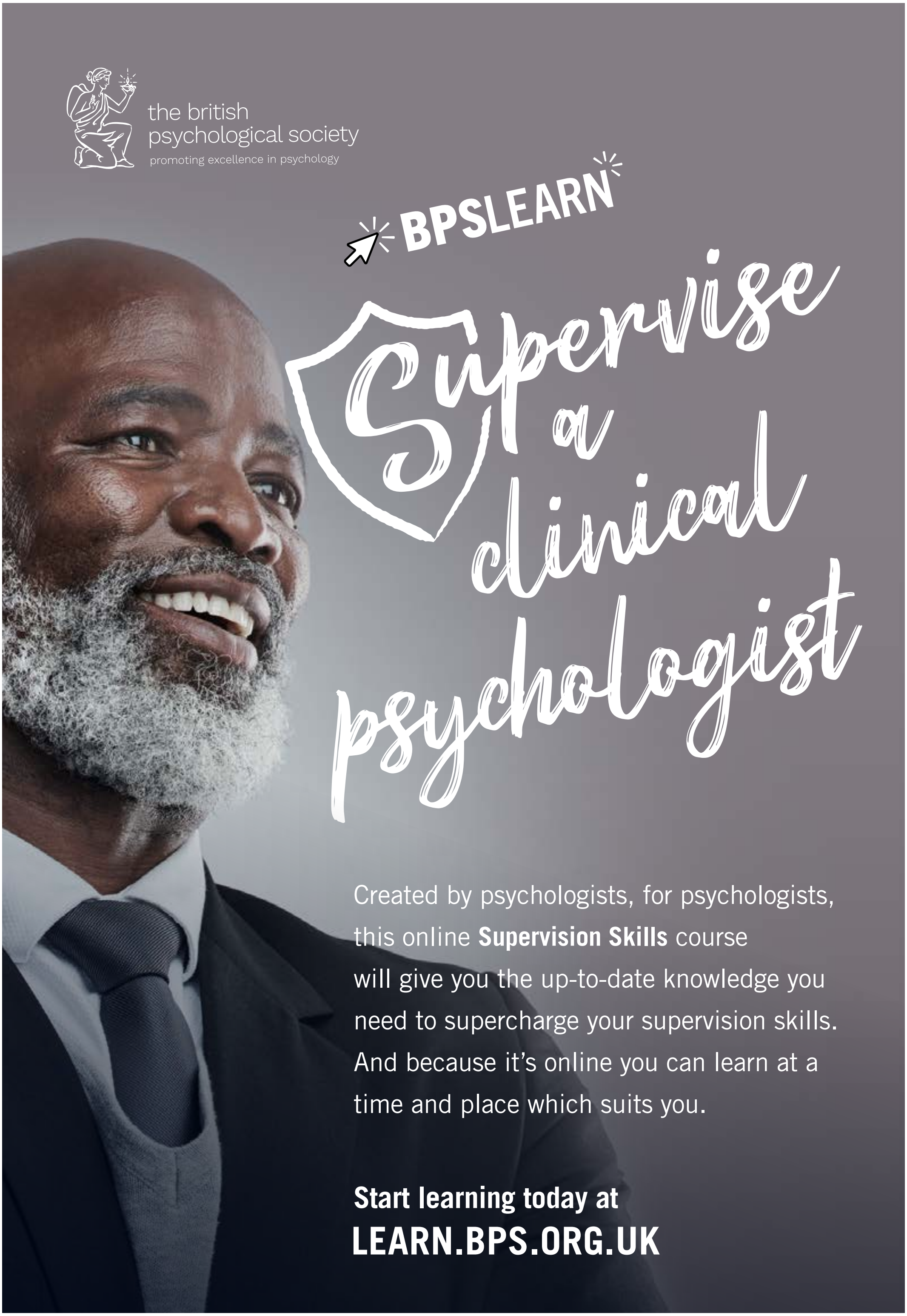

call to art

for persons with disabilities

if we want
to be part of this story
we have to write
our own chapters
we have to paint
our revolution across blank spaces
we have to dance
and stomp upon our space on the land
and make it sacred
we have to cross the stage
and speak from the centre
not the side, not the back
we have to capture our images
and rid ourselves
from the tinshaking-streetsitting-pityme-pictures

we have to embroider our history
on coloured cloth
and wave flags of freedom
we have to name this apartheid
crush it with our art
prise open a new way
with our pens/brushes/feet/voices/cameras
embracing the space we carve
the place we sculpt

Shelley Barry, 2011

Published in *Rethinking Africa: Indigenous Women Re-interpret Southern Africa's Pasts,* edited by Bernedette Muthien and June Bam (2021). Jacana Press. Reproduced with permission of the author.

Editorial: Interrogating Disability

We had so much interesting and relevant material that we obtained agreement from the DCP Publications Comittee to make this a double issue across May and June. The editorial is repeated at the start of each part.

THE PAPERS contained within this special DISABILITY double issue have been produced under – as for many other 'Disabled' people – a very real life threatening cloud of the global COVID pandemic. A cloud that remains with us, no matter how many able bodied people (within and without government) pretend that it has disappeared, or that it is 'back to business as usual' (see paper by Dawood, Sunderalingam and Ranieri). This collection is concerned with making sure that we do *not* return, to either the 'usual' or the 'normal'.

It is increasingly clear that the current global economic and political systems are not fit for purpose on a heating planet, with what should be considered criminal (and growing) levels of inequality and oppression resulting in war, racism, genocide, poverty and the continuing extinction of many of our animal cousins and the natural world. The discipline of 'psychology' is neither exempt (nor exonerated) from these influences, emerging as it did from a Euro-American context in the nineteenth century, rife with scientific racism and a nascent eugenics movement. Indeed, many common statistical tests used by psychologists bear the name of eugenicists (https://nautil.us/how-eugenics-shaped-statistics-9365/). Psychology was quick to adopt 'scientific' principles and methods, to bolster its emerging professional status and the power of its 'findings'. The problem is, of course, that a lot of these 'findings' have since been robustly critiqued as built upon human assumptions and bias, including instrument bias.

A state model built on 'psychological principles'? Look no further than South Africa under apartheid, with Hendrik Verwoerd as a social psychologist and a founding father/premier for a brutal social engineering project determined to enforce the unequal segregation of 'races,' on the basis of evidenced 'IQ disparities'. (Although the British had already started this project in a more subtle and arguably more pernicious guise, during colonial Empire rule.)

Science has moved on – the observer is inextricably linked with (and influences) what is observed – there is no 'objective' viewing point on this planet; instead, our perceptions, positionality and relationships are key (Johnson & Carroll, part one). With regards to compiling this special issue, then, it became clear as we linked/met up as a participatory online collective – some who identified as 'disabled,' others not – that we were all were agreed this should largely be an 'internal' perspective on 'Disability' – i.e. not an external 'objective psychological' dissection of 'Disability,' which can often descend into an 'othering' of experiences (Pellicano & den Houting, 2022). A simple fact underscores our decision – we are all potentially disabled at some point in our life. The 'internal view' potentially awaits us all.

This collection is thus about 'us' – not 'them and us' – and it is also about critiquing and disrupting corrosive (yet still popular and powerful) 'lenses' for viewing Disability, including individualising and neo-liberal narratives of Disability as personal tragedy. This involves challenging not only false scientific or medical/psychological absolutes, but highlighting implicit cultural attitudes that foster 'ableism', i.e. the view that a 'perfect' (usually white) body exists as 'normative' (and aspirational) and anything 'lesser' is to be pitied or 'disavowed' (Ableism 101, part one). Yet, in one way, the human body is key too.

Disability covers a fluid, fluctuating and embodied set of experiences, where the needs and limitations of the body impact on the ability to survive, in a neo-liberal world built on production and consumption. The deadly emergence of a global COVID pandemic in 2020 has not only exacerbated existing inequalities and vulnerabilities, it has strengthened the continued emergence of what has been termed 'necrocapitalism' (Bannerjee, 2008). That is, where organised powers accumulate gains off dispossession and death – whether extractive neo-colonial corporations or ableist discourses around whose life is 'worth more,' when it comes to oxygen ventilators.

Given this context, it is thus no accident that there is a distressingly strong correlation between poverty and Disability, further exacerbated by the current 'cost of living' crisis. We thus have an article outlining the recent (and fraught) material context of Disability in the UK by *The Guardian* 'Disability' correspondent, Frances Ryan (part one). Given the centrality of survival needs, we have two further complementary articles about the 'disability benefits system': firstly, Saffer and O'Riordan (part one) on supporting people with Disabilities navigating the Kafkaesque maze of the 'benefit' system and secondly, Allan et al. (part one), with a Scottish perspective on a similar phenomenon, where the system itself (wittingly or unwittingly) ends up piling on further abuse and trauma, onto the 'disabled' experience.

Broaching geographical borders further – given Disability knows no boundaries – we have an overview of a new rights based disability framework for Northern Ireland by Mac MacLachlan (part one) and – yet further afield still – a perspective from Leslie Swartz (part one) on Disability in the Global South. Continuing the Irish theme of disability rights, we have Johnson and Carroll (part one) on Disability Justice in the context of UK Mental Health services.

In part two, returning to the earlier editorial theme of IQ tests and 'racial differences' we have two papers focusing on: firstly, co-producing experiences (and suggested support) for people with 'learning disabilities,' by John, Richie and Kate Theodore and, secondly, a narrative focus on 'surviving COVID' by Grant and Grieve. 'Learning disabilities' are a 'client group' for clinical psychologists, both qualified and trainee alike, although the term (and the construct behind it) remains critically contested, given it both 'others' and infantilises.

Finally, an article by Ktenidis and Wood focuses on how disability is taught and critiqued within a particular DClinPsy training course (at one point in time), along with several letters from disabled trainees (and The Minorities Group within the BPS) requesting the 'reasonable adjustment' retention of hybrid adaptations to all teaching. The Group of Trainers in Clinical Psychology (GTiCP) co-chairs are engaging with The Minorities Group over this, although broader institutional 'constraints' remain a formidable challenge.

Several articles thus also attempt to highlight critical and emancipatory models that challenge not only how Disability is constructed, but how it is entrenched, replicated and marginalised, by ableist economic and socio-political ways of viewing the world (Henkeman, 2018; Urena, 2019). As we mentioned at the beginning of this editorial, this world *must* change, if we are all to survive sustainably and with universal rights and dignity, into a better (and more compassionate) planetary future. (Visit, too, the 'Culture Corner' for alternative resources to help shape a new and fairer world.)

Let us use our professional power as psychologists not only to inhabit the 'clinics,' but (as needed) to take to the streets, seeking solidarity in finding ways to shape humanising policies and just transformations (Pillay, 2020). (That is, searching for an improved new world order too, such as *Psychologists for Social Change, Disabled People Against Cuts,* or *Sisters of Frida* et al.) After all, the world bends and shapes the 'psychological' constantly. To paraphrase an old anti-apartheid saying, *no normality, in an abnormal society/world.*

A thank you to our student editorial intern Nour-Eleman Abdlsalam for her help with proofreading these issues.

The Interrogating Disability Collective

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DCP UK Chair's update

Roman Raczka

Reflection on Allyship

What is Allyship, and who is an Ally?

ALLYSHIP is a relatively new term, one not everyone will be familiar with. In my NHS role we have been reflecting on this as part of our Equality, Diversity and Inclusion work and so I thought it may be helpful to share some of my thoughts.

The act of Allyship has been defined as 'when a person of privilege works in solidarity and partnership with a marginalised group of people to help take down the systems that challenge that group's basic rights, equal access, and ability to thrive in our society.'

This means taking an active and consistent effort to use your privilege and power to support and advocate for people with less privilege. Allyship is about working towards diversity and inclusion by standing up for the rights of those who are marginalised. Allyship is a life-long process that requires constant learning, reflection and action.

Remember, 'ally' is a verb not a noun. Just because you say you are an ally, does not mean you *are* an ally. And just because you were an ally at some point in your life, does not mean that you're an ally *for* life.

Why is Allyship important?

The act of Allyship means

- displaying an acknowledgement of oppression and inequality which can highlight this injustice to others.
- exhibiting a sense of responsibility and commitment to promoting equality and not just leaving it up to marginalised groups.
- helping to build solidarity with marginalised groups.

How to be a good ally

- Treating the challenges that other people are dealing with as your own, and putting their voices first, too.
- Consciously working to confer the benefits and privileges that you enjoy to those who do not.
- Seeking to understand the perspectives of others, while also recognising that there are real differences in lived experiences – and you don't fully know what it feels like in their shoes.
- Committing to ongoing self-examination, learning and introspection.
- Standing up for and speaking up about the things you believe in.
- Serve as a mentor or a voice for someone who doesn't have a voice.

Useful resources

Allyship at Work helps you understand your privilege and positional power and learn specific actions you can take to show up as an ally in the workplace in the short video:

What is Allyship? – YouTube

..and the collection of resources on the Lean in Allyship at work website:

https://leanin.org/allyship-at-work

The BPS campaign for 2022/23 is Tackling social class inequalities #Makeit10

We know that social class-based discrimination has negative impacts on people's life-chances, widens health inequalities and limits opportunities. In order to truly 'level up', eliminating the discrimination associated with social class is vital. The BPS campaign is to have social class added as a protected characteristic to the Equalities Act. There are currently nine other protected characteristics and the intention is for 'social class' to become the tenth and **#Makeit10**.

The Covid-19 pandemic has highlighted the incredibly unequal society in which we live, and the damaging impact this has on people's physical and mental health, life chances and opportunities. There is much evidence to show the role of social class in exacerbating the effects of the pandemic – including on infection rates, illness and deaths.

Adding social class as a protected characteristic within the Equalities Act would provide people with the same legal protections against being discriminated against on the basis of social class or social economic status.

The campaign will aim to focus on four main areas, where there is evidence for revising the Equality Act to include social class – education, health and healthcare, business and industry, and communities and housing.

The campaign aims include:

- share research and evidence and call on the UK Government to #Makeit10 and include social class as a protected characteristic.
- work within the BPS ED&I framework, improve BPS internal processes to demonstrate a commitment to tackling social inequality and social class within BPS and the psychological professions.
- provide opportunities for young people from lower socio-economic environments to study, be mentored, and enter the psychological professions.

The DCP Pre-Qualification Group

update from Katie Knott (PQG In-Training Co-Chair) and Esther Bowen (PQG Pre-Training Co-Chair)

Selection and interview prep: Pre-qual event and networking evening
We saw enormous success from our latest pre-recorded pre-qual event, with 1823 views to date. A DClinPsy Q&A document is being produced and when ready for dissemination, will be shared widely.

Expanding our network: DCP England event
DCP England event is being planned with a working group set up to facilitate the organisation of the session:

- Dates to be finalised around September 2022.
- The event will be held as an online webinar. Free places for PQG members, funded by DCP England.

Recruitment and vacancies to the Pre-Qual Committee:

- Recruitment and retention continue to prove challenging in the pre-qual group with 11 committee vacancies to fill.

Other ongoing projects:

- Alternative handbook – the committee are working with BPS staff to form a working group with questions to be finalised by June and survey to be distributed to trainees via GTiCP directors list.
- Assistant Psychologist Guidance – document sections have been written and discussed by group, awaiting amendments from meeting to be completed.
- Clinical training issue of the Covid bulletin – to be shared on social media to ask for expressions of interest in contributing.

The group are very active on social media! Please follow on Twitter and Facebook.

Power Threat Meaning Framework Committee

update from Jan Bostock and Gilli Watson, Co-Chairs, PTMF Committee

The Power Threat Meaning Framework has been developed as an alternative to more traditional models based on psychiatric diagnosis, and applies not just to people who have been in contact with the mental health or criminal justice systems, but to all of us.

The Power Threat Meaning Framework (PTMF) continues to reach a wide audience via invitations to speak, remotely, to several teams and podcasts in the US and a plenary and workshop at a Global Psychiatry conference in Lithuania in September. Italian, Swedish, Norwegian, Portuguese, Danish, Korean and Russian translations have been proposed or are in development, along with the existing Spanish one.

The PTMF committee organised a very successful BPS/DCP virtual public engagement webinar on 'Understanding and Applying the Power Threat Meaning Framework' that was held on 24 May. This webinar introduced key ideas from the Power Threat Meaning Framework (Johnstone, L. & Boyle, M. 2018) and illustrated how these can be applied in a range of settings including acute mental health settings, training staff and experts by experience, and using the PTMF to foreground racial trauma. The webinar offered an introduction to the ways the PTMF can be used to inform psychological formulation, team discussions and training, organisational change and personal understandings of distress.

PTMF Good Practice Examples on the BPS website

https://www.bps.org.uk/power-threat-meaning-framework/good-practice

There are a range of examples included within the following sub-sections:

- Peer led/community groups
- Professional practice
- Teaching and training
- Influencing systems and organisations
- Influencing policy/societal level change

If you have been involved in similar practice projects that draw on the PTMF and would be happy to share them on the website, please get in touch with the PTMF committee using the following link.

If you wish to find out more about or liaise with any of these projects, please email on ptmfinpractice@gmail.com

If you are using the PTMF ideas in any aspect of your work, large or small please feel free to share using this link.

Climate and Ecological Emergency

update from Annie Mitchell – Community and Clinical Psychologist

The urgency of the Climate and Ecological Emergency was highlighted by Anthony Guterres, Secretary-General of the UN at the launch of the Intergovernmental Panel on Climate Change (IPCC) Working Group II.

> *'Now is the time to turn rage into action.Every fraction of a degree matters. Every voice can make a difference. And every second counts.'* (February 2022)

He described the report as 'an atlas of human suffering'. As psychologists we have a moral and ethical responsibility to play our part, along with others, to mitigate that suffering. Public engagement with the Climate and Ecological Emergency is ever more vital.

As awareness of the critical urgency of the Climate and Ecological Emergency increases, alongside our growing understanding that the impacts are already most affecting those who have done least to cause the harm, we psychologists need to be prepared for engaging with the individual and public mental health implications.

New entrants to health professions, including ours, are increasingly tuned into this and are joining the dots with their awareness of all the social and environmental determinants of health and wellbeing, including poverty, trauma, racism and colonialism. It is therefore good news that the Group of Trainers in Clinical Psychology has set up a Planetary Health Sub-committee to engage with the implications for training.

The Doctorate in Clinical Psychology at the University of Exeter recently held an inter-professional day on Planetary Health, and all the materials can be found here. Contact Tony Wainwright t.w.wainwright@exeter.ac.uk for more information.

Our colleagues in psychiatry have made a commitment that from 2022, every new psychiatrist will receive sustainability education as part of their specialist training. Could we say the same? It can be hard to know how best to engage as psychologists with positive climate action, but our list of ideas has been recently updated; more suggestions would be warmly welcomed. https://www.bps.org.uk/member-microsites/division-clinical-psychology/climate-change

Division of Clinical Psychology Annual Conference 2022

Facing Threat and Uncertainty Together: Maintaining momentum through global, professional and personal challenge

This year's online conference 13 and 14 October 2022 acknowledges the extraordinary context that clinical psychologists continue to work within, reflecting the critical issues of public health, social justice, conflict and climate.

Global society has undeniably faced a major threat over the past two years. Whilst COVID has remained the predominant theme, the world has also seen shifts in attitudes towards climate change and social justice. Now, we are confronting urgencies to act, unknown in any other period in recent times.

Many people have been forced to reflect on their health, safety, work and relationships in ways that were unexpected and sudden. As the pandemic enters a new phase, some are moving forward, feeling stronger and empowered by the experiences they have survived.

For others, the pandemic and its consequences are never ending.

Some will be re-evaluating their priorities and principles, in light of the challenges they have faced. There is a danger that these polarities in experience will lead to further divides in society.

Clinical psychology has a role to play in helping society understand different perspectives and positions. This is important given the ever-changing world we live in.

Whether we are considering global warming, social divides, stigma faced by the people we support or the ongoing pandemic; we all need to find ways to align our priorities to work together.

Within NHS practice and training, clinical psychologists are also experiencing huge change as the implications of the long-term plan and subsequent policies are felt.

The challenge remains for us, as ever, to translate the wider changes in society into what is most meaningful to those we support in our work. This can become harder when it feels that the landscape in which we work is continually shifting.

The question then arises; how do we maintain momentum in the face of threat and uncertainty?

We are delighted to be able to confirm three of our Keynote speakers:

Professor Deborah Lee from Berkshire Traumatic Stress service brings her expertise in trauma and compassion to the issues of leadership.

Professor Victoria Tischler from the European Centre for Environment and Human Health in Exeter, will share her innovative research and passion for the power of creativity at times of challenge.

Dr Lucy Johnstone, Consultant Clinical Psychologist, sharing her insights into social justice as a mental health trainer and campaigner, and co-lead of the Power Threat Meaning Framework.

The conference will include discussion of approaches that have emerged over recent times, to support those who use, and those who provide services, across diverse and often challenging environments. As we look towards the year ahead, we invite insights into how we can maintain momentum as a profession, in the presence of the threat and uncertainty still felt by many.

This will be a virtual live-streamed event, enabling speakers and delegates to join and contribute to the discussions from wherever they are.

The conference programme will be varied, offering a range of papers, symposia, posters and short 7-minute presentations.

To book your place:
https://www.bps.org.uk/events/dcp-annual-conference-2022/registration

Dr Roman Raczka
DCP-UK Chair

A public health crisis is a disability rights crisis: Health inequality and ableism in the pandemic

Runa Dawood, Daisy Sunderalingam & Veronica Ranieri

Whether we identify as disabled or not, the pandemic has brought issues relevant to disability rights to the forefront of our minds. It is timelier than ever to develop an understanding of disability rights concerning the pandemic. This opinion piece describes disability challenges during the Covid-19 pandemic. Person first language is not adhered to here, in line with conversations in the disability rights movement (Botha et al., 2021). It is important to note that in conveying disability experiences during this period, it is understood that no two experiences are the same. Similarly, disability is a broad term, and the pandemic may have produced differing needs across areas of disability, such as physical and mental health and intellectual disability. Our hope is in beginning a conversation around the intersections and nuances of these issues.

Living with a disability during the Covid-19 pandemic

THE challenges of the pandemic on people with disabilities are multitudinous. The risk of illness and loss of life may be disproportionately higher for certain people with disabilities (NHS, 2022). Other burdens of the pandemic which have disproportionately impacted marginalised groups include economic challenges, lockdown, isolation, distancing, vigilance with hygiene and sanitation, as well as increased social inequalities, including amplified discrimination, racism and negative impact on work, employment, and social systems (Devakumar et al., 2020; Office for National Statistics (ONS), 2019). In a recent survey conducted by one of the authors, disabled individuals reported significantly higher levels of depression, anxiety and stress than the general population, arising from the first and subsequent lockdowns (Ranieri, 2022, 2021). When accompanied by disruptions and increased difficulty in accessing health care, an exacerbation of health conditions may result and, in turn, affect psychological wellbeing (Drum et al., 2020; News, 2020). Such lower psychological wellbeing amongst disabled people has been linked to greater loneliness and isolation (Rotarou et al., 2021; Sharpe et al., 2021).

Whilst isolation is common amongst disabled people (ONS, 2019), disabled individuals also had a different relationship with lockdown restrictions. Disabled people reported significantly higher levels of perceived pressures in relation to staying home during the first lockdown. Conversely, disabled respondents also reported significantly lower levels of perceived coercion than non-disabled people arising from lockdown. These findings indicate that disabled people were more likely to report that it was their choice and idea to stay at home, and that they felt they had more control over whether they stayed home, during the first lockdown. It is possible that these perceptions were linked to a greater sense of safety and familiarity from being at home. However, they also highlight that disabled individuals experienced more inducements, offers, force or threats made by others towards them in relation to staying home during lockdown. As lockdown eased, such pressures continued, as disabled people reported a greater push by others to leave the house. Such findings may suggest that disabled people's needs and wellbeing were overlooked by those around them and that lockdown policies may have provided a sense of safety rather than coercion for this group.

Ableism in the Covid-19 pandemic

Since the Coronavirus outbreak, we are seeing that individuals who would not normally identify as disabled are also suffering some of the constraints of living in a world that is ill-equipped for their health needs, including the associated emotional impact of having such health needs (Maison et al., 2021). Examples of this pertain to the need for accessible work or study adaptations, vigilance of health symptoms and adoption of additional precautionary measures, and preparation for isolation and the emotional impact of such isolation. Managing additional anxiety and fear regarding whether others, governments and our society will take care of us, if we became ill, were commonplace. The pandemic has emphasised our reliance on one another and shared similarities.

Nevertheless, a key difference remains. For those who have a longstanding relationship with disability; physical isolation and anxiety over health, would have previously not been a shared narrative with the societal mainstream, but instead would have been tied in with narratives of marginalisation; i.e. the notion that certain individuals do not have the same human rights or access to society as others and are implicitly deemed less important based on ability. In these troubling times we see these dynamics of marginalisation maintained, as echoed across social media in the sentiment that people *'shouldn't worry, because it only really impacts older adults and those with pre-existing health conditions'*, communicating that at-risk groups are worth less or are expendable. Those who are at high-risk of experiencing serious health consequences if they were to develop COVID, find themselves disproportionately reliant on others who hold power over their safety. They are reliant on the majority of individuals to adhere to guidelines and reliant on those setting the guidelines to consider them. Disabled people are also relying on others to be advocates for the importance of their survival and existence.

Furthermore, the seriousness of disabled people's concern requires acknowledgement and validation before moving towards alleviation. People deemed 'high-risk' in this pandemic will likely be experiencing high levels of anxiety, understandably as they are also subject to greater levels of a real risk. For individuals with health conditions there has been a domino effect; the heightened public risk will not just have an impact on their personal risk, but also an impact on access to routine medical treatment, carers, transport and other sources of support (Thorlby et al., 2020). It's important that in our hopes to help alleviate painful levels of anxiety, we aren't invalidating normal fear responses to actual threats, particularly for those, and the loved ones of those, who are at higher risk of such complications. When considering the impact of social isolation, it is important to note that such individuals may have resources from lived experience on how to manage isolation.

Disability marginalisation is highlighted in instances where disabled individuals have asked for access to work, to study or participate in society – and have been met with barriers (Ryan, 2021; Trainee letters, this issue). They have historically struggled with access to education or accessible working (Burchardt, 2005; Young-Powell, 2019). Regarding the current adaptations provided in the light of this pandemic – when applied nationally and globally – remote working adaptations, for example, are not currently perceived as 'unreasonable'. The pandemic has therefore highlighted a 'double standard' that exists when applying provisions for those with disabilities versus wider society. In a similar vein, calls to 'return to the office' stand in contrast to the ostensible flexibility and accessibility that has been offered during the pandemic, as disabled individuals may find themselves pressured into unsafe situations and deprived of the temporary accessibility that had been granted. Furthermore, non-adherence to the societal expectations of getting 'back to normal' has entrenched previous stigma towards disabled people: encapsulated in a notion echoed over social media, that protecting disabled people impinges on people's rights to return to a pre-pandemic existence. This reflects a form of scapegoating that we have seen across minoritised groups during the pandemic, for instance, in relation to vaccine hesitancy (Bhanot et al., 2021; Morgan, 2021).

Psychological contributions during the pandemic

One objective for psychologists is to look for evidence-based resources and pointers to help the public with managing the psychological impact of the pandemic. This is problematic when psychology typically has a long-standing punctuation of understanding disability predominantly in terms of individual impairment, conceptualising suffering as derived from apparent individual, rather than *social* burdens. The Social Model of Disability (Union of the Physically Impaired Against Segregation cited in: Oliver, 1990) turns this narrative on its head, by arguing that individuals are disabled due to an inaccessible society, rather than the perceived limitations of their own bodies. Under this lens, disability is framed as something forced upon people by way of exclusion through societal barriers such as discrimination, segregation, inaccessible transport and housing (Oliver, 2009). The value of this perspective consists in its ability to allow individuals to externalise the difficulties associated with disability and alleviate personal pressure to adapt to normative societal expectations.

Though this may sit uncomfortably with many psychological interventions aimed at understanding and alleviating intrapsychic suffering, using psychology to understand and work with disability requires an understanding of the complex interactions between these different systemic aspects. Furthermore, it is the cultural contexts, for example neoliberal capitalism, that create ableist frameworks around such psychological work (Goodley & Lawthom, 2019). In the pandemic as an example of this, we have seen the urgency to prioritise resources, finances and even lives based on ability. It is imperative to consider social disparities and explore how intersectional identities such as race, class and gender, may impact differentially on disabled people (Gillborn, 2015).

To further stress the politically charged and oppressive related nature of cultural behaviour in the pandemic, we have seen the intersectional links with these issues of disability discrimination in relation to racism, for example in the Public Health England report citing race as a factor of COVID vulnerability (PHE, 2020), over the incidence of those from marginalised ethnicities being forced into high-risk work and social situations. Black and minority ethnic people disproportionately became critically ill with confirmed coronavirus (ICNARC, 2020), racism and discrimination, including microagressions and violence, was also amplified towards East Asian communities, and discrimination towards Chinese people specifically increased (Coates, 2020; Devakumar et al., 2020; Sohrabi et al., 2020). A further intersectional impact exists for class, where we have seen economic deprivation increase the risk for those from vulnerable health groups in the pandemic due to challenges related to work, care and the additional financial expenditures of living within a pandemic (Zarkov, 2020). Poorer populations have been made more vulnerable by limited access to resources, employment and suffering impractical benefit schemes (Ahmed et al., 2020). Therefore, integrating social model thinking into psychological perspectives is required within and beyond the pandemic, linking seamlessly with intersectional, cultural and economic perspectives.

How psychologists can help

In psychology, we can do a lot to understand these tensions and focus on the experience of oppressed groups by advocating against marginalisation, in order to achieve social justice. We can also refrain from contributing to marginalisation through interventions that hold an awareness of the disability rights movement. Whilst we currently have a role in supporting the public with Covid-19-related anxiety and low mood resulting from self-isolation, we can draw on the wisdom of those who identify as disabled by understanding how they have historically coped with such difficulties. A key aspect of isolation is that we are globally isolating together and the narrative around it is not one of marginalisation and exclusion based on a protected characteristic; social isolation is overlapping but separate from social exclusion, as the latter conveys marginalising rather than challenging circumstances.

Whilst these disability issues emphasise the challenges for those who are at high-risk from COVID, these issues are not exclusive to physical health, and it's important to highlight the impact specific to mental health conceptualisations and provisions during the pandemic. For example, those with serious and enduring mental health difficulties have received similar stigma surrounding their additional needs during the pandemic. Isolation may in itself hold serious consequences and the right for specific adaptations should be viewed in light of overall disability rights. Paradoxically, the media has portrayed these needs against wider society's despondence with lockdowns, undermining mental health needs and perpetuating an unhelpful dichotomy between the needs of those who have physical versus mental health risks during the pandemic. We can therefore ask ourselves as psychologists: in what ways can we provide support around mental health and wellness, without neglecting the aspects of this pandemic that amplify the experience of marginalisation for high-risk or other vulnerable groups?

Therefore, whilst the current context has created various narratives of stigma, discrimination and divide, it is important for psychologists to use these experiences to come together and advocate for equality and social safety whilst acknowledging the stressors and unique needs for groups that possess social inequalities (Marmot & Allen, 2021). This requires holding an intersectional perspective at the forefront of our thinking and utilising disability narratives to enhance, rather than take away from, developing an in-depth understanding of the multitude of challenges experienced during the pandemic.

Final thoughts

A global crisis may shift our collective attention to finding physical safety, but it does not dissipate, and perhaps instead excaerbates, reports of marginalisation. Whilst we need to work together globally to confront this crisis we can also work together to ensure that everyone is protected equitably. Disability issues are not exclusive to those who identify as disabled; we are all, at least to some extent, conscious of the possibility of acquiring disability and, in the UK, protected by the Equality Act 2010 (2010) in ill-health. We would hope in such situations to feel safe and cared for by society. Disability rights are for all and are also pertinent to (and impacting upon) just about any individual who cares for, is related to or is a friend of someone who is disabled.

This piece is written in part to communicate the difficulties encountered for those who continually fight for access and equal rights, to critique how this is conventionally framed in psychology, and towards more thoughtfully considering broader experiences of marginalisation. Whilst clinical psychology has a role to play in supporting mental health, it may also have an important role in advocacy for marginalised groups, in terms of advocating on individual, research, consultancy and policy levels. The hope is that during this pandemic, whilst pressures increase and anxieties are raised, we can acknowledge the additional needs of vulnerable groups in society. It is also a hope that we can learn from disability communities and from their frustrations, not only in coping with the constant anxiety around health and the ongoing distress of isolation, but in learning how to make society more accessible for everyone in the future, even after the immediate (and heightened) Covid-19 pandemic has come to an end.

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Ableism 101

Nick Wood

Clear Summary

- We give a Background to the Topic
- We discuss what is 'Ableism'?
- We give some examples.
- We talk about what we might do, to change Ableism.

Background

WHEN it comes to disability – it is more often a question of when it will happen – not if. The 'open-enrolment' nature of disability may be part of the reason ableism has been such a contentious topic, even among experts who study stereotyping and prejudice. According to US projections, given a 75-year life expectancy, current newborns will average 11 years with disabilities that limit their activities, (Nario-Redmond, 2019). For those who live past 75, they can expect an additional four to five years of disability (Melzer et al., 2000) – and this is within the most privileged and resource available corners of the world, i.e. (Western, Educated, Industrialised, Rich and 'Democratic': WEIRD countries).

The concept of disability itself is highly contested (McDermott & Turk, 2011). Who qualifies as 'disabled' – and who does not – continues to be a moving target, since defining characteristics change depending on the source, setting, and historical time period – let alone shifts within the same individual, depending on when, where and with whom they are interacting. For this reason, many definitions of disability focus on supposedly 'concrete' age or developmental specific activity restrictions related to self-care (e.g. bathing, dressing) and other activities of daily living (e.g. managing money, shopping). Questions about activity restrictions typically focus on what people cannot do, i.e. 'deficit' models (e.g. 'Can you get outside the home?'), which often fail to account for the use of technologies and other (potentially available) modifications, such as the relative lack or availability of ramps to and from a wheelchair user's destination. Underlying this view is the notion that disability has an intrinsic 'essence' which inhabits an individual, damaged body - rather than fluidly existing within embodied socio-cultural contexts, where the shifting social (and political) realities can either aid or impair (and often both).

Definition

The term ableism emerged out of the disability rights movements in the United States and Britain to serve as an analytical parallel to sexism and racism, for those studying disability as a social construction (Wolbring, 2012). With interdisciplinary origins, ableism has been defined as 'ideas, practices, institutions, and social relations that presume able-bodiedness, and by so doing, construct persons with disabilities as marginalized… and largely invisible "others"' (Chouinard 1997, p.380). Nario-Redmond (2019) described the 'A, B, C's of ableism' as (a) Affective emotions or attitudinal reactions, (b) Behavioural actions/practices, and (c) Cognitive beliefs/stereotypes, which go beyond general negativity. An example offered was the emotional emergence of disgust or pity (affect), followed by an offer to 'help' or simply avoid (behaviour) – especially if one believes the person with a disability must need assistance or cannot think clearly (cognitions). (Although the terms overlap, 'disablism', on the other hand, is active disability focused prejudice: Simpson & Thomas, 2015.)

Yet ableism affects the apparently 'able-bodied' too, as many impairments are not physically apparent in, or on, the body. Alternative definitions describe ableism as 'a doctrine that falsely treats impairments as inherently and naturally horrible and blames the impairments themselves for the problems experienced by the people who have them' (Amundson & Taira, 2005, p.54). According to Hehir (2002), ableism is 'the devaluation of disability that results in societal attitudes that uncritically assert that it is better for a child to walk than roll, speak than sign, read print than read Braille, spell independently than use a spell-check, and mix with nondisabled kids as opposed to other disabled kids' (p.2).

At its core, ableism contributes towards disability oppression, by privileging a nondisabled perspective and (implicitly or explicitly) promoting the inferior and unequal treatment of 'disabled' people (Campbell, 2009). Ableism is premised on a 'normative' and aspirational ideal that not only includes 'fit' able-bodiedness and rational mindedness, but may also implicitly include additional intersectional 'desirables' such as youth, masculinity, wealth, thinness and whiteness (Dirth & Adams, 2019).

The possible processes of ableism

However, like racism, ableism can operate at multiple levels affecting personal self-perceptions, interpersonal interactions, and intergroup relations. Like these other prejudices, there are both individual and institutionalised forms of ableism and discrimination as well (see Brown & Leigh, 2020, for free access to *Ableism within Academia*). These forms may vary both within and across countries (Rohwerder, 2019; Scior et al., 2015; Swartz, this issue). Even though anyone and everyone can become 'disabled', disability carries a disadvantaged and marginalised minority status with a horrifying eugenics history and legacy.

Disability experience is influenced by intergroup power dynamics and the material environment, in ways that shape ableist attitudes, stereotypic beliefs, and discriminatory behaviours (Dirth & Adams, 2019; Nario-Redmond, 2019). As an example, one obvious ableist lens is the neoliberal myth of meritocracy; that is, everyone achieves as to their 'innate' ability and worth. Those who struggle to survive 'at the bottom' are almost always those hampered by structural, ideological and physical/embodied barriers – and are then accordingly deemed as less 'capable' and accordingly of less 'value and worth,' with opposition towards providing them meaningful support (Goering, 2015).

Disability prejudice is varied in expression and in particular, can be 'benevolent and kind', paternalistic, pitying, and inspired by 'charitable' intentions that nevertheless allow for the justification of control, restricted rights, and dehumanising actions. For example, as more disabled people are gaining employment and access to higher education, ableism in the form of jealousy and suspicion can emerge, especially when accommodations are framed as 'special privileges,' such as extra time on tests and parking permits. (Perhaps somewhat akin to some white views on 'affirmative action' within unequal racialised societies.) Disabled people at the receiving end of this prejudice and jealousy may internalise these media dominant ableist beliefs and further feel underserving and fraudulent – an excellent recent review of 'self-perceptions' and coping with stigma within the autistic population is provided by Han, Scior, Avramides and Crane (2022).

Further Examples of ABLEISM:

- 'Non-disabled' people failing to consider their standpoint – e.g. occupying disabled toilets, parking spaces etc.
- Disabled people seen as 'broken', i.e. dependent, needy and incompetent — general advice is to ask before helping – and wait for permission.
- Feeling entitled to know how people became disabled. 'So what happened to you?' (Perhaps akin to the not infrequent white response to people with darker skins, in white majority Western countries: 'so where are you from – no, I mean really from?')
- Being 'inspired' by 'bravery' narratives from disabled performances – and expecting disabled people to conform to bravery narratives. (This is usually experienced as condescending and patronising.)
- Starting from disbelief and assuming disability is always visible, e.g. 'But you look so well!' (The underlying belief often perceived is, 'perhaps you're making it up for pity?')
- Through unthinking use of language: 'Figures of speech': e.g. 'the lame leading the blind.'

All expressions of ableism only serve to reinforce damaging stereotypes, discourses and 'normative' power imbalances within current social structures and are generally harmful to those impacted (Hackett et al., 2020). Clearly, as psychological professionals, we need to be cognisant of our own underlying assumptions, beliefs and attitudes, as these can also be harmful and damaging for those we interact with, as well as unwittingly collusive with oppressive (ableist) power structures. One example we have attempted to be careful about, in this issue for example, is finding ways to respectfully represent the voices and experiences of people with 'learning disabilities' – whose voices are often obliterated by well-intended professionals speaking 'for' them, sometimes after ascertaining 'cognitive inferiority' (Grant & Grieve; John, Richie & Theodore, this issue.)

So what can we do about ableism?

i. From the personal to social: Finding the path

Apart from our own personal work confronting (our own fear and 'projected' disgust of) disability, there is a need to *become aware* and *challenge the operation of ableism in the spaces around us* – i.e. disrupting the 'normative' (and exclusionary) expressions of ableism. We need to be more aware of what unseen barriers are operating towards full participation – and finding ways of reducing these barriers to increase both access and representation. Bringing disability into 'normative' spaces does not just mean mainstreaming or having a token public or media presence for people with 'disabilities', it also means challenging ableist perceptions and values.

One example of this occurred during a British Sign Language (BSL) course I undertook, as part of my doctoral thesis on 'developmental Deaf cognition'. Our tutor was profoundly Deaf herself and a native BSL signer – she told us her Deaf daughter was pregnant and they were both hoping her unborn child would also be Deaf too. There was a gasp of horror from some of the learners and I too, found myself (internally) querying this expressed wish. A conversation ensued – mostly in our tutor's second language, spoken English – and the full extent of all of our ableist views were exposed. Implicit in our assumptions is that what we perceived as a 'disability,' should not be reproduced. For our BSL tutor, though, Deafness was the (aspirational) norm – and our use of spoken English could potentially have excluded her, or reduced the power of her conversational voice.

It is clear that along with representation there should also be changes in what is valued, as a more complete representation of the diversity of being human – effectively a decentring/transformation of 'able-bodied' constraints, values and current hegemony (Ubisi, 2021). This means legitimising (and valuing) different stories and forms of embodiment (Loja et al., 2012). For an active resource around this, see Alice Wong's (2020) *Disability Visibility Project.* We need to encourage and support stories of resistance and change from 'the margins' of ability (Wong, 2018).

What is also needed is making visible the currently invisible – that is, fostering hidden stigmatised identities to not only allow revelation, but perhaps, even cherishment of difference? The majority of disabilities are not overtly apparent, but the road to disclosure is fraught with shame, fear and risk (Tay, et al., 2018). The benefit shaming of disability and trial by media further fuels discourses that attempt to discredit and undermine the experiences of disability, adding to its distressing experiential weight (Saffer & O'Riordan, Allan et al., this issue).

It took me several years before I revealed to my employers my own various chronic illnesses and acquired disabilities – the delay was out of fear I might lose employment or be seen as 'broken' and inferior (internalised ableism). But there came a point when I realised in order to function I needed support – and that required taking the risks of occupational disclosure. (The Equality Act, 2010, is a blunt tool and not always an effective deterrent to prejudice and discrimination.) For me, it worked out, but I also carried various other intersectional privileges that assisted with this, not least being a white cis-het male with professional status and means, albeit currently disability retired. Those at the most brutal cutting edge blade of ableism are the 'disabled' who are also black, women, queer, impoverished, etc (Whitesel, 2017; Johnson & Carroll, this issue).

ii. From the social to the global: The road to equality and justice is both broad and long

Disrupting 'Normative' Spaces – Disability Justice and Activism:

Political activism around disability rights may have shifted public perceptions to some extent towards greater 'tolerance' – as well as engendered some degree of legal protection – but this is far from a battle won (Dixon et al., 2018; Nario-Redmond, 2019). Two recent BBC Documentaries in 2021 (*Silenced* and *Targeted*), for example, emphasised the brutal ongoing violence (both overt and covert) towards many disabled people.

There is a need for the profession – and ourselves as psychologists, whether disabled or not – to explicitly and consistently support disability rights and presence and to find ways of fostering this. (I am not aware of any research into the effectiveness of the 'double tick' system for 'disabled' applicants into clinical psychology courses, for example – and would welcome any information about this.) However, it would not surprise me if, even here, the playing fields are not level, and certain disabilities (e.g. dyslexia) are accepted above those requiring additional personal care, perhaps. That is, certain disabilities are perhaps seen as more 'acceptable' than others – with perhaps more readily available 'reasonable adjustments' – and with cheaper cost implications?

This official support (or 'allyship') needs to extend into personal and clinical/social spaces too, where effective ways of challenging varied expressions of disablism, racism etc., need to be taught, to build a kinder and more inclusive community. This may include work with clients, peers, supervisors, within public spaces and institutional hierarchies etc., (Paluck, 2011). This is in keeping with the BPS ethical code – and, interestingly enough, perhaps even more in keeping with 'relational ethics,' which emphasises ethical issues as emergent in our relationship with others (including the Earth) and as not necessarily internal attributes that are 'permanently owned' (Mapitsa & Ngwato, 2020; Metz, 2022). Relational ethics have emerged from a number of African systems of thought and practice that emphasise the 'we-ness' of being – as opposed to the individual narcissistic bubbles of neoliberal capitalism (Weintrobe, 2021) – and is a reminder of how much Western psychological models have to learn from 'elsewhere' too (Ratele, 2019).

Finally, it is clear that disability permeates all sections of society and that the Disability Struggle is an integral part of all struggles to create a more just world – we not only need to 'mainstream' disability and build solidarity around us, but find ways of harnessing overlaps with intersectional global struggles too (Davis, 2016).

Conclusion

It is clear that we need to be aware of – and, wherever possible, adopt an active stance towards socio-political issues, that both constrain and shape our own (and others') cognitions/experiences, wellbeing and mental health (Bhugra et al., 2022; Sloan & Brush, 2022). Growing up during apartheid in South Africa, for example, it was apparent to me there could be no neutral or 'objective' position, as 'fence sitting' was a confirmation of the status quo – and, to paraphrase the *South African Council on Sport* during apartheid, there can be 'no normality in an abnormal society.' The idea of psychological models being predicated on 'universal and objective truths' is one riding on an outdated and over-simplified view of science, not fully acknowledging the constraints of (WEIRD) positionality and the inherent limits of human theorising (Saini, 2019; John, 2021). We need to fully realise how much western models and perspectives have been shaped by the white colonial enterprise and emergent capitalism – one of the architects of apartheid in South Africa, the assassinated Prime Minister Hendrik Verwoerd, was a psychologist – and he used psychological 'evidence' to justify the social engineering of apartheid, i.e. in terms of 'varied racial abilities' in intelligence (Nicholas, 1993).

Within disability this notion of varying ability has been reinforced by the use of language – it was not long ago the term 'deaf and dumb' was phased out of use, for example. 'Disability' itself has been critiqued as a label of implied deficits, with euphemisms such as 'special needs' also found by some to be inadequate (Gernsbacher et al., 2016). The ongoing 'coloniality of disability' emphasises both (black) 'otherness' and impaired 'productivity', i.e. human value being primarily defined within the 'marketplace' (Swartz, this issue, Soldatic & Grech, 2016). Rao and Kalyanpur (2020) emphasise the implicit global colonisation by Western disability 'models' under a universalist guise, silencing local and indigenous knowledges, that may potentially offer more 'strengths based' and transformative possibilities.

Ableism is thus a largely invisible and historically resilient construct that negatively colours how we view a large swathe of society – a group which may well, in the long run, include all of us too. We need to continually examine our own beliefs and position with regard to both disability and the prejudices it evokes, perhaps undertaking (at times, as needed, with others) – a form of 'decolonising the mind,' interrogating our own 'ABC's' of disablism (Nario-Redmond, 2019; Wa Thiongo, 1986). That is, after conducting action (practice/teaching), ensuring embodied (self/supervised) reflection (and ensuing) learning, as potentially required components towards rupturing internalised (and external) ableist discourses and beliefs (hooks, 1994; Ktenidis & Wood, this issue). Continuously updated professional guidance, support and exposure to disability rights and the meaningful presence of disabled voices and bodies, may help to further disrupt (and shift) 'normative' spaces. What other ways can we learn about – and challenge – ableism, within our social and 'clinical' spaces? I recommend reading the voices and perspectives contained in this special 'Disability' issue for a start…

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The critical context of disability in the UK: Rachel's story is our story

Frances Ryan

I first met Rachel a decade ago, just after the UK government cuts first fell. The forty-four-year-old uses a wheelchair because of arthritis of the spine and joints, on top of a string of other health conditions – fibromyalgia, Crohn's disease and Lupus – and since 2006 she has relied on a care package from her local council to enable her to live independently in a bungalow in the New Forest. But as social care reductions spread across the country, in Rachel's words, her care was 'just getting cut, cut, cut'. In 2010, Rachel's local authority stopped her visit from a care worker who helped her get ready for bed. Her cleaner and gardener went a few months later. The following year, they pulled her evening care call too, which meant the end of her having a hot dinner.

In 2018, for my book *Crippled* (Ryan, 2019), I went back to see Rachel and how more government cuts had impacted her life. To survive, she'd been living off stored casserole she cooked on 'good days.' Other days, she ate fruit or slices of bread. In the years since we last spoke, Rachel had lost her remaining piece of care: the assistant who helped her get up in a morning. She'd been told she could keep it if she paid her council £200 a fortnight. In theory, disability benefits would cover some of the cost but in austerity's onslaught, nothing hits alone: the same month Rachel was handed her social care bill, she was transferred to the new Personal Independence Payment (PIP) (BBC, 2013) – and promptly had her benefit cut.

Rachel hadn't been able to earn a wage since the late 1990s – before becoming disabled, she worked as a nurse to the elderly – and with no way to pay her council's costs, she had her support package entirely removed. 'I've no care at all now,' she told me. 'Nothing.' With no carer to help her cook, Rachel's GP said she was now malnourished. Rachel is often too weak to transfer into bed herself, and without a care assistant she has no way to move. On her worst nights, she sleeps in her wheelchair.

It would be convenient to believe that what happened to Rachel was a one-off, a sad but ultimately rare blip in an otherwise compassionate and fair system. But in reality, it is emblematic of what we might call Britain's systematic removal of support for disabled people in recent years – or in the words of the United Nations in 2016, the 'grave and systemic violations' of disabled people's rights (UN. Committee on the Rights of Persons with Disabilities, 2016).

From the election of the Coalition government in 2010, over the course of a decade, services for disabled people have undergone a cacophony of cuts: including the bedroom tax, abolition of Disability Living Allowance (Gentleman, 2011), the rollout of Employment and Support Allowance (Gentleman, 2011), the closure of respite centres (Clegg, 2018), and welfare rights help (Ryan, 2017), as well as the mass underfunding of the NHS and social care system (NHS Support Federation, 2021).

Such rights had been hard won by disabled activists and their allies over the last seventy years, all the way from the 1940s' formation of universal healthcare through the NHS to the 1990s and the Disability Discrimination Act (Disability Discrimination Act, 1995), enshrining disability rights into British law for the first time. Disabled people who for centuries had been excluded from society – institutionalised or forced to rely on piecemeal charity – were now increasingly welcomed into education, the workplace, and the public sphere.

This is not to view the past with rose tinted glass. Even with the advent of state support and legislation, many people with disabilities in Britain continued to face stark inequality. But it is to say that much progress had been slowly achieved. From a period where disability was seen as a personal failing and place for philanthropy, increasingly, disabled people could rely on a safety net to help in times of need.

It is remarkable how quickly gains can start to be lost. Buoyed by the global financial crash of 2008 and a political climate in which the economy's ills were blamed on a 'bloated benefit bills', the newly elected Conservative-Liberal Democratic government and media alike targeted the so-called disabled 'scroungers' (Walker, 2012). The scale of this was staggering – and in doing so, pulled vast sums of funding from multiple strands of disability support. Research carried out by think-tank Demos and the disability charity Scope estimates that by 2017–2018 about 3.7 million disabled people would collectively lose £28bn as a result of the reforms (Butler et al., 2013).

The consequences of this over the last decade are undeniable. By 2021, Boris Johnson was announcing a widely derided social care plan (Walker, 2021) that contained no real help for funding or quality of services, whilst wheelchair users were left waiting 14 hours to get to the toilet (Gregory, 2015). As disability benefit cuts hit, 75,000 disabled people were forced to give up their benefit-leased cars between 2013–2018 (Bloom, 2018) and with it, their only chance of independence. Economic hardship only deepened; a further 300,000 disabled people across the UK were plunged into 'absolute poverty' by the fourth year of the Coalition government (Gall, 2015). Meanwhile, more than six in ten people referred to food banks in early 2020 were disabled – three times the rate in the general population (Weekes, 2021).

Throughout it all, however, disabled people have been at the forefront of the fight back, challenging government repeatedly in the High Court (McVeigh, 2016; & Disability Rights UK, 2021), protesting outside – and even in – Parliament (Weaver & Perraudin, 2015), and lobbying for legislative change from their beds (Ryan, 2014).

In the early months of 2020, coronavirus brought a new obstacle to disabled people. Those who had for the last decade endured squeezed services from austerity suddenly found themselves facing the sharp end of a pandemic – simultaneously at greater risk of coronavirus than the general public, while least likely to be able to access food and medicine, as they were forced to shield at home for months.

At the same time, emergency measures to shield citizens from the economic fallout of the pandemic, such as the temporary £20 Universal Credit uplift (Holland, 2021) noticeably missed out many disabled people. Charities subsequently warned that hundreds of thousands of disabled and chronically ill people faced being pushed into poverty, after being left out of emergency measures to bolster the social security system, simply because they were on an older form of benefit (Butler, 2020).

Similarly, emergency coronavirus legislation sparked concern among many disability organisations – most notably over the bill temporarily removing the legal duty on councils to provide social care to all who are eligible (Disability Rights UK, 2020). Disabled people who were already living with a stripped down care service after years of cuts now faced a further loss of rights, with 4.5 million additional people becoming unpaid family carers in a matter of weeks in the pandemic, to fill the cracks (Carers Week Research Report, 2020).

As I wrote in the updated version of *Crippled* at the start of the pandemic, for all the lab work and vaccine hunts, it is ultimately society itself that pandemics put under the microscope. The coronavirus laid bare the frailty of Britain's social contract after a decade of cuts – public services that had been starved of funding, millions of people in insecure and low-paid work, and a social security system unfit for purpose. In turn, it shone a light on some long-ignored truths: universal healthcare is a non-negotiable good; public services are precious resources to be invested in for hard times; each of our lives is more dependent on others than we may think.

It would be naive to suggest one event alone could alter attitudes to disabled people and the state, no matter how seismic. Indeed, whilst a new coronavirus variant propelled England deeper into the pandemic in winter 2021, the government were lining up yet more attacks on disability services: research by the Labour Party in December 2021 found the government's latest budget contained plans to make £70m of 'stealth' cuts for disabled people over the next three years (Chappell, 2021).

And yet it would be remiss to ignore the chance to learn lessons from the last two tumultuous years – or indeed, the last decade. The pandemic fallout unequivocally exposed the myths at the heart of government cuts: ill health can happen to any of us at any time; the welfare state is not actually a drain or a burden but a precious form of collective insurance against life's challenges, including disability.

It is in all our interests to work to strengthen that insurance policy, be it building more social and accessible housing, increasing the rates of social security to meet the cost of living, funding the social care system and giving users more control over their care, to providing support to help disabled people into work if they are able and choose. Achieving this is clearly a long and difficult task but increasing the number of disabled people in power is surely one vital step; currently, the UK Parliament has just five MPs who self-describe as disabled (Pring, 2019), whilst fewer than one per cent of journalists have a disability (McEachran, 2012), despite disabled people making up 22 per cent of the general population. As the old disability rights slogan chimes: 'Nothing about us without us' (Wolff & Hums, 2017).

As the shadows of austerity and the pandemic loom, we are in many ways at a crossroads in British society: we could stay as we are and continue on the path of inequality and individualism or we can take a leap for real change, in which a society of equality and collectivism could see more disabled people have the opportunity to lead full, secure and dignified lives. It would be understandable to feel hopeless at this point but fatalism is as much of a danger. One of the greatest challenges to building a more progressive society is believing it is possible. In the coming months and years, Britain must channel such hope – and turn it into action. Rachel and the millions of disabled people like her depend on it.

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'People don't fit boxes': The responses of people with disabilities to the disability benefits system

Jessica Saffer & Emer O'Riordan

Easy read summary

- People with disabilities face more money problems than people without disabilities. These problems have got worse over time.
- This paper talks about two pieces of research.
- This research found that people with disabilities have problems with the benefits system.
- The authors give ideas for how psychologists can help people with disabilities.

Introduction

POVERTY is a significant problem in the UK, with growing inequalities affecting the financially deprived and societally marginalised most sharply, including people with disabilities (Duffy, 2017). People with disabilities and their families are known to have higher costs of living than the general public (Scope, 2019). Inflation increases and cost of living are also at an all-time high (Office for National Statistics, 2021, 2022), which undoubtedly leaves people with disabilities in precarious financial positions following over a decade of cuts affecting services which support them.

The 2008 global financial crisis led to economic recession in the UK and the introduction of austerity measures by the government (Gamble, 2009), although the long-term reduction in benefit and social care funding started before 2010. The austerity programme led to social welfare cuts that disproportionately impacted the most vulnerable in society (Psychologists for Social Change [PSC], 2016). Of those impacted, people with disabilities were particularly affected by austerity measures (Duffy, 2014), with cuts to local government leading to tightened eligibility criteria for access to social care support, as well as overall reductions in benefits (Malli et al., 2018).

The changes to the benefits system have resulted in many claimants being subjected to reassessments for their benefits, stricter assessments, and harsh sanctions, leading to numerous claimants having their benefits cut (Beatty & Fothergill, 2015; Grover & Soldatic, 2013). Alongside welfare reform, a narrative of 'strivers and skivers' intensified (Afoko & Vockins, 2013, p.4), possibly fuelled by contemporary policies. This increased the stigma associated with claiming benefits and the media representation of people with disabilities becoming that of 'scroungers' (Briant et al., 2013).

The particularly harsh nature of the austerity measures in the UK and their impact on the lives of people with disabilities led to The United Nations Committee on the Rights of Persons with Disabilities (2016) inquiry. The report emphasised that the cuts encroached on the human rights of people with disabilities and perpetuated the negative public portrayal of disability benefits claimants. While stigmatising public discourses and a battle for citizenship and status have been present historically for people with disabilities, particularly those with learning disabilities, these worsen and public scrutiny intensifies during times of economic and political uncertainty (Keilty & Woodley, 2013). The cuts also increased health inequalities, with adverse effects on people with disabilities' physical health (Arber et al., 2014; Power, 2016) and on their mental health (Barnes et al., 2016; Cheetham et al., 2019). Austerity measures increased social isolation, while leading to reductions in wellbeing and autonomy (Malli et al., 2018).

While austerity measures in the UK were initially forecast to continue until 2014, this was extended to 2018 by Chancellor George Osborne (Kirkup, 2014). Subsequently in 2018, the Prime Minister, Theresa May, indicated that the extended austerity programme could end in 2019, following the UK's exit from the European Union (Stewart, 2018). However, while austerity was declared as ended, the social deficits resulting from cuts remained (Quilter-Pinner & Hochlaf, 2019) and there was no reversal to the extreme cuts (Wren-Lewis, 2020) or injection of money into the systems. Additionally, the Covid-19 global pandemic introduced new economic challenges and instability, and while short-term measures may have protected some benefits claimants, such as the increase in Universal Credit and Working Tax Credit entitlements, these have since been removed and the long-term economic response to the pandemic is uncertain (Emmerson et al., 2021). The programme of cuts has created huge deficits in services and without plans to restore funding and a drastic change in policy, services will continue to perpetuate a chronically unjust situation (Quilter-Pinner & Hochlaf, 2019).

Method

The current paper presents a reflective summary of the results of two clinical psychology doctoral theses which explored the experiences of navigating the UK benefits system for people with physical health disabilities (Saffer, 2017) and people with learning disabilities (O'Riordan, 2021). Saffer's (2017) study investigated the experiences and identity of people with physical health conditions who made disability benefit claims in the UK since 2010. The research investigated how claiming disability benefits affected individuals' daily functioning and physical health; emotional wellbeing; ability to participate or engage with their community; how others, including family, friends and members of the public, responded to claimants; and their sense of self. Informed by this study, O'Riordan's (2021) research asked these questions to people with learning disabilities. Both studies used interview data to develop grounded theory models (Charmaz, 2014). Fifteen participants with physical disabilities (Saffer, 2017) and twelve participants with learning disabilities and one family carer had individual interviews, and five participants with learning disabilities took part in a focus group (O'Riordan, 2021).

Results

While the results of Saffer's (2017; Saffer et al., 2018) and O'Riordan's (2021) theses were constructed within different categories and presented in different grounded theory models, they found that their participants had very similar experiences of the benefits system. The authors discussed the overlap between their categories and felt that the results could be understood and presented together under four interrelated themes. No data or experiences were left out, although some were recoded under a different category.

1. 'This flaming rollercoaster': Navigating a complex benefits system

In both studies, one of the main issues described by participants was the complexity and inaccessibility of navigating the 'circles and roundabouts' (O'Riordan, 2021) or *'wild goose chase'* (*Eve,* Saffer*)* of the disability benefits system. Claimants described a system that was dehumanising and unsuitable, as it was riddled with uncertain, inconsistent and confusing or *'gibberish' (Mary,* O'Riordan*)* processes and outcomes.

Some found it difficult to understand which benefits they were entitled to and felt that the system had become *'so confusing' (Adam,* O'Riordan*)* that even people who supported them didn't understand. The application forms were experienced as lengthy and *'very, very badly worded'* (*Irene,* Saffer*)*, causing difficulties for those with learning disabilities, mental health problems, and/or physical difficulties, for example those who found it difficult to hold a pen for long periods of time.

> *'You really need a blumming PhD to fill the blumming form in.' (Hazel,* Saffer*)*

> *'…everything needs to be put in easy read. Easy to understand, not just easy read…' (Tara,* O'Riordan*)*

Participants felt that the system was unsuitable for people who are unwell and for those who have fluctuating or degenerative conditions. They explained that scoring is through use of a points-based system, based on yes/no answers, which does not permit people to fully explain their conditions and the impact of these on their lives. Some felt that the system was geared towards those with physical disabilities, leaving participants with learning disabilities and mental health needs feeling disregarded.

> *'It's like they seem like they are just having a chat with you but they are not. Like everything that you say is assessed against a criteria.' (Oliver,* Saffer*)*

> *'…they want trick you up and catch you out.' (Yusuf,* O'Riordan*)*

When attending an assessment, participants referred to the assessor's lack of knowledge about particular disabilities and also told us that the assessment staff were *'not very clear' (Julie,* O'Riordan*)*. This lack of transparency was felt by some participants to have an insidious quality.

> *'… they will smile and act nice, but they're not.' (Daisy,* O'Riordan*)*

Additional difficulties were described when participants were not informed about changes to their benefits, the rationale for certain procedures and changes in the system. Some claimants described feeling shocked at discovering cuts to their own benefits when they noticed their money running out.

> *'I thought, money was still coming in, I thought, fine, terrific … but nah.' (Leon,* O'Riordan*)*

Participants described the precarity of the benefits system left them feeling *'like walking a tightrope…' (Adam,* O'Riordan*)* or as if they were *'on this flaming rollercoaster… up, down, up, down… going round and round' (Mary,* O'Riordan*)*. They reported feeling worried and fearful about how to navigate the system and there appeared to be a deep sense of distrust in the system, with claimants feeling anger and frustration.

2. *'We're a different species': Being judged and stigmatised in society*

Participants in both studies encountered societal stigma and judgment relating to their use of the benefits system as well as their disabilities. They described feeling implicated by the negative rhetoric that was associated with welfare reform, leaving them labelled as *'benefit scum' (Frankie,* Saffer). Implicit in these stereotypes was the view that participants were just *'sponging' (Katie,* O'Riordan*)* from the system or *'a benefit cheat' (Adrienne,* Saffer*).*

> *'I heard someone once, oh you're going out, oh you're on benefits, you shouldn't be going out…' (Daisy,* O'Riordan*)*

Participants felt that this rhetoric was maintained by negative media portrayals of people claiming benefits. This *'benefit porn' (Grace,* Saffer*)* was described as casting aspersions on the credibility of all benefits claimants and felt to be extremely stigmatising for participants.

> *'You look at the press it's always about the benefits. You know Channel 5 all their programmes: "Life on Benefit Street", "Holiday on benefits" and things like that… people believe it all.' (Adrienne,* Saffer*)*

Participants wondered whether such media enabled the government to *'justify all these cuts' (Bryony,* Saffer*)* and noted that while the public were aware of the negative discourses around benefits claimants, they were largely ignorant to the *'suffering' (Louise,* Saffer*)* of people with disabilities as a result of cuts.

Participants additionally faced stigma linked to their disabilities which impacted how others viewed them and interacted with them. This led others to '*look down their noses at you…' (Eve,* Saffer*)* and left participants feeling viewed as *'a piece of dirt you just picked up off a shoe' (Craig,* O'Riordan*).* Participants consequently felt devalued and dehumanised.

> *'There are definitely people with attitudes like maybe that perhaps see me as somehow less of a person and even just in the way that language is used in society.' (Molly,* Saffer*)*

> *'Having a learning disability, it's like… you're not part of this world or this community, it's just feels like… we're a different species to other people.' (Mary,* O'Riordan*)*

These perceptions of people with disabilities as lesser than others seemed to contribute to participants being infantilised and denied autonomy by the general public, their family and the staff and services who support them. While participants felt that the wider public were *'casting us out' (John,* O'Riordan*),* they also felt exposed to judgements based on how their disability was perceived by others and whether it was viewed as genuine.

> *'…mental health is always put to the bottom of the pile.' (Louise,* Saffer*)*

3. *'I'm a completely different person': Losing one's sense of identity*

Participants described feeling as though they had lost themselves through repeated interactions with a judgmental, stigmatising society and a complex benefits system which *'obstructs your day and your life' (Mabel,* O'Riordan*).*

> *'I used to teach and do reports. It's like I'm a completely different person. It's like your life's been taken away.' (Adrienne,* Saffer*)*

Participants were *'held in this climate of fear' (Caroline,* Saffer*)* which had consequences for their mental and physical health. Claimants felt *'really frightened' (Julie,* O'Riordan*)* of all interactions with the benefits system, feeling as though they were *'living on a knife edge' (Bryony,* Saffer*),* anticipating that they could face cuts or losses to their benefits at any time. The stress and worrying this engendered contributed to or exacerbated existing mental health difficulties.

> *'…it was my mental health 'cause I was thinking about – worrying about things, you know…' (Craig,* O'Riordan*)*

> *'I went into a low mood, I was becoming more depressed… like the sun's shining but all you see are dark clouds, and you cannae see any way out of…' (Dean,* Saffer*)*

Stress could have a knock-on effect on participants' physical health, and with limited finances and reduced mental and physical health, participants became isolated and limited in what kind of lives they could lead.

> *'…everything sort of, everything became small. Just me and my little estate.' (Grace,* Saffer*)*

Many experienced difficulties paying for necessities, and some had to make the difficult choice between eating and heating their homes.

> *'I wouldn't have been able to pay the electricity, the gas, the water bill, the heating bill and eat. It would have to be one or the other.' (Adrienne,* Saffer*)*

Many participants felt hopeless about their futures while claiming benefits but recognised that while they may want to move away from the benefits system, they could not survive without benefits.

> *'…want to get away from that system and you have to get it otherwise 'cause you won't be able to… pay your bills…' (John,* O'Riordan*)*

Some participants, while desiring independence from the system, feared it, as being perceived to be *'too able' (Christopher,* O'Riordan*)* could lead to cuts. Participants seemed to become caught in a 'dependence trap', whereby their negative experiences with the benefits system left them less confident about how to achieve the independence that disability benefits ostensibly aims to support.

Across the two studies, participants described shame and guilt attached to claiming benefits, with many being wary about disclosing to others that they were in receipt of benefits for fear of judgement. This shame was also internalised with participants adopting self-stigmatising beliefs about their use of disability benefits.

> *'Judgements come along with that [telling people I claim benefits]… Even my own self judgement.' (Grace,* Saffer*)*

Internalising the 'strivers or skivers' discourse left claimants feeling worthless, viewing themselves in terms of their work capability and perceived productivity.

> *'…people like me have no worth because I'm not producing right now in terms of making anything.' (Frankie,* Saffer*)*

> *'Am, with benefits, sitting on it, does kind of impact the way I feel because obviously I wanna just feel like I can go work, earn a normal wage and not have to rely on the benefits system.' (Katie,* O'Riordan*)*

The stigma associated with claiming benefits seemed to reinforce the stigma associated with having a disability, and left participants feeling they need to '*almost [apologise] for my existence.*' (*Molly*, Saffer) and feeling hyperaware of their disability.

> *'Because I didn't want to be like as I am in the first place.' (Michael,* O'Riordan*)*

Participants also noticed themselves judging the authenticity of other claimants, alert to potential *'fakers' (Josh,* O'Riordan*)* who might be fraudulently claiming benefits.

> *'…when you walk into an assessment office you see people on crutches and you think this guy has crutches but does he, is he putting this on when I really have a disability?' (Kelvin,* Saffer*)*

4. 'We just try and keep each other afloat': Fighting back

While participants described a loss of identity and resources, 'being consumed by the system' (O'Riordan, 2021), they identified a range of strategies to help them manage the difficulties they faced. For some, trying to *'accept' (Chris-*

topher, O'Riordan*)* the system and focus on *'the positive things'* (*John,* O'Riordan*)* enabled them to create some space for their own lives. For others, holding hope for a future move into employment or maintaining an identity separate from their disability and their use of benefits enabled this.

> *'Me, I'd rather have a job and be able to buy my girl better things and look after her better you know. I don't want to be taking money like this, just to live and buy food…' (Jonathan,* Saffer*)*

Participants drew on family, friends and professional help to manage the practical, emotional and financial difficulties engendered by the benefits system, as well as gaining a sense of solidarity from others in their community.

> *'…because they are in that same road, they are very helpful, nice and very understanding…' (Mabel,* O'Riordan*)*

> *'Cos so many of us are in this situation we just try and keep each other afloat really.' (Bryony,* Saffer*)*

Professional help was particularly useful when it helped participants overcome financial and practical issues they could not have managed alone.

> *'…she scrapped it [debt]' (Bob,* O'Riordan*)*

However, at times, professionals did not help, while third-sector organisations also suffered from cuts and were thus less accessible.

Some claimants were motivated by a *'fighting spirit' (Louise,* Saffer*)* that encouraged them to keep *'fighting it'* (*Julie,* O'Riordan*)*, with participation in this research being one way in which they hoped to enact change.

Political beliefs enabled participants to view the stigma associated with claiming benefits as being *'…just an excuse to get rid of the welfare state' (Dean,* Saffer*)* which '*scapegoated' (Caroline,* Saffer*)* people with disabilities. Participants felt angry about this, using this anger to fuel activism; through becoming self-advocates, contacting politicians, speaking to local media sources, and writing opinion pieces. Participants did this not only for themselves, but for the wider disability community and other benefits claimants.

> *'It's not just for myself, it's for everybody out there that is in the same position.' (Dean,* Saffer*)*

> *'…help people in the future make like people getting benefits less stressful' (Adam,* O'Riordan*)*

Summary

Participants claiming benefits in both studies spoke about the difficulties they faced when trying to navigate a complicated, dehumanising benefits system. These difficulties interacted with a social and political context where to have a disability and to claim benefits were widely disparaged. Participants found this left them not only living in poverty, which limited their lives, but also with a poor sense of self and identity. Despite this, many discovered ways of responding to the benefits system and society that sustained them.

How can clinicians respond?

These findings are of value to professionals who work with individuals with mental and physical health and learning difficulties. They provide insight into the ways in which psychologists can practice to alleviate some of the distress that can be associated with claiming disability benefits.

Participants in both studies highlighted the powerful impact of having support. In order to identify what support individuals may need, clinicians could routinely ask about benefits in assessments. Before addressing psychological needs through therapeutic work, clients' basic needs of security, shelter and access to food need to be ensured (Maslow, 1943). Psychological staff may need to signpost or refer clients to social services or third sector organisations that can support them to meet these needs. Connecting disability claimants to community-led peer support groups may allow them to meet others with shared experiences, gain a sense of community and enable them to become involved in their own self-advocacy.

Psychologists may use the power granted by their professional roles to provide important clinical advocacy for clients who are having difficulties with disability benefits claims and assessments, if other local advocates are not available, by providing formal letters, supporting clients to complete forms, appeal claims and attending assessments. There are several guides and examples of how such support can be offered (e.g. Hewitt et al., 2017; Watts, 2018), as well as other ideas of how psychologists could offer support through benefits clinics and training (PSC Southwest, n.d).

The detrimental impact of having difficulties with benefits claims on participants' mental health was evident in both studies. Stigma and judgement impacted on claimants' identities, exacerbating the distress experienced. Psychologists have valuable skills in meeting clients with warmth, respect, empathy and non-judgement which can provide an alternative experience to difficulties encountered within the benefits system and enable trust to be built. Psychologists also hold skills in formulating distress, and it is important to incorporate and validate the impact of the wider context when meeting clients who have experienced stigma and maltreatment in society and the benefits system. This may serve to reduce some of the stigma experienced by claimants, by seeking to appropriately contextualise problems outside of themselves. Psychologists can draw from a range of therapeutic approaches which may be particularly suited to externalising stigmatised discourses, addressing stigma and associated shame and building hope and values-based identities, such as Narrative Therapy (White & Epston, 1990), Compassion Focused Therapy (Gilbert, 2009) and Acceptance and Commitment Therapy (Hayes et al., 1999).

It is important to ensure that professionals are conscious of the impact of current socio-political context on the communities we serve and that we provide safe places of care for clients who have been affected by stigmatising discourses. Psychologists can support colleagues to draw links between individuals' mental health and the wider context, including through formulation sessions and consultation.

Psychologists occupy roles as both clinicians and skilled researchers, and it is important that the economic, social and political conditions which impact on people's wellbeing are adequately researched and that this is disseminated widely. However, Beresford (2016) has argued that there are limits to what can be achieved by simply highlighting distressing narratives to the public and assuming this will lead to change. Psychologists must be active in searching for solutions to the conditions that lead to the distress and challenging policies which threaten the wellbeing of marginalised groups (Kinderman, 2017). We can lobby at a national level to raise awareness of the harmful psychological impact of government policies and to challenge any potentially stigmatising narratives, and this may have a greater impact on the wellbeing of our society at large.

Both studies described here have attempted to draw attention to issues around claiming benefits for people with disabilities and to amplify the voices of participants with lived experience of this. As a profession and as clinicians, we must work towards practicing in ways which aim to address and alleviate the difficulties that benefits claimants describe.

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What researching the benefits system has taught us about being trauma informed when people encounter traumatising systems

Stephanie Allan, Helen Roberts, Moya Clancy, Vik Nair, Charlie MacKenzie-Nash, Karina Braekkan, Claire Matrunola, Maddie Blanche, Michelle Jamieson, Simon Stuart & Andrew Gumley

WHEN considering how people experience and communicate their psychological difficulties, it is well recognised that clinical psychologists should consider the broader historical, cultural, systemic, organisational, and societal influences (Karatzias & Buxton, 2016). Interactions with social security systems have the potential to be predisposing (Wickham et al., 2020), precipitating (Dwyer et al., 2020) perpetuating (Machin & McCormack, 2021) and even protective (Simpson et al., 2021) factors for people experiencing mental health problems which makes knowledge of the system of great relevance to applied psychologists. Many people claiming disability benefits for mental health problems in the UK report that the process is complex and can trigger feelings of powerlessness, threat, shame, humiliation, stigma and for some can be re-traumatising (McGrath et al., 2015; Ploetner et al., 2019). These interactions with the benefits system signal deeper intersectionalities of disability, poverty, culture, and identity and have profound implications for how clinical psychologists engage with and support people with experiences of claiming disability benefits.

In Scotland, all public service workers including mental health professionals are expected to deliver trauma informed care (The Scottish Government, 2021). While we acknowledge that trauma informed care is not an uncontested concept (Birnbaum, 2019), with the benefits system being potentially both traumatising and re-traumatising, it appears pertinent to consider how psychologists can support people they work with in a trauma informed way. Harris and Fallot (2001) propose that five main principles underpin trauma informed care: safety, trustworthiness, collaboration, choice, and empowerment. Safety is constructed as being both physical and psychological. Trustworthiness relates to transparency and consistency. Choice offers individuals control and personal agency, important in the context of trauma where individuals have previously felt they had no autonomy. Collaboration aims to re-address the inherent power imbalances that often exist within services and emphasises the importance for clients to be actively involved in their care. Empowerment offers a strengths-based approach within a validating environment where people's experiences can be communicated and understood.

We are a group of psychologists in the West of Scotland who aim to do research that expands understanding of psychological, social, and interpersonal mechanisms underpinning distress, which means taking a focus on the complex systems in which people reside. Our loose collective is underpinned by a belief that lived experience membership in our group is essential because we want to do research that is useful for people living with psychosis and other complex mental health problems. In this paper, we will consider key findings from the following three empirical studies through this trauma informed care framework:

1. A DClinPsy doctoral thesis exploring people's experiences of claiming Personal Independent Payment for Post-Traumatic Stress Disorder (Roberts et al., 2021).
2. A book exploring people with mental health problems experiences of sanctions (Jamieson, 2020).
3. A participatory social welfare study (Ploetner et al., 2019).

We will reflect on the research exploring people's experiences of the benefits system and consider the implications of these experiences for trauma informed clinical psychology training and practice. We will identify how the benefits system may block safety, trustworthiness, collaboration, choice, and empowerment and consider how psychologists can resist (or at least ameliorate) the impacts of these in everyday clinical practice.

Safety

Common from the research findings was the sense that claimants felt unsafe. Claimants felt that the DWP had constant and unboundaried access to their lives, which came with the ability to inflict harm, and as a result they lived with a sense of dread and threat. For example, many people spoke about a fear of finding a surprise 'brown envelope' which could mean being summoned to a medical assessment and then losing benefits. Others described the impact of being sanctioned:

> *'It's fucking frightening man… my mental health was rock-bottom. I mean, I've been in children's homes, young offenders, rehabs, detox, you name it man, I've not missed it! For them to go like that, right, boom! Sanctioned, man. You're like that to yourself, "Right, where do I go from here?' Where do I go from here?"'* (Jamieson, 2020, p.38)

Claimants accessing ESA worried that they would feel so much despair that they would kill themselves if found fit for work. In keeping with this, a recent report by the BBC found 35 people with mental health problems have died after the termination of their benefits (BBC, 2021). Claimants reported that the constant stress about losing their benefits had a cumulative negative effect on how they managed their wellbeing. Some went as far as to describe that it felt like being 'on trial'. Assessors asked questions about self-harm and suicide in a way that is traumatising, i.e. 'why haven't you killed yourself yet?', asked to see self-harm wounds/scars (Bloom, 2018) or asked invasive questions such as how often they changed their underwear (Hutcheon, 2021). Believing and validating the impact of people's negative experiences of claiming benefits could begin to facilitate people feeling understood and sow the seeds of psychological safety. For both trainees and experienced clinicians alike, these findings suggest a need to educate about the realities of the benefits system and to consider what blind spots we may hold when trying to hold a space that feels safe for claimants. Clinical psychology educators should consider specific teaching on the benefits system and include lived experience involvement in curriculum development. When working clinically, this sense of threat demands psychologists always consider the broader context. For example, feeling being watched can perpetuate fear and avoiding doing valued activities such as volunteering/engaging in hobbies which can in turn perpetuate continued psychological distress, loneliness, marginalisation, and isolation. Additionally, avoidance likely extends to areas which impact psychological research and development, including taking part in clinical research or patient and public involvement groups. Being trained in formulation means psychologists have a skillset to understand clients in the context of the broader political and societal situation of living in poverty (Ahmed, 2017). Clinicians who do not know much about the benefits system and its impact on the people we work with may feel uncertain and anxious when working with people encountering adversity. Therapist anxiety is linked with increased likelihood of therapist drift with anxious clinicians even going as far as to decrease key therapeutic processes such as exposure for clients – reducing client access to the best evidence-based treatments (Waller & Turner, 2016). Education about the benefits system may reduce uncertainty and empower clinicians to do their best work.

Trustworthiness

The social security system can act as a block to trust. Throughout the studies, claimants frequently spoke about feeling disbelieved by assessors during their medical assessment and felt that their mental health problems were dismissed and minimised. Another key theme was also that claimants could be mistrustful of other claimants believing them to be not genuine – seemingly a microcosm of the power process of surveillance enacted by the DWP (Foucault, 1982).

> *'The press with benefit scammers going on holiday, blah blah… the wrong type of people have been claiming it, but they make it worse for the majority who are genuine'* (Ploetner et al., 2019, p.15)

Narratives about benefit claimants being fraudulent are widespread in society and public stigma towards claimants is common (Baumberg et al., 2012). However, benefit fraud is rare (Department of Work and Pensions, 2021) and the focus on 'fraudulent' behaviour has been encouraged in the media for many years in such a way that it seems to have entered the public consciousness (Jamieson, 2020). The extent to which participants spoke about their suspicion of other claimants warranted comment. Approaching this belief from a psychological lens, claimants distrusting each other may give credence to the role of shame and stigma in claiming benefits. The blaming model of stigma proposes that people with stigmatised identities (Saeed et al., 2020) use defence mechanisms such as splitting to reduce anxiety associated with having that stigmatised identity. The negative views expressed towards 'other' fraudulent claimants in opposition to the claimant describing themselves being genuine may function through this process. Psychologists working with claimants should be aware of the potential for claimants to internalise societal stigma, be curious about where the person's response has come from, consider the ways in which this may intersect with how clients understand their own identity and could even act as an isolating block to accessing peer support from other claimants. Psychologists hold power to affirm or debase stigmatised identities by rejecting or upholding mainstream discourses about claimants and communicating this with clients through their words and actions.

Collaboration

All three pieces of research foregrounded the importance of claimants feeling that they needed support in the system, often with practicalities such as completing forms. As a group, we reflected that this could sometimes sit awkwardly within clinical practice where there might be concerns about whether providing evidence to support a client's claim was a role for a clinical psychologist. Additionally, because DWP forms are typically focused on what people cannot do or struggle with and foreground clinical diagnoses as explanations for problems (Syrett, 2018), it may feel opposed to how psychologists are used to working with and writing about clients. However, supporting claimants on their journey and providing evidence in the form of supporting letters means collaborating with a claimant towards a shared goal. Furthermore, poverty can mean people struggle to attend appointments both in person and online. Previous research has indicated the importance of welfare rights staff supporting claimants and being dependable as a factor associated with lowering stress in claimants, even if the welfare rights staff could not resolve their issues (Mustafa et al., 2020). Clinical psychologists encountering people on their journey in the mental health service can play an important role in normalising people's difficult experiences and validating their emotional reactions in the context of a boundaried and dependable therapeutic relationship.

Choice

Our research suggested people claiming benefits for mental health problems frequently described feeling that they often had no choice within the benefits system and had to endure rigid bureaucracy. People claiming benefits also are forced to answer questions in a structured format without being able to set an agenda for what is spoken about in terms of their experiences and problems. Where possible, psychologists should offer choices in how and when people engage with appointments. Writing letters to support claimants can be done in a manner which is trauma informed by collaborating in a way wherein the claimant is able to control what is shared about them. Transparency can be offered by co-writing or at least sharing letter content if a person wishes to see it. Additionally, when writing letters more generally about clients that we work with, it is important to be mindful that even everyday clinical letters may be seen by the DWP and an awareness of this should be embedded when trainees are taught how to report on clinical encounters in a way which both empowers and honours the experiences of individuals that psychologists work with.

Empowerment

> *'the fact that I've got to get my psychologist to give proof, it's quite crap… like I've got to get evidence from a higher up person that you're speaking to'* (Roberts et al., 2021, p.84)

Claimants reported that having decisions made about their disability by strangers both during assessments and later by anonymous decision makers left them feeling powerless. Clinical psychologists should take care to not replicate disempowering dynamics. While our results spell out a useful role for psychologists in supporting claimants by providing evidence in the form of letters, some claimants reported that it felt inherently disempowering that the DWP system needed the words of a clinician to validate their struggles. While some claimants reported valuing access to a clinician whose professional testimony would give their case credibility, it seems the case that mental health professionals should be aware that they usually hold more power than the claimant to define what problems they have in the eyes of disability benefit services. When supporting claimants, psychologists could emphasise that the client is ultimately the expert in their life and while psychologists can bring certain expertise about mental health problems and clinical letter writing, this in no way dismisses or invalidates how someone understands their own experience. Ultimately, clinical psychologists have a potential opportunity to support claimants and can empower someone that is in an incredibly disempowering position.

Summary

In conclusion, the purpose of this paper was to consider a slice of the findings from a programme of research exploring the psychological consequences of claiming benefits for people with mental health problems through a lens of trauma informed care. Psychologists should be aware of the potential for being impacted from the work they do when supporting claimants in such a challenging system and continue to make use of ongoing and regular supervision and practice self-care (Karatzias & Buxton, 2016). Systemic problems usually require systematic change, and we cannot do it all alone. Not all psychologists wish to be active on social issues, but those who do may also consider becoming involved in groups such as Psychologists for Social Change to find community with others, access social support and resist oppressive systems. In the interests of space, we have not described specific benefits in detail and have assumed some prior knowledge on topics such as sanctions, if this is new to you – we recommend reading organisations such as Child Poverty Action Group for more information (Child Poverty Action Group, n.d.).

We end with some small yet powerful ways in which psychologists can empower the people we work with to access benefits to which they are entitled for mental health problems:

1. Offer to write supporting evidence to access benefits or challenge sanctions.
2. Read and share service user led writing: https://recoveryinthebin.org/ (Recovery in the bin, 2022) or https://deargp.home.blog/ (Dear GP, 2022)
3. Consume mainstream benefit claimant coverage critically.
4. Read guides on how best to write supporting letters: https://asylummagazine.org/2018/08/supporting-claimants-a-practical-guide-by-jay-watts (Watts, 2018)
5. Collaborate with service users in delivering teaching about the benefits system.
6. Conduct research on this topic which includes people who have experienced the benefits system in positions of influence and leadership during the research process.
7. Discuss poverty and how it intersects with other identities such as race, gender and migrant status within any Equality, Diversity and Inclusion (EDI) work that you do. We conclude with providing an example below of how this has been implemented by some of our group members in Glasgow.

Implementing EDI in routine practice – a case example

We (Dr Vik Nair and Dr Moya Clancy, Clinical Psychologists) developed an EDI reflective group for research assistants involved in the Glasgow site of the AVATAR2 (Garety et al., 2021) clinical trial. AVATAR2 participants (individuals with a diagnosis of psychosis), are often from marginalised ethnic and socioeconomic groups and experience higher levels of stigma – with many claiming benefits and familiar with the issues highlighted in this paper so far. Empowerment is central to the AVATAR2 trial, and we soon recognised that issues of culture, diversity, accessibility were crucial considerations in our interactions with participants. EDI is currently being incorporated into the delivery of trial and therapy across the AVATAR2 trial. We hoped that a space to reflect on these issues would benefit the work we are doing so we decided to meet once every three weeks for an hour and a half over Microsoft Teams.

Having had no previous experience of setting up such a group, we aimed to apply Harris and Fallot’s (2001) principles of safety, trustworthiness, collaboration, choice, and empowerment throughout. This provided us with a theoretical framework for trauma-informed practice across settings and imparted a common language for speaking about EDI issues. To establish safety and trust, we spent time in initial sessions establishing group boundaries, clarifying processes and expectations for the group. To facilitate discussions of EDI related topics, we discussed our understandings of power means, blending our own individual reflections along with existing avenues of thought. We discussed Smail's definition of power (2005), incorporating notions of subjective experience along with behavioural and social understandings of power as regulation mechanisms for humans living in hierarchical social structures (Gilbert, 2001; Leary & Baumeister, 2000). We also discussed the idea that features of identity frequently have implications for individuals' status and that many participants may perceive themselves as being less worthy than others, despite the aspirations set out in the Equality Act (Equality Act, 2010).

We encourage group members to discuss ideas related to these topics, inviting dissent while acknowledging that this can be hard to voice even within a nominally 'safe space'. To embody choice, members bring discussion topics of their own, raising issues arising out of their contact with either trial participants or previous life experience. We facilitate discussion and often share our own professional reflections to encourage broader formulation or discussion about how we operate in the various roles we and others potentially play. We hope that providing this space for consideration of the inequalities facing the people with whom we are working will help research assistants to improve understanding and empathy for participants and represent participant experiences more faithfully and accurately. We hope that this space allows us all to reflect on, acknowledge and consider the impact of our biases, power, and assumptions and to minimise the impact these have on our work. While the example provided here speaks to providing training and support for junior psychology staff, for senior staff working in clinical settings an aim could be to help our clients by better understanding their needs and how to offer help. While this is largely uncharted territory in clinical trials, we believe that this is a worthwhile and meaningful venture that adds to the value of the work we are doing and its possible impact on peoples' lives.

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Structure, power and practice: Designing a new rights-based national clinical programme for people with disability in Ireland

Malcolm MacLachlan

IN Ireland the state health service (AKA Health Service Executive, or HSE) operates through a plethora of state provided, state-funded, independent and private providers. National Clinical Programmes (NCPs) are the mechanism through which clinical design, leadership and innovation are supported across providers. Clinical programmes have been developing over the last decade and now exist in 31 areas, such as anaesthesia, critical care, diabetes, heart failure, and neurology. An NCP has a Clinical Lead, a Programme Manager, Clinical Advisory Group and Multidisciplinary Working Group.

In March 2020, a new clinical programme in disability was commenced. The scope of the programme is all types of disability, including intellectual (learning), sensory, physical, and cognitive disabilities; autism, people experiencing long term effects from head injury, or in minimally conscious states, and some people with rare genetic disorders. The disability programme was the first programme in Ireland where the clinical lead role was competency-based and appointed though an open competition, that is, open to all professions. The other programmes have had, and continue to have, clinical leads appointed on the basis of professional background (medicine, with a couple of co-leads in nursing). Here I describe how the National Clinical Programme for People with Disability (NCPPD, aka the disability programme) has evolved and how it has tried to incorporate a rights-based approach, including challenging power and privilege in governance and team structures, and supporting new interdisciplinary practice. My account is a personal one as the first clinical lead for the programme.

Terminology and hegemony

So 'National Clinical Programme for People with Disability' is a bit of a mouthful, but chimes with the terminology of the United Nations Convention for the Rights of Persons with Disability (CRPD). Whilst I would have preferred not to have the word 'clinical' in the title, for now, this was necessary to establish the programme as having equal status and clout in relation to other programmes in the service. While in the UK 'disabled people' is preferred, in most countries 'people/persons with disability' is used (for a brief discussion on such terminology, see MacLachlan, 2021).

While 'clinical' certainly does not mean 'medical', one of the challenges has been to de-medicalise mindsets; including among psychologists. The 'medical-model' is hegemonically woven through clinical settings and different terminology is required to make people aware of this, challenge it and instil a rights-based ethos. Thus 'care', is services and supports; 'treatment' is intervention; 'co-morbidity' is co-occurring. 'Diagnosis' may be classify or identify or describe or, more usefully, formulate. However diagnosis is not necessarily incompatible with these alternatives and may be informative (for instance, for people with Down's Syndrome or Prader Willi Syndrome). But diagnosis will rarely be decisive in the needs-led, person-centred approach we have been developing. It does however remain a key to unlock some gateways to services and supports, something we are working to change.

Conceptual clarity is often lacking in clinical training, leading to a bungling together of ideas that have important differences. So while illness or disease may lead to disability, most people with disabilities don't have illnesses or diseases associated with their disability, and most are usually well, not unwell. People with disabilities do sometimes have difficulties associated with 'impairments' in functioning, often resulting in social exclusion and a lack of opportunity to participate in society. People with disabilities also do greatly benefit from medical interventions, and sometimes these are associated with their disability.

So positioning medicine as a discipline which is greatly valued, while not subverting other disciplines to its current structural dominance, is a difficult balance. It is difficult for service users as well as service providers, of all disciplines. Some of my medical colleagues are actually more supportive of this than some of my other colleagues. I have been disappointed to find that some clinical psychologists are among those in the health and social 'care' professions who cling, most limpet-like, to medical terminology and are reluctant to eschew the power associated with it.

Structure and dominance

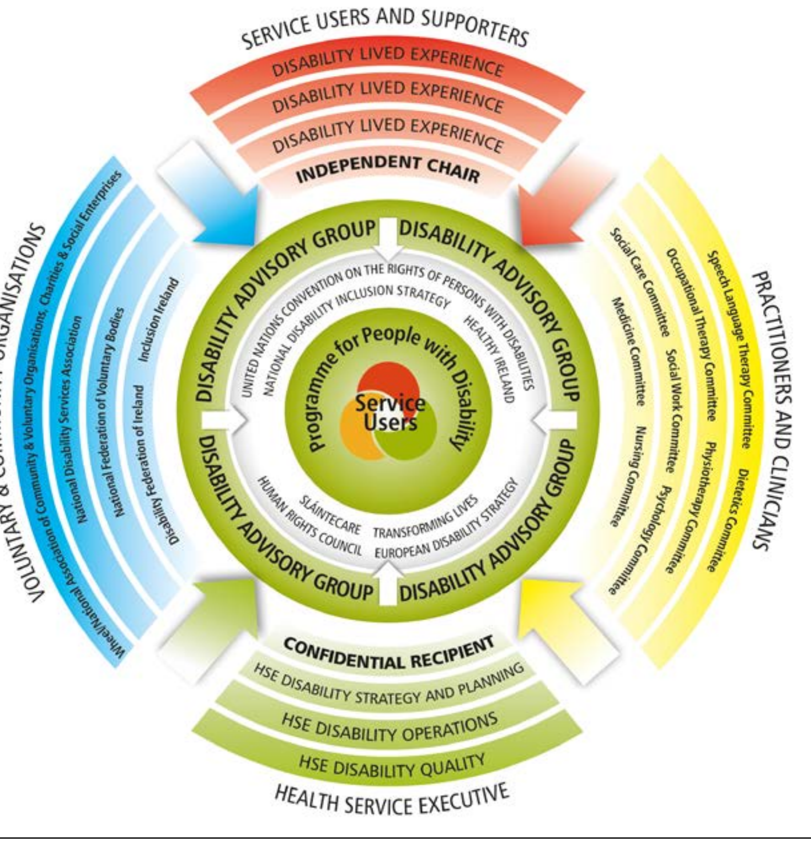
The conventional governance for national clinical programmes in the Irish system is that the clinical lead is a medical practitioner, and the clinical advisory group (CAG) is comprised of medical practitioners (generally medical consultants) nominated by the relevant professional medical colleges (e.g. college of psychiatrists, college of paediatrics). The Clinical Advisory Group itself has a multidisciplinary advisory group feeding into it. This latter group has some influence, but no power, as the decision-making power resides with the Clinical Advisory Group and the Clinical Lead. This structure therefore secures power within one profession and conflates the interests of postgraduate professional medical colleges with the responsibility of the clinical programmes to design services for the population. Obviously these interests are not always coterminous. Such a structure therefore is a rather blatant example of social dominance (Sidanius & Pratto, 2001), reflecting the social capital and habitus of medicine as an institution (Bourdieu, 1994).) and subjugating other disciplines through ideological power (Boyle & Johnstone, 2020; Foucault, 1973). This structure effectively filters the views of other disciplines though a single disciplinary lens; ultimately priming those from other disciplines to think through medical models, a process that can also be described as 'disciplinary capture' (see Rochford & MacLachlan, 2022, for a brief discussion in the context of clinical teams).

Implementation of the CRPD is the core business of the disability programme. The CRPD promotes a social- and rights-based model of disability, often not aligned with the traditional 'medical model'. It was therefore important to have designed a structure for the governance of the programme, that would incorporate the values of participation of people with disability ('nothing about us without us'), establish parity of esteem between different professions, and allow us to benefit from the benefits of diverse perspectives in healthcare decision making (Mitchell et al., 2015); whilst also embracing the need to change the systems through constructive disruption. There is now strong evidence that more democratic and distributed models of leadership in clinical teams results in both more effective decisions and reduced clinical risk (Manser, 2017; Salas et al., 2018; van Rensburg et al., 2016; Kearns et al., 2021). Put simply, drawing on the diversity in teams though non-hierarchical working is better clinical practice.

The Disability Advisory Group Structure

As noted already, the ethos of the CRPD made a strong case for the clinical lead to be appointed on a competency basis and for this to be an open competition. Once this position was appointed, the power vested in the clinical lead and the programme manager (Michael Walsh) meant that we could effectively design our own structure for the programme. After consultation with a range of different stakeholders the structure we developed is shown in Figure 1 below.

Figure 1: A schematic of the structure of the Disability Advisory Group (DAG) for the National Clinical Programme for People with Disabilities (NCPPD) in Ireland



There are four types of representation on the Disability (we preferred not to use 'clinical') Advisory Group (DAG). Their advice is framed – but not constrained – by key international (UNCRPD, European Disability Strategy and the Human Rights Council) and Irish (Sláintecare, Transforming Lives and the National Disability Inclusion Strategy) policies and instruments. Three members of the DAG are nominated through an open call to civil society organisations representing people with lived experience of disability. Four members are from service providing umbrella organisations funded by the HSE, but constitutionally independent from it, with one general community development umbrella organisation. There are three positions representing HSE disability operations, quality (which overlap) and strategy; and one for the post of Confidential Recipient (who receives confidential complaints made regarding disability and older people's services, and who is a person with a disability). There are nine different professions represented, each by an individual, who is also the chairperson of a profession-specific subcommittee of between 5–8 members, who are nominated by their professional representative organisation. In the case of psychology, they are nominated by the Psychological Society of Ireland (PSI) and the committee of the Heads of Psychological Services in Ireland (HPSI); the latter comprised of mostly clinical but also some counselling psychologists.

The DAG meets quarterly to advise the disability programme (clinical lead, programme manager and project officer) and is chaired by an independent chair who is a person with lived experience of disability. Currently this is the CEO of the autism advocacy organisation AsIAm (As-I-Am). We establish Task Groups, to address specific tasks. Currently we have groups on developing the role of digital and assistive technology, the development of specialised services, and developing a model of services and supports for adults with disability. At the beginning of Covid-19 we established a Task Group to develop clinical guidance on conducting remote assessments in disability services.

Reconfiguration of Community Disability Teams

Prior to the establishment of the programme there was already a progressive programme of reform underway. Over the last two years we have had the opportunity to support and strengthen that reform. One of the central structures for this has been the reconfiguration of a mismatch of different types of disability services for children – which previously had pockets of excellence, some weaknesses, and in some cases gaps with no service at all. This was restructured into 91 Children's Disability Network Teams (CDNTs). These teams comprise between 15–35 clinicians, who are in the most part from the disciplines of psychology, occupational therapy, speech and language therapy, physiotherapy, and social work, with administrative support. Depending on the historical provision of staff in the area, the teams may also involve nursing and dietetics, and have sessional inputs form paediatricians. We are working to standardise the teams to include all these professions, with hopefully some input form psychiatry too. As they are community-based specialist networks they also work with general practitioners and interface with primary care teams. The Clinical Lead for the CDNTs – referred to as the CDN Manager – is recruited on a competency basis and may be drawn from any profession. They have overall clinical responsibility for the work of the team, whilst individual clinicians are also of course responsible for their own practice.

These teams are rights-based, needs-led, person-centred and interdisciplinary rather than multidisciplinary, and they work collaboratively with families towards agreed goals through family centred practice. Many of our network teams only reconfigured towards the end of 2021 and so the process of restructuring – often working with new colleagues, and in new ways, and in new settings – has been difficult for many service providers. It has also increased waiting lists in some areas and been frustrating and distressing for service users. As the new teams adjust to the new structure and adapt their practice and cultural expectations, we expect services to improve, and for the experience of providing the service to also improve. At time of writing, I would say that most practitioners and many service users embrace the ethos but are struggling with the practicalities and disruption that such large-scale change has caused. While we do not lack the financial resources to employ more staff, we do have a real shortage of qualified 'health and social care professionals' (HSCPs) and we greatly need to increase our pipeline of supply from professional training courses. This is another issue we are advocating for.

Collaboration with WHO

The World Health Organization's Europe Region office is currently developing a 'European Framework for achieving the Highest Possible Standard of Health for People with Disabilities'. One of the modules within this initiative will be on Leadership & Governance. Our clinical programme has been asked to collaborate with WHO Euro through co-chairing a working group on 'Rights-based Leadership & Governance', which will apply to disability services, but will also be relevant to cognate services, such as rehabilitation, mental health, aging, and children's services. The group will comprise of a range of Irish and international expertise in this area. In many countries transition to a right-based model of service is a struggle. The output from this working group will provide guidance on rights-based leadership and governance structures that can support this transition. We also intend to produce a 'tool' to measure this. While the work of this group is only getting underway, I imagine that it will address issues such as governance structures across government departments, person-centred and needs-led services, service user representation, interdisciplinary working, competency-based leadership, democratic decision-making within teams, and the role of professional bodies, among others. We will also need to address privilege and power dynamics; including the structures, cultures and practices necessary for promoting real implementation of the CRPD within disability and other services.

Emerging dos and don'ts

For myself as the clinical lead for the NCPPD I have developed a few guiding principles – dos and don'ts – over the last two years; and so I tentatively share these admittedly half-baked ideas.

The first is *don't use your own profession as a frame of reference.* It is very easy to think through your own profession, and what particular models of service, allocation of resources or appointments to new positions, will mean for the standing of your own profession, or indeed you own reputation with colleagues. This is certainly a challenge for some of my medical clinical lead colleagues.

Another principle is *do think systemically* and to relate this to using available resources as effectively, efficiently, and equitably as possible. Such systems-thinking has brought me into conflict, particularly with psychologists, regarding the relative allocation of clinical time to assessment and to intervention, especially in the context of very long waiting lists in some areas. It is perhaps the difference between wanting to do the very best for the person sitting in front of you, and wanting to do the very best for the population needing the service. Neither is wrong, both are correct, but they do often have very different and difficult implications for how services are provided and experienced.

A third is *don't tolerate bullying, professional dominance, or disciplinary capture,* and don't be 'nice' about understanding the structural forces that sustain them and constrain others from addressing them. I believe that unless a clinical lead models intolerance for oppressive behaviours, then service users (who are often marginalised through their own experience of oppression) are unlikely to receive services that are truly empowering, person-centred, and effective.

Fourth, *do be inclusive, about everything*! While often very time consuming in the short run, it is time saving, more just and effective in the long-run. Being inclusive of course means supporting the participation of people with disability in decision-making processes. It also means identify some allies in 'the system' who can help you change things, but equally it means genuinely seeking to understand, address or allay the fears of those who don't want to change.

My final guiding principle – but I am hopeful to identify more! – *do have a Theory of Change* (Breuer et al., 2015) to guide what you are doing. You may not want to share this theory with others, and it may change as other things change, but it will help you think through how structures and power relations influence and sustain the current situation. It will also help you think through how most effectively to harness the resources you can muster.

Conclusion

I appreciate that not all clinical psychologists will want to embrace structural and power issues in their efforts to improve their own or other's clinical practice. For those who do, such issues determine the settings and conditions in which we work (MacLachlan & McVeigh, 2021); and these in turn influence the experience and effectiveness of disability services, or indeed any type of service. It is humbling to think that Kurt Lewin (1943) embraced these sort of ideas and provided the roots for theories of change, about 80 years ago. We are yet to really embrace them in the clinical sphere in helping us create the sort of organisational and culture change that is so necessary to design and deliver right-based services.

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Disability in the global south: The colonial past in the embodied present

Leslie Swartz

MOST disabled people live in low- and middle-income countries, and there is a well-established link between disability and poverty (World Health Organization and World Bank, 2011). Disability, especially in low-income contexts, may be associated with further impoverishment, and poor people are more likely than others to become disabled, partly because of greater exposure to violence, poor nutrition, environmental toxins, parasites, and infectious diseases. Though disability can and does occur anywhere in the world, the pattern of disability mirrors other patterns of social exclusion and exploitation (Watermeyer et al., 2019).

It will be clear from other contributions to this issue that disability, as currently understood, is not just about bodily impairment. Disability is constituted in the relationship between impairment and environmental conditions, including conditions in the social environment. Furthermore, categories of disability are never absolute, and are constructed in various ways, often by those with power, similarly to the ways that different 'racial' categories are constructed (Swartz et al., 2020). None of this suggests that impairment is not 'real' or that disability is no more than a social or discursive construction, but it is important to note here because of the role that disablist ideas have played in the construction of disability in the racialised 'other'. As Imada puts it:

> *In the broadest sense, colonialism demanded able bodyminds from subordinated subjects. Colonial projects imposed impossible regimes and expectations of self-regulation its subjects would not be able to perform. Thus, the colonized were* ***always already figured and constituted as disabled,*** *whether because of their perceived unproductivity as laborers; embodied racial-sexual differences; "unchaste" proclivities of their women;*

> *susceptibility to moral contagion and infectious diseases; or inability to learn. In the undulating colonial hall of mirrors, the inversion of these qualities – too much learnedness and the adoption of European manners, for example – could mean colonized people had failed to maintain the vigor of their 'race.' Thus, we begin to see how disability operated as a flexible and capacious concept and a very useful weapon during the incarceration, elimination, and removal of unfit colonial Others.* (Imada, 2017)

What is clear from Imada's analysis, is that the colonial 'other' was constituted as disabled through a host of bodily and discursive interventions. These include work regimes which led to injury and disease, and the conflation between 'disability' and 'moral impurity' as categories. Most damning, perhaps, is Imada's insight about a discursive catch-22: the colonised 'other' was viewed as deficient and disabled almost by definition, but when a colonised person broke categories and became learned in the sense recognised by colonisers, this led to another form of disablement – the disablement of those who become degraded by breaking ties with their inherent 'primitive' nature. In the field of psychosocial disability or mental disorder, there are long traditions where departure from 'true' native identity has been constructed as inherently disabling (Swartz, 1985, 1987).

The power of ascription and categorisation is something which should never be overlooked by psychologists, but it is important to recognise that this power of naming went along with direct power over the body. Central, for example, to many colonial economies were extractive commercial practices. These included large scale agricultural monoculture involving the use of harmful pesticides which are neurotoxic (London et al., 2012), the use of alcohol as a form of in-kind payment for labour, leading ultimately to high rates of foetal alcohol syndrome (De Jong et al., 2021), and dangerous and disabling mining practices (Livingston, 2005; Van Onselen, 2021), to name a few. It is important to note that aspects of these practices continue to this day (Laudati & Mertens, 2019).

Given the state of global inequality and the demands on postcolonial economies, it is probably not surprising that until relatively recently, disability as a key concern for international development practice has been somewhat neglected (Watermeyer et al., 2019). The transition from the UN Millenium Development Goals to the Sustainable Development Goals has been associated with considerable activism around disability inclusion (Groce, 2018; Hashemi et al., 2017). A paradox of the development landscape is that it may be the case that in countries and contexts where everyone is very poor and resources very scarce, the difference in living conditions for disabled and nondisabled people and their households may be relatively small. As economies develop, a gap between disabled and nondisabled people and their households opens and grows (Kett et al., 2019). A key question, then, for the wellbeing of disabled people and their households in the Global South is that of inclusion. Within the disability and development literature, it is well established that disabled people in the majority world have poorer access to education, health care, employment, political participation, and even participation in some cultural and religious practices, to name a few (Watermeyer et al., 2019). Approaches which both target the particular needs of disabled people, and, crucially, which mainstream disability into all development projects have been widely recommended (Berghs et al., 2019).

There is an irony in all these development processes and practices, and irony highly relevant to the work of psychologists in the field of disability rights and inclusion in the global south. As I have shown, disablement has been and continues to be a key feature of global inequality. Indeed, colonialism and its complex aftermaths are in many ways constitutive of disability. At the same time, the international development industry, and efforts to increase disability inclusion and participation, tends to be funded from countries which have the funds to pay for such projects. Many of these are former colonial countries, and/or countries which continue to benefit financially from global inequality. This argument, of course, is a much simplified version of the debates about what Moyo famously termed ‘Dead Aid’ (Moyo, 2009; Sakue-Collins, 2021), and there is not the space to go into these debates here. But there is a particular intersection here between the more general debates about disability and international development, and the roles played by psychology and psychologists in the context of disability in the global south.

Psychological services in many low and middle income countries, and certainly in Africa, are few and far between (Okechukwu, 2021). Most Africans, even those with diagnosed mental health problems, will never consult a psychologist. Given more general patterns of exclusion, this is likely to be even more true for people with disabilities, who experience major access challenges (Munthali et al., 2019; Vergunst et al., 2017). Psychologists wishing to work to improve disability access and participation cannot work only or primarily at the level of direct one-to-one service provision; the focus if resources are to be appropriately used must be on strengthening systems and services within local and national contexts, and engaging with policies far outside the conventional realm of psychology practice. Mac MacLachlan, recipient of the American Psychological Association’s International Humanitarian Award, draws attention to what he terms ‘macropsychology’ (MacLachlan, 2014). Similarly, Alan Kazdin, American Psychological Association’s Gold Medal Lifetime Achievement Award recipient, stresses the importance of engaging with large scale systems of power and care (Kazdin, 2018). These approaches, amongst others, offer important challenges not only to how psychologists work but how we think about ourselves and what we do.

A key feature of my own work and that of my colleagues on disability rights and access, largely in southern Africa, has been through trying to work at a number of levels. These include a full spectrum from partnering with grassroots disabled people’s organisations (Mji et al., 2011), to using psychological theory to understand exclusionary and disablist practices (Watermeyer, 2012; Watermeyer & Gorgens, 2014; Watermeyer & Swartz, 2016). Projects which focus on questions of the politics of voice are central here – a key role of psychological practice in general is to help people find and tell their own stories and narratives. Throughout the world, and especially in lower-income contexts, disabled people have been and continue to be unheard, spoken about rather than engaged in conversation, ignored and silenced.

A psychological perspective on these issues shares much, of course, with other approaches to development work. But for me a key feature of what psychologists bring to the work is a well-developed appreciation of the emotional processes which are brought in to play in any attempts at change. Some years ago, for example, I was at a large disability rights conference in a very poor African country. With some rapidity, what looked like a meticulously organised programme morphed into a long session; delegate after delegate angrily recounting disabling and oppressive experiences that they had had. This supplanted the planned agenda for the day, and it was clear that the disabling legacies and current conditions with which participants lived their lives had profound psychological effects. It would be easy to pathologise these effects as problematic, but the rage and the grief, it seemed to me, were appropriate reactions to past and current conditions. One role of the psychologist in a context like this, is to understand and accept the strong feelings, but also to have the words to contain these feelings so the business of such meetings can continue (usually in a slightly different form) so the goals can be met.

A highlight for me in my career as an academic psychologist and disability rights activist has been my close association with the Southern African Federation of the Disabled (SAFOD), which represents Disabled People’s Organisations in ten southern African countries. I was fortunate to be asked by SAFOD to do research capacity development work for the organisation (Swartz, 2018). Key for me in this long engagement was grappling with the realities of exclusion and injustice. For example, one of my most talented trainees was a young disabled man who, because of his disability, had not had much schooling. He understood research concepts better than many of my graduate students do. But he will probably never have the writing skills to write a single-author publication. Exclusion is real, and it has longstanding consequences. One of the products of exclusion, though, is lack of confidence. I found particularly with some of the disabled women that I worked with that as they gained confidence in themselves by being part of a supportive group, they became better and better at learning and applying the research skills in which they were being trained. A key feature of this training was that the focus was never on the emotional development and concerns of trainees – we had no mandate to focus on that. So nothing in the training looked or sounded like a psychotherapy or psychological skills group. Our work was to develop research skills. But conditions of respect, safety and an understanding of the importance of support for people to speak, were, I believe, a key part of what facilitated technical research skills development. With Covid-19 and the improvement of internet penetration in Africa, a key question is whether such trainings could be offered successfully on a virtual platform. This remains to be seen, but any engagement, in person or virtual, it seems to me, needs to take account of the emotional consequences of disablement and social exclusion. This needs to be done not by trying to treat these emotional issues as pathologies to be rectified, but by allowing space for what they mean to people and how they go about their business in the world.

This said, it is clear that as a privileged white South African nondisabled man, I inevitably bring to all my partnerships with others my intersectional privilege and the reality of colonial history in which we all remain embedded. It is important to recognise that development work is a compromise, politically and personally. Psychological training and skill, I believe, can be helpful not in breaking down power imbalances (I believe that many development workers try to wish away power imbalances by denying their own power) but in taking responsibility for them and living with the contradictions of the work. A key contribution of psychology to making a more equitable world with and for disabled people is to understand and live with the reality of inequity.

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Constellations of disability: 10 Principles of disability justice

Tumu Johnson & Emily Joy Carroll

The principles:

- Intersectionality
- Leadership of those most impacted
- Anti-capitalism
- Cross-movement solidarity
- Wholeness
- Sustainability
- Cross-disability solidarity
- Interdependence
- Collective access
- Collective liberation

(Sins Invalid, 2015)

Introduction

IN this article we will explore the US Disability Justice (DJ) framework proposed by Sins Invalid (2015) in the context of UK mental health services. We will do this by considering some of the principles presented in the DJ framework, centring relational, intersectional and anti-capitalist ideas that pose important questions for people working with Disabled people, who may also be Disabled people themselves. We propose that these questions upset the normative narratives through which we understand ourselves and our relationships.

The social model and disability justice

The shift from the individual, medical model to a social model was a revolutionary one. Viewing Disability as socially constructed became a popular understanding and the adoption of the Social Model by many Disabled people was an empowering move (Clifford, 2021). The push towards social solutions to a social problem was catapulted into the academic spotlight, the worlds of health and social care and education, and most importantly, it was being driven by Disabled people themselves. 'Rights not charity' and 'nothing about us without us' have become commonly heard slogans that encapsulate so much of the ethos of the model and its application to the real world/into our lives. It has contributed to real world progress and laid the ground for advancements such as direct payments (Glasby, 2005) and ramps on buses.

Fair and deserved criticisms of the social model have been presented; fighting for Disability rights as a single-issue, in its universalism, has the tendency to lose sight of the bigger picture. It uplifts Disabled people who hold power in other aspects of their identity and social location. It has in many ways failed to make space to connect with the fights for racial justice, LGBTQIA+ liberation and at times leaves groups of Disabled people, such as the learning Disabled community, behind (Goodley, 2001).

One major strength of the social model is in its applicability, which was an intentional move (Oliver 1983; 1990). Written into legislation (Disability Discrimination Act 1995) and becoming increasingly popular in the late 90s, the Social Model led to an increase in access to public life for Disabled people in areas such as public transport (see 'Then Barbara met Allan' on BBC iPlayer).

Whilst not losing hold of the merits of the Social Model, we believe that a Disability Justice lens can add to the scope of thinking about Disability. Developed in America, by Sins Invalid (2015), the Disability Justice framework acknowledges that all systems of oppression are intertwined and must be examined as such. It offers a political position that through the intersecting fight for *disability* justice, *all* people can get free.

Whilst people who are Mad and neurodivergent, and those with experience of mental health services differ in their perspectives of whether they are 'disabled' (Beresford, 2002), both the Survivor movement and critical mental health movements have a long and powerful history in fighting for their liberation too (Russell & Sweeney, 2016). We do not have the space here to cover these in depth, but these movements have intersected with the *Disability Rights Movement,* at times in parallel and at times separate. Disability Justice fully recognises Mad, distressed, traumatised and neurodivergent people as people disabled by capitalism. We include these people in our definition of Disabled people throughout.

Ableism in the UK

Ableism is discrimination in favour of non-disabled people, and across their life-span it has a significant impact on Disabled people. In the UK, this impact is demonstrable in many contexts, for example, 29 per cent of working age Disabled people live in poverty compared to 19 per cent of non-disabled adults, they are almost twice as likely to experience personal violence (Office for National Statistics, 2019) and almost twice as likely to be unemployed (Scope, 2022). We live and work in a context where terminally ill people are refused benefits and thousands of deaths of Disabled people have been linked to benefit cuts (Healing Justice London – Deaths by Welfare project) – cuts that we must remember have violated our Human Rights (Disability Rights UK, 2019).

During this global pandemic, blanket *Do Not Rescucitate* orders have been placed on Disabled people without their consent, and discriminatory health measures (such as frailty scores) used to determine access to critical care, with a wholesale disregard for the clinically vulnerable (Amnesty International, 2020). And if we look to our professions, there are times we have got it very wrong – Psychologists in job centres or Psychologists with a say in cutting/awarding care budgets of those service users accessing their teams. Embedded in our fields are the use of IQ tests, the curtailing of freedom through psychiatric incarceration, and complicity with deeply racist and ableist institutions such as the police. At a more granular level, we see the use of language which upholds harmful constructions of 'care', 'carers, 'function' and 'independence' with a lack of critical curiosity.

Our experiences of professional training have so far left us wanting more. The lack of Disabled trainees and inflexible training schedules that embody a non-disabled norm are areas we have noticed ableism operating.

Ableism is a potent force that is insidious, pervasive, and seldom spoken of. Thinking about and uncovering ableism opens a Pandora's Box that is understandably uncomfortable and overwhelming. Ableism remains a fundamental organising principle in our society; the disadvantages faced by Disabled people not only need to be acknowledged but addressed. They tell us that we have not yet achieved Disability rights, let alone justice.

Disability, needs and relationships

In the context of UK mental health services, a critical Disability stance is not widely held, and disability is frequently understood as individualised, medicalised and sometimes even something to be 'overcome'. Emerging research has found that within family therapy literature, constructions of disability as individual and medicalised predominates (Haydon-Laurelut et al., 2013). There is of course, as always, resistance. For example 'Ability', sat proudly in the widely used Social Graces acronym (Burnham), is challenged by Reeves & Jones's 'Dissing the Graces' (2014), organising our thinking away from individualised notions of 'ability' and towards Ableism.

There are various places where we are promised that Disability will be 'put on the table' (the vagueness of this statement is intentional) – 'diversity and inclusion' strategies and training, through the legal category of 'protected characteristics' found in the Equality Act (2010), or with the Social Graces model, often only to be checked off, when it concerns a visible or physical Disability. These responses can feel formulaic, sterile, 'competency'-based and removed from the relational level. There is also an emerging trend of revering 'lived experience' (such as being a Disabled person) as Truth, a position known as 'standpoint epistemology' (Collins, 1990) examined and critiqued by Olufemi Táíwo (2020). However, despite its benefits, representation alone is not systems change and in a social context where institutions can accrue social status through claiming to be 'diverse and inclusive', 'putting disability on the table' must be interrogated.

Congruent with Mia Mingus' ideas of 'access intimacy' (2011) and the context of psycho-emotional disablism (Thomas, 1999, 2007; Reeve, 2012), it is in relationships that our needs are met, unmet and left somewhere-in-the-middle. It is in the navigating of needs that we also navigate Disablism in relationships: assuming needs are all the same, not-seeing needs, pathologising needs, making too big a deal of needs, not owning up to when you miss needs. Needs are needs. As opposed to the idea of 'special needs' (relating to disability) and 'normal needs' (relating to non-disabled people), disability justice invites us to vision and work towards a world where no needs are 'othered' and where we are interdependent by virtue of our shared humanity, however sticky this gets.

Within our own relationship we have been talking about Disability Justice for a few years, teasing out the intricacies together, through our lived experiences of Disability and our feminist, anti-capitalist foundations. Held by our dear friendship, our conversations are painful, hilarious, challenging and necessary. We have found a home in each other. Not just a political home, or home on paper, in which abstract ideas sail above and past the awkwardness of our interacting and differing needs, but in an everyday *relationship*. We think it is within our relational dilemmas, where we have to confront the seeming incompatibility of 'I need to rest now', 'you need help coming out of a panic attack' that a disability justice solidarity is attempted and interdependence is forged.

The sticky reality, into which Disability theory rarely fits neatly, is the context we imagine our readers find themselves in: working in services. We know many professionals who strive for a liberatory practice, but it is in the awkward rub of everyday relationships, where we are perpetually navigating multiple, sometimes contrasting, needs, that we struggle towards disability justice. We watch this unfold in realities such as the unfunded peer support group being offered an inaccessible meeting place for free, deciding whether to go ahead with a sibling providing BSL interpretation in a crisis meeting when the interpreter has cancelled, or the feeling of guilt and shame in taking a day off in understaffed teams, despite knowing you need it.

Alongside changing the ableist structures we live within, we feel that the move towards Disability Justice is in these small acts within our everyday relationships. It is in those mundane moments on google when you dig and dig to find the correct number for the community centre to find out access requirements, in the awkward conversations with families or colleagues, where disablist assumptions have taken root. Keep going! Sometimes we worry that we are not competent, experienced or skilled enough to support someone with a particular experience. Whilst of course there are specific things to learn, such as using communication aids, sometimes this fear comes from the idea that we do something *different* with Disabled people than we usually do, when we try to meet their needs. But we remind ourselves that it is those same relational skills that we use with everyone, which should remain at the heart of our work (Hodge, 2013). Relational competency, meeting people where they are at, asking what they need, asking not assuming, are the skills we need. In relationships we learn to support one another. Independence is a myth. In truth we are an interdependent species. The whole ecosystem is a system of reliance.

Intersectionality and anti-capitalism

INTERSECTIONALITY 'We do not live single issue lives' –Audre Lorde. Ableism, coupled with white supremacy, supported by capitalism, underscored by heteropatriarchy, has rendered the vast majority of the world 'invalid'.

ANTI-CAPITALIST POLITIC In an economy that sees land and humans as components of profit, we are anti-capitalist by the nature of having non-conforming body/minds.

Sins Invalid, 2015

> *'capitalism cannot function if we are all to become fully human'* (Bhattacharyya, 2018: p.x)

Disability is constructed at the meeting point between people and an ableist world. Disability Justice takes us a step further, thickening our understanding of the other intersecting contexts within which Disabled people live (White, 1995), such as white supremacy (consider the whiteness of 'service user representation' and racist health inequalities in the mental health system), heteropatriarchy (such as Disabled people not being given proper sex education or support to be sexual, as well as the rate of sexual violence towards Disabled women), or transphobia and homophobia (for example the global discourses which describe transness and queerness as a mental illness).

Furthermore, DJ sees disability through explicitly anti-capitalist eyes. Capitalism has a symbiotic relationship with racism, its roots in imperialism and slavery and its branches alive at borders, in prisons and at the forefront of ecological and indigenous destruction. Disabled people too are categorised and produced by capitalism and cannot escape, whether 'in work' or not. 'Pre-disabled' (Lakshmi-Piepzna, 2017) and disabled minds, bodies and spirits are of course harmed and traumatised by work every day, despite it being a hallmark of 'wellness' and 'recovery' within neoliberalism (Cosgrove & Carter, 2018). But Disabled people find themselves at a very specific juncture with capitalism, where we are asked: are we of any use? And if not, we ask: can we live?

In the UK context, Morris (2018) argues, the rise of neoliberalism has destroyed any sense of 'security' from 'social security' for Disabled people. In this system, the state (not yourself or your doctor) assesses whether you are fit for work, terminally ill people are made to meet with Work Coaches, people are left without vital personal care, starve, are driven to suicide (National Audit Office, 2020); we could go on and on and on… In a perversion of the social model, Disabled people's 'needs' become 'subjective', contested and often denied – or, in the words of late activist Debbie Jolley, co-founder of *Disabled People Against Cuts:* "denying benefits, denying illness and denying disability" (Jolley, 2013). People in the Work Group are sent degrading text messages from the Job Centre saying 'nobody ever drowned in tears', and needs are understood as 'negative beliefs' or 'illness behaviour' (Waddell & Aylward, 2010), which we can 'CBT away' (Friedli & Stearne, 2015; Jolley 2013).

In fact it is the *government's* 'magical thinking' – that has rebranded 'grave and systemic violations to the rights of disabled people,' as described by the *United Nations* (DNS, 2016) – as 'Welfare Reform'. It has created a 'benefits' system which is in fact so torturous and abusive, it is designed as an 'incentive to work'. Core to this, is the 'set of beliefs that insist that individuals can only rely on themselves and their family for support; and that it is only paid employment which will provide the necessities for survival' (Morris, 2018); a hetero-patriarchal, capitalist fantasy.

Disability, intersectionality and anti-capitalism in services

All of us work with Disabled people in our work but 'disability' is only spoken about in pockets of the system, and is sometimes entirely absent in discussion. 'Disability talk' is reserved for working with learning Disabled or physically Disabled people over *there,* not distressed, neurodivergent and/or traumatised people over *here* . For example, within mental health services, disability may solely be seen as the language of Care Co-ordinators giving 'practical support' with 'benefits' and 'social care', separate again to 'therapeutic work'. This creates a false separation between material needs such as food, safety, housing and what gets called: 'mental health', when we know that these social inequalities and disparities are all key determinants of mental distress (Marmot, 2020). We know capitalism organises Disabled people's lives but this neoliberal, individualising approach obscures this fact. In this process, disability (as well as its meaning in our lives) remains separate, untouched and undiscussed in therapeutic conversations.

Parallel to this, 'disability' may also take centre stage in services, where someone's impairments are attributed as the cause for everything; Deafness is seen as the reason someone feels depressed, or someone's impairments are seen as the reason for relationship conflict. We could describe this as a type of reductive hypervisibility or 'overshadowing'.

Disabled people's positions are neither stable nor singular, but always in flux, fabricated at an intersection of disablism's various threads, and the threads of other oppressions and privileges. Take the relationship conflict being put down to disability; Disabled people's care for their partners is often invisibilised whilst the care *they* receive is described as 'selfless' and worthy of praise (in line with disablist narratives of the Disabled person as a burden). Consider how care within relationships operates through gendered prisms (Jones & Reeve, 2014), how access to benefits or financial freedoms can shape this, how it is also shaped by structural racism and poverty, how being a parent organises this or how you are positioned when Disabled and queer and trying to access adoption services. Our conceptualisation of disability within services must be intersectional, to support people with their non 'single-issue lives'.

Much like other processes of marginalisation, Disabled people rarely get to be complex people, 'both/and' people. Both proud of my traumatised gifts and full of grief for them too, both more at risk of sexual violence *and* to be desexualised, both 'out' and proud as a Disabled person on training but concealing self-harm scars in certain contexts. There is not an arrival place where we are not 'disablist', where we are 'anti-oppressive'. We are not proposing taking 'a disability justice'™ approach to 'know what to do', but to be open to these continuing questions which demand flexibility and solidarity, whilst recognising the wholeness of Disabled people's lives.

There is disagreement within professional circles about the scope of our roles when it comes to supporting access to 'material need' vs 'only' providing 'therapeutic talk'. It sometimes feels that a both/and position on this dilemma is hard for some professionals to tolerate. It could be argued though, that those familiar with systemic ideas are practised at working at different levels of language and meaning, able to move between social discourse and interaction (Cronen, Johnson, and Lannamann, 1982). This flexibility sometimes seems to fritter away when faced with the highly technical language of Benefits forms. As a result of discomfort with deficit language, diagnostic language and the black and whiteness the forms demand, professionals can sometimes struggle to write what is necessary in order to secure the benefit, or avoid forms altogether. Examples such as the Benefits Clinic (PSC, 2022) and the work of Jay Watts (2018), who firmly place accessing benefits on the agenda of psychological support are helpful here, as well as approaches which actively resist the separation of material and emotional needs in our talk (White, 1995; Afuape, 2011; Campbell, Tamasese & Waldegreave, 2015).

Recognising wholeness

RECOGNISING WHOLENESS: People have inherent worth outside of commodity relations and capitalist notions of productivity. Each person is full of history and life experience.

'Mind over Matter', posits the idea that we can overcome our circumstances with a 'positive' or the 'right' mindset, that our minds are a rational, logical entity, which is separate from our hearts. Cartesian duality remains a philosophical position underpinning the way we think about ourselves and others (Latoo et al, 2021). It is implicit in so much that, even when brought to our attention, it is hard not to slip into phrases, understandings, and actions based on understanding the body and mind as separate and absent of spirit, place or community. This is key to our existence under capitalism, where we are convinced that mental determination, divorced from our bodies, disconnected from emotion or feeling, is the way to succeed. Neoliberal individualism fragments community by pushing the idea that self-reliance is preferable to interdependency (Ramon, 2008) and fragments *us* into yet further 'parts' as well.

Recognising wholeness in services

Services continue to be dominated by deficit-based, medicalised, individual and neoliberal answers to the question of human suffering (Cosgrove & Carter, 2018). In these services and systems which can feel disembodied, and which are invested in our fragmentation, recognising wholeness can feel like going against the tide. We would like to explore two possible ways of recognising wholeness: holistic practice and solidarity.

Holistic practice

In many ways, we have seen an increase in holistic practice within and beyond services. In some places, we see an openness with how distress shows up in our bodies and the many holistic ways that we can keep 'well'. Anecdotally at least, it seems that lockdown accelerated this in some services. One example is the support for outdoor talking therapy, where therapeutic conversations between client and therapist take place on an outdoor walk within nature. The direct benefits of interacting with nature were recognised in the literature (British Psychological Society, 2020; Cooley, 2020).

Spirituality is included in some Psychosis services where practitioners hold space for Spiritual understandings of hearing voices and responding as such. This is another example where there is an expansion of possibility, one which allows us to welcome someone's spirituality into the therapy room, consider their connections to their religious community and be open to the role of faith in healing.

Trauma-informed work is another area that has expanded, with dedicated trauma services set up and practitioners being trained to deliver trauma-informed care. As many survivor activists have advocated, distress is understood through people's life experiences and it is understood that the body remembers. Trauma-informed services can offer a deeply attuned service where the person and their life history is held and considered and in which thoughtful care and support is provided.

However, despite these steps towards recognising people's wholeness there are still numerous critiques of these shifts. Within services, trauma remains narrowly defined, often ignoring ongoing or structural trauma (Carter, 2007), such as racial (Kinouani, 2021) or medical trauma, leading to the exclusion of particular groups from support services that require a PTSD diagnosis (Stubbs et al, 2017). There is a marked hypocrisy in a context where we might invite someone to share about how their faith helps them 'recover' from 'mental health problems' while we pathologise understanding those 'symptoms' through 'Jinn', for example.

Mindfulness has become a commonly used term to describe a wide spectrum of practice used within services to varying degrees. The Ancient Eastern and Buddhist origins of the practice are often not shared or explored, with 'self-regulation' the focus. This is mirrored in the wellness industry where corporations place mindfulness on every 'self-care top tips' checklist. If we are not being sold a spot at a 'wellbeing' day sponsored by a beauty magazine, then we are being offered mindfulness on our lunch breaks - instead of better working conditions. Of course, there is nothing wrong with mindfulness in the workplace *in itself*, but not when it is introduced in a neoliberal attempt to make workers responsible for their wellbeing (read productivity) even within systems and contexts that are bound to burn you out and which are maddening to their core (Cosgrove & Carter, 2018).

Each fragmented part of ourselves is an opportunity to be sold something and acts of living have been confined to our weekly 'wellbeing hour'. We have come to a place where we are sold 'holistic wellness' – a superficial stitching together of our 'selves,' with the sole purpose of profiteering from a desire to care for oneself (tend to our fragments) and a desire for wholeness. We are told by health services and adverts alike, that we are individually responsible for our health and if we find ourselves sick, distressed, exhausted or dying, it is our fault.

Looking forwards, it is important to learn from examples where holistic practice is already taking place in a complex and embodied capacity. Healing Justice London (HJL) embed this approach throughout their work holding regular, free of charge, healing spaces that include body work, whilst simultaneously resisting the Ableism of systems such as the Department for Work and Pensions (DWP), by leading research into deaths linked to welfare reform (Death by Welfare, Healing Justice London, 2022). They acknowledge collective histories, including colonialism and 'intersectional issues' (2022, b) and adopt trauma-informed ideas in their practice. In doing so, they are forming an understanding of healing that connects people's material realities, with their personal lived experience, the wisdom of those in their communities, and the structural and systemic forces that treat us in such a way that our bodies become the site of emotional and physical pain. This way of working shows the world that it is not only possible to move towards Disability Justice in our practice, but also that it is happening now.

Traditional understandings of distress and healing that have *always* proposed the body, mind and spirit (and often the collective) as one are often an aside, and have been framed as lacking 'evidence'. In recent times, services and policy makers have started to recognise the health benefits of long-ignored practices from marginalised groups, such as indigenous communities (Marya and Patel, 2021). The key to many of these practices is that they are communal. We will now look to collective ways of recognising wholeness, using the example of solidarity.

Solidarity

Solidarity recognises our wholeness through interdependence and relationship. Solidarity is not charity, it builds grassroots power, not philanthropic or state power. It is based on our interconnectedness and the knowledge that 'if they come for you in the morning, they will come for me at night'. Solidarity dissolves the performativity and 'disposability' culture within certain ways of practising identity politics, and sees all people as deserving of care.

Layers of solidarity and interdependence surfaced during the pandemic through webs of Mutual Aid groups, many of which are still going strong. But community care is not new; marginalised communities have been looking after each other for a long time – take for example the Police monitoring groups of the 70's/80's (The Monitoring Group, 2021) through to the *CopWatch* groups of today which look out for people at more direct risk of state violence, such as Disabled Black people. This care is evident in the spreadsheets created by Queer Family that are shared between loved ones and that make sure those in crisis are supported, knowing that it is impossible to rely on the often meagre or completely absent support of the state. We see this self-organised survival in the plethora of Disabled people led groups supporting people through the welfare, health, housing and social care systems (*Winvisible, London Renters Union's Disability Justice Caucus,* and many user-led facebook groups).

Solidarity in mental health services

One area that may come to mind when thinking of solidarity within services is the move towards Peer Support, but the examples do not sit comfortably with the professionalised Peer Support field within NHS and voluntary services. A key consideration when thinking about professionalised 'peer support' is that the support is often, in fact, one way. You, the service-user receive 'peer support' from a 'peer support worker'. Capitalism demands individualism, but true peer support, both the support *and* resistance which has existed in communities forever, is mutual, and is interdependent. Within projects such as Talk for Health, which is based on mutual sharing and feedback, everyone is both giver and receiver. In a context of deep social alienation, the rise of therapy and the sometimes hollow, one dimensional promise of identity specific belonging, for many people the Talk for Health community is a rare experience of practicing interdependence across difference. It is through *mutual* connections that we get familiar with the green shoots of something beyond capitalism.

To be clear, these reflections are not to say that both non-professionalised and Professionalised peer support cannot be a life-changing, highly-specialist and powerful form of support: keeping people alive, loved and protected, despite being in crisis from the state's criminalising and violating interventions *(Hearing Voices Network,* 2022; *Project Lets,* 2022; *Fireweed Collective,* 2022; Icarus Project & Freedom Centre; *Campaign for Psychiatric Abolition,* 2022; *Hearts & Minds,* 2022; *Leeds Survivor Led Crisis Service,* 2022). The peer support in our lives, both formal and informal, have kept us alive and made us feel like a life as ourselves could be possible. Peer Support *can* interrupt and challenge oppressive discourses about distressed, neurodivergent and Disabled people, but we must interrogate its wholesale co-option by institutional organisations that are divorced from these politics. By applying an anti-capitalist lens we can start to see how capitalism wants us to do peer support and how we must not be fooled. Part of this is recognising *what* we are doing when we do 'peer support', and these critiques are to that end.

The rise of low-paid or unpaid, depoliticised and institutionalised peer support has been solidly critiqued. In the context of growing corporatisation in health and social care, we must stay alert to co-option and at the same time, we must support workers. Peer support workers are especially likely to experience stigma, low pay and other struggles at work (Moran, 2013). We need services where there is proper pay, appropriate supervision by peer specialists, career development and full sick pay. These protections would go some way in protecting peer workers when they encounter punitive, disablist, sanist responses when challenging (if they want to!) the status quo. Strikes such as that of care workers in care homes (supported by residents: Grieg,

2021) or the current (at time of writing) *University and College Union* (UCU) staff strikes, show us that you cannot care for recipients of care, without caring for workers.

This widening of our lens moves us towards cross-movement solidarity, which might seem difficult to apply to our contexts. This often means solidarity with marginalised experiences that we have not lived and being open to learning about experiences that are unfamiliar to us. Within services and training courses this becomes the necessary way forward from where we are. As we explored, it might look like showing solidarity with strike action. On training courses, it may be asking for access adjustments that do not directly affect you and being open to learning about experiences that are unfamiliar. *Docs not Cops* and *Prevent Prevent* are great examples of cross-movement solidarity resisting Islamophobia, xenophobia and racism in health and social care.

Solidarity must be cross-disability. It asks mental health survivors to join with Deaf siblings, physically Disabled people to join too, so too neurodivergent siblings and our learning Disabled friends. And it goes on. Those of us who are labelled as 'unproductive', 'invalid', 'unworthy', 'unfuckable' (Srinivasan, 2021), recognise the similarities of our experiences. In services this leads us to question practices such as the exclusion of learning Disabled people from mainstream services. We recognise that all our lives are threatened under this system and that our connection is a strength. We also value our bodies in their entirety, in the sickness and pain, as well as the pleasure and wisdom.

Solidarity in all these places rages against a system invested in keeping us confined to our allotted positions. Our solidarity is strong and a force to be reckoned with, and it must not leave people behind. If othering, exclusion and harm is the real sickness, then solidarity is a remedy that includes all of us.

Conclusion

In this paper we have tried to show a constellation between critical understandings of disability, and the context for Disabled people in the UK and mental health services, elucidated by Disability Justice principles. We do not dream of 'services' and 'benefits,' but collective liberation. We dream of a solidarity where Disabled people's needs are not seen as individual, 'other' or burdensome, but are recognised as collective, inevitable and human.

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