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Article:

Goodley, D. orcid.org/0000-0002-0660-5671 (2018) *Understanding Disability: Biopsychology, Biopolitics, and an In-Between-All Politics*. *Adapted Physical Activity Quarterly*, 35 (3). pp. 308-319. ISSN 0736-5829

<https://doi.org/10.1123/apaq.2017-0092>

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Understanding disability: Biopsychology, biopolitics and an in-between-al attitude

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Acknowledgements

Thanks to Kirsty Liddiard, Rebecca Lawthom, Katherine Runswick Cole and Tanya Titchkosky for conversations and feedback on this and many other pieces of writing. And thanks to Donna Goodwin and Janice Causgrove Dunn for patience and support.

Abstract

What do disability labels give us and what do they steal from us? How possible is it to live our lives without categories when life – which encompasses these nebulous categories of culture, society and relationships – is so, well, necessarily categorical? These questions are typical of the kinds of questions asked by scholars of critical disability studies which is an interdisciplinary field that brings together people interested in understanding the meaning of disability and contesting the exclusion of disabled people from mainstream society. In this brief provocation I want to explore disability labels through recourse to three perspectives that have much to say about categorisation, disability and the human condition: the biopsychological, the biopolitical and, what I term, an in-between-al politics. It is my view that disability categories intervene in the world in some complex and often contradictory ways. It is up to us to work out how we live with these contradictions. One way of living with

contradictions is to work across disciplinary boundaries: thus situating ourselves across divides and embracing uncertainty and contradiction in order to enhance all our lives. I will conclude with some interdisciplinary thoughts for the field of Adapted Physical Activity (APA).

Introduction

This paper was written following my introduction to the diverse thought surrounding adapted physical activity through an invitation to present a keynote paper on critical disability studies at the North American Symposium of Adapted Physical Activity, Edmonton, 2016 and subsequent engagement with people at various sessions of conference. My paper begins with some questions. What do labels give us and what do they from us steal? How possible is it to live our lives without categories when life – which encompasses these nebulous categories of culture, society and relationships – is so, well, necessarily categorical? Could one live a radical life without labels? And when one thinks of education, APA or any other profession – and the institutions that work on the bases of sifting and sorting individuals on the basis of dis/ability - how might we theoretically approach the question of categories in ways that are beneficial to disabled people, their allies and associated practitioners? In short, what is in a label? In this brief provocation I want to explore disability labels through recourse to three perspectives that have much to say about categorisation, disability and the human condition: the biopsychological, the biopolitical and, what I term, an in-between-al politics. It is my view that disability categories intervene in the world in some complex and often contradictory ways. It is up to us to work out how we live with these contradictions.

The biopsychological

Let me start with the **biopsychological**. This perspective is one well known within the APA community and one that has been an ever-present epistemology in my professional life. I teach onto an MSc course in Psychology and Education. This reflects my undergraduate training as a psychologist. This course seeks to interpolate graduates into the discipline of psychology. By the end of the course, students graduate with a qualification that is recognised by the British Psychological Society (BPS). Students then have the essential psychological training that they need to move forward into the various practitioner roles we have come to associate with psychology including educational, clinical, organisational and counselling psychology. Leaving to one side, for now, my own cognitive dissonance in relation to supporting the upkeep of the discipline of psychology through my own teaching (and ignoring too how psychologically and physiologically dirty it makes me feel) one key aim of the course is to introduce students to:

Psychopathology, psychological disorders, biogenic and neuropsychology.

These are just a taste of the curriculum required by the BPS if the course is to be recognised as a true conversion masters course in psychology. To be psychological is to know psychological disorder. Because, we are taught, when we know deficit we can understand capacity. This is the classic pathogenic (rather than salutogenic) approach that has served psychology, medicine and their pseudo-disciplines for many years: understand the abnormal in order to comprehend the normal (see Watson,

2004). And in so doing posits the normal as already there in the background not requiring interrogation nor consideration (as if we already know what normal actually is). In the field of critical disability studies we would understand this as an example of the **individual model of disability** that tends to understand the problems of disability in terms of deficiencies, deficits and limits associated with specific sensory, physical or cognitive impairments (see Goodley, 2016 for an overview of this approach). This model under-girds a lot of practice in APA: in the identification of those individuals that APA practitioners will then work with; in the forms of intervention that seek to change embodied practice and in the language of disability that abounds in APA and its related professions.

For many disability studies scholars these words of deficiency are the work of the devil. In Britain, in the 1970s, disabled people's organisations defined their activism in direct opposition to medicalizing, individualizing and psychologizing terms of disability reference. Proponents such as Mike Oliver (1990, 1996) developed a counter-hegemonic view that while impairment existed, disability was the proper focus and real concern of disabled people and their allies. Oliver and his comrades drew on the distinction on the work of the Union of the Physically Impaired Against Segregation, who already back in the mid 1970s, had promoted a politicised perspective on disability (UPIAS, 1976). UPIAS made a distinction between impairment (the presence of some form of measurable cognitive, physical and sensory substantive difference) and disability (the socio-political, historical and cultural exclusion of people with impairments from mainstream life). In latter years this

definition of disability was reframed in terms of disablism, defined by Carol Thomas as:

‘a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being’ Thomas (2007: 34)

Here, for many disability theorists and activists, is the real focus of their activism and work: the eradication of disablism in the lives of people with impairments. The irony is that the in politicizing disability and defining disablism, the social model left impairment unchecked, under-theorised and ignored. Impairment remains, for social modellers such as Oliver, the elephant in the room.

Responses in the disability studies literature to this over-sight can be categorised in a number of ways. First, is a prolonged ignorance by social modellers who simply continue to ignore impairment. As Mike Oliver famously put it in his 1996 book, disability was a shared collective concern but impairment was merely a private, personal experience. His interests were in disability, not impairment. And any attempts to focus on the latter rather than the former would ‘water down’ the social model.

The second response, is an embracing (or re-embracing) of impairment as a reality. Writers such as Carol Thomas (1999), Tom Shakespeare (2006) and Simo Vehmas and Nick Watson (2013) have argued that impairment is a real entity, meriting

recognition, understood as a pre-social phenomenon that we come to know in our relationships with our bodies, minds and other people. The Nordic relational model of disability – for example – is an approach that recognises impairment and situates it in a network of relationships between bodies, minds, society, welfare systems and culture. This approach would, I assume, readily fit with the majority of research in APA which seeks to respond to impairment in ways that promote physical activity.

A third response is what we might term an enculturation of impairment by cultural theorists such as Mitchell and Snyder (2015) in the States and Shelley Tremain (2005) in Canada. By this I mean there is a turn to the cultural, historical and social constitution of impairment as a real thing that exists and becomes known in the world through culture. Enculturation refers to the ways in which cultural discourses and practices come to know and constitute objects (such as impairment) and human subject (impaired people). This approach has been especially important in bringing together social scientific and humanities disciplines to synthesise understandings around the historical, social, economic, cultural and systemic constitution of disability and its opposite ability. Indeed, as I argue in my Goodley (2014) book, disability can only ever be made through direct reference to its opposite ability; and it is these oppositional processes that find the making of entities that we consider to be ab/normal or dis/abled. Here, then, impairment and disability are pulled away from a disciplinary anchoring in psychology and medicine (as is often the case with the individual model of disability) and resited in the social world.

A fourth response to the question of impairment is offered by phenomenology. Rod

Michalko (2002) and Tanya Titchkosky (2003), for example, have come to write about how blindness and dyslexia are felt and known through the body's relationship in the world. Impairment is a deeply complex embodied and cultural phenomenon that is felt physically, emotionally and politically.

In recent years talking about impairment has become less controversial in disability studies literature. And this opening up of impairment talk is something I very much welcome. But what about my discipline's place at the table? What might psychology offer to our understandings of impairment?

Let me return to my teaching on the MSc Psychology Conversion course and the requirements of the BPS. And thanks here to my colleague Dr Jill Smith, Sheffield Hallam University, for sharing her teaching notes: notes that she delivers as part of her teaching on a course on autism. The BPS expects us to identify and elaborate on a number of specific categories. One of these is autism. The BPS also expects us to convey the meaning of a number of distinct psychological perspectives. One of these is the biopsychological. So, this is a taste of what I do (borrowing from Jill).

Powerpoint Slide 1

As we learnt in week 1, autism is currently diagnosed based on observed impairments in three areas....

Powerpoint Slide 2

‘Triad of Impairments’ (Wing, 1981)

- Language and communication
- 2. Social and emotional development
- 3. Flexibility of thought

We need to look at theory to understand how these areas became the diagnostic criteria for autism

Powerpoint Slide 3

Major theories of autism

- These are based on psychological (cognitive) and/or medical ideas about autism
- They each position autism as 'within the individual' and so are linked to the medical (or individual) model of disability as we will see in the session today

Powerpoint Slide 4

The main theories of autism

Theory of Mind

Executive Function

Central Coherence

Empathizing-Systematizing

Powerpoint Slide 5

Theory of Mind

(Baron-Cohen et al., 1985)

- ToM is the ability to empathise with others and imagine their thoughts & feelings
- Typically develops around the age of 4
- Baron-Cohen et al. believed this cognitive process to be impaired (or deficit) in autistic children

Let me interrupt the teaching session there and ask, as I do with students, what does this story of a specific disability category offer us? And what does it take away?

Biopsychology feeds into a peculiarly 21st Century form of identity politics that Nicolas Rose and colleagues have termed **biological citizenship** (Rose and Novas, 2004). Autism constitutes an example of a contemporaneous project that links citizenship to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as a species. One becomes known through the category of autism permitting us to understand this category:

- In terms of deficits that require diagnosing;
- As an administrative object that releases the state to act and offer its welfare, social care and educational services;
- As a functioning and functionalist category that pulls in the resources of what Mallet and Runswick Cole (2016) term the autism industry that encompasses a

smorgasbord of treatments, interventions, cures, specialist equipment and technologies of the self.

- And, in many cases, autism becomes a master narrative for people around which to politically organise, explain one's peccadillos and celebrate diversity as evidenced by these images here:

Interestingly, in my teaching experiences and in conversations with colleagues who work as educational psychologists, when we examine the nature of autism-as-impairment we inevitably reproduce scientific, disciplinary, methodological and analytical debates. This is not to say that we dismiss autism as not existing. Far from it; as good constructionists we are interested in the making of things. But this is the not the same as conceding autism to some naturalistic, pre-social, biological, untouched-by-culture thing, as the disability studies realists such as Vehmas and Shakespeare (or individual model of disability) might argue. Their perspective is an either / or one – either one has to accept that impairment is real or risk falling into some kind of restless, silly/fruitless relativism. This setting up of a right or wrong way of approaching disability labels is, at best, narrow minded and, at worse, ignorant of the dynamics ways in which we work as human beings to make sense of our worlds. Understandings of the reality of impairment will differ depending upon the person or a given time in a person's life. Realism, and I doubt its criticality, fails to get to grips with the truly categorical workings of society. Realism wants to do away with the complexities of category-making and shout, instead, 'look there is reality, there is autism'. This the tactic adopted by the neurodiversity movement where more than one real version of autism is claimed as difference – nor disorder – but real difference

associated with differently wired brains (see Runswick-Cole et al, 2016). However, the practice of claiming reality is another word game. If we accept that the meaning of lands and mountains changes dependent upon an indigenous (**Aotearoa**) or non-indigenous (New Zealand) perspective then we can surely accept that a label such as autism (which has shifted expression, cause and form since its inception) is a complex moving category.

The biopolitical

Any discussion of the application of disability categories to human life itself inevitably moves us into a discussion of **biopolitics**. Such a move is one that I personally made when I undertook my PhD thesis in a sociology department in the 1990s in Britain. So, forgive me for offering a 101 introduction to Michel Foucault's biopower. Let us take Rabinow and Rose's (2006) conception of biopower which involves:

- (1) one or more truth discourses about the 'vital' character of living human beings with an array of authorities considered competent to speak that truth (for example, autism as a neurological fact described through neuropsychology);
- (2) strategies for intervention upon collective existence in the name of life and health (diagnosis and educational intervention in relation to autistic children);
- (3) and modes of subjectification, in which individuals work on themselves in the name of individual or collective life or health (autistic people, their families and a panoply of professionals that work around them internalize the category of autism).

So, just as autism is diagnosed so it releases a tidal wave of biopolitical (im)possibilities about the self and the population. Biopower cannot help but produce in excess of itself and this leads to what we might term Biopolitical activism. This is precisely what Hardt and Negri (2000) had in mind when they synthesised their theory of Empire. Their work critical analyses the kinds of knowledge produced by globalization, the economic expansion of late capitalism, rapid developments in communication and the impact of biopower on the subjectivities, living conditions and activism of 'the global citizen'. As myself and Rebecca Lawthom have written elsewhere (Goodley and Lawthom, 2011), human subjects of the Global North and the Global South are hybridized and mixed: a complex 'global' amalgam. At the heart of Empire is the Foucauldian notion of biopower. Discourses of biopower are re/produced in institutional regimes (of family, school, healthcare and welfare setting, prison and workplace) in the context of the new world order; comprised of the bomb (USA), money (transnational corporations) and ether (the Internet) (Balakrishnan, 2000: 144). Our sense of selves and others are made through biopolitical constitution of our subjectivities.

Subjectivity is a constant social process of generation ... the material practices set out for the subject in the context of the institution (be they kneeling down to pray or changing hundreds of diapers) are the production processes of subjectivity ... the institutions provide above all a discrete place (the home, the chapel, the classroom, the shop floor) where the production of subjectivity is enacted. (Hardt and Negri, 2000: 190)

As we argue in Goodley and Lawthom (2013) global citizens are more and more likely to come into contact with biopower through the rapid global expansion of the capitalist free-market. This is classic Foucault.

Biopower designates the regulation of the security and welfare of human lives as its primary goal (Žižek, 2008: 34). Biopower regulates life from the interior of subjects, a power that human subjects embrace and reactivate of their own accord (Rustin, 2002: 453). Ideas from psychiatry, psychology and education, for example, know no fixed boundaries as they are caught up in plural pan-national exchanges of information and communication. ‘Empire’ refers to a globalized biopolitical machine (Hardt and Negri, 2000: 40) – or biopolitical capitalism (Abbinnett, 2007: 51) – through which theories and practices of subjectivity, being and psychology spread across the globe, infecting or affecting citizens in every corner of the world. As Balakrishnan (2000: 143) puts it: Empire is a diffuse, anonymous network of all-englobing power: a phantasmic polity. Its flows of people, information and wealth are simply too unruly to be monitored from metropolitan control centres (Goodley and Lawthom, 2013: 372).

To label or not to label is a question asked by all of us as we are caught up in the excesses of globalised biopolitics - or Empire for short. And, yet, the labels abound in even coming to ask the question:

To label or not to label?

Citizens commission on human rights

Please visit <http://www.cchrint.org/>

This film demonstrates the biopolitical maelstrom that young people often find themselves caught up in. You will see different labels being applied here. Instead of Autism, ADHD or Compulsive Defiance Disorder, the young people claim the categories of activist, inventor and entrepreneur. Interestingly, these labels are broadly associated with success and achievement. They are markers of ability rather than disability: hardly surprising when we live in a contemporary society that emphasises self-sufficiency, autonomy and independence in a time of welfare cuts and austerity (Goodley, 2014). This leads us to consider the ways in which biopolitics creates categories of disability and ability. Here we have to think about the new categories of human enhancement or advanced humanness that prejudice our thoughts:

Gifted and talented

Cognitive enhancement

Prosthetic support

Technological advance

The rebooting of humanity

All of these futuristic – and sci-fi depictions of a human life made less ordinary – remind us that the human is anything other than a fixed, biologically situated, intellectually known, ahistorically constituted, non sociologically understood

phenomenon. Now is the time to deal properly with this complexity. I would suggest that APA practitioners and researchers are all too aware of the cultural and social shaping of the body. An interdisciplinary space that seeks to enhance human movement brings to bare on the body a myriad of complex and sophisticated practices. The body becomes marked by these practices in search of improvement. One wonders, then, to what extent we are moving away from a focus on normalisation to a socio-historical period of individual enhancement. Such a move raises some serious ethical and political questions for us all.

An in-between-all politics

My third perspective desires and rejects categories with equal measure. It is a necessarily bifurcated position: one in-keeping with my own inter-disciplinary training as psychologist-turned-sociologist. To desire disability whilst also being repulsed by what disability categories do fits with what Judith Butler (1993) frames as a use-and-refusal politics and what Tanya Titchkosky heralds in her work as an in-between-al politics of disability (see for example her superlative 2011 *The Question of Access*). For feminists, it is referred to as living with the paradoxes of patriarchy. For disability scholars it reminds us of living in the complex world punctuated by the divergent practices of disablism (the erasure of disability) and ableism (the promotion of an isolationist autonomous citizen). And perhaps, most of all, an in-between-al perspective learns most from postcolonial figures such as Frantz Fanon (1976) and Sylvia Wynter (2003) who start with the categorical reality that the black man and woman do not exist, recognises the brutal rejection of such a state of affairs and physically seeks to decolonise the very register that allowed such shit to exist in the

first place. An in-between-al politics puts into action Tanya Titchkosky's (2011) invitation to imagine what might occur in the space between – and in reverberation from each side of the binary relationality – of distinct oppositional positions;

Disability – Ability

Abnormality – Normality

Impaired – Non-impaired

Crip – Normative

Disruption – Status Quo

Biopsychological – Biopolitical

So, my call is for a frictional politics (a term I borrow from Jasbir Puar, 2012) that keeps in tension these opposites as part of what we might term a DisHuman positionality (Goodley and Runswick Cole, 2014). A DisHuman perspectives disavows labels – it desires them at the very same time that it rejects them and this contrary relationship of back and forth goes on and on. Becoming DisHuman posits that thinking about the human always involves thinking about disability. One cannot separate the two nor, in our frictional world of labelling, could be separate these two phenomenon. It is possible to see some radical work being done in this in-between-al space. An example is provided by the JusticeforLB campaign which brought together a recognition that a young man with the labels of autism and epilepsy was allowed to die in a service setting (through drowning in the bath) because his humanity was not taken seriously. JusticeforLB is a DisHuman campaign¹: it thinks of what it means to

¹ Please see <http://justiceforlb.org/> and follow @JusticeforLB on Twitter.

be human through a consideration (and challenge to) the ways in which we think of those who have intellectual disabilities. It starts with disability and then through this demands that we ask more broader questions about humanity including:

- o Who do we value and why?
- o Is everyone invited into the human category?
- o What happens when people see only a label and not the human?
- o How might we learn again about our common humanity through the politics of disability?

Indeed, inspired by the activism of JusticeforLB, Humanactivism.org is a website that seeks to capture the impacts of austerity and cuts to services on the everyday lives of people with intellectual disabilities in Britain. It starts with a very human question: can people survive with out support systems around to support them? It also plots and captures a number of very human moments of support associated with self-advocacy, work and community living. And humanactivism.org reports on one key finding: people with intellectual disabilities are often the most skilled and capable at looking after other people with intellectual disabilities. This is a DisHuman frictional moment – when we think of disability we think of humanity and, crucially, in order to emphasise particular elements of humanity (that risk being quashed by austerity) we should turn to disability.

You see, the problem with those who want to either find the realities of impairment or the falsities of impairment is that they ignore disability's dynamic relationship with

humanity. We need to embrace an in-between-al politics (captured by the DisHuman perspective) that allows us to understand what labels simultaneously give and take away whilst keeping in mind that our real concern as educators should always be the enhancement of humanity. This will involve us re-imagining that is there; nurturing our relations to what is there thus raising our awareness of the complex relationship that we have with labels. Now is not time for an either / or approach to our thinking and practice. For APA this way of thinking would seek to always questioning the consequences of our professional, empirical and theoretical interventions. What is gained but also lost when we seek to improve human movement of someone with a physical impairment? What assumptions of deficit, failure and lack do we bring with us when we find disability? How else might we think of disability other than as an object requiring rehabilitation? What kinds of relationships and new ways of thinking are prompted by the presence of disability? How does APA contribute to and contest the commonly held view that disability is undesirable and therefore in need of erasure?

Conclusions

I am no expert on APA. Nor do I have experience of the nuanced and complex debates in this field. That said, I am aware that APA starts with the biopsychological register when it finds the very subject and objects of its research and intervention: namely disabled people. My sense then is things get quickly biopolitical; as we consider the tensions, debates and justifications for professional interventions. We also find ourselves considered the consequences of participating in APA. Here, I think before long, we will find an in-between-al space where we to and fro between the

positivities of naming and addressing disability alongside recognizing a shared commonality. APA is a field that, as the editors of this volume in their personal correspondence reminded me, that focuses on the moving body. But what do we do to this body and what are the potential consequences? APA embraces such things as running blades and sport wheelchair technology with the explicit aim of improving performance and maximizing the functions of the impaired body. This is all well and good but how might such practices feed into contemporaneous discourses associated with human enhancement? These very practices clearly rely upon economic and cultural capital to grow and tend to benefit people in high-income nations in the global north. Human enhancement also feeds into austerity politics and neoliberal attitudes that place responsibility for human flourishing in the individual bodies and minds of individual citizens rather than the state. What we do with disability in our professional lives will have huge implications in the wider world.

Disability and APA benefit from this liminal space of in-between-ness precisely because it invites in interdisciplinary conversations and dialogues. Disciplines prematurely feel that they already know the answers to their problems. Too often the questions that discipline's seek to answer are limited and, at times, plain stupid. Interdisciplinarity makes the foundations of disciplines shaky and their belief systems shaky. Such movement is absolutely essential if we are to work alongside disabled people as experts on their own life trajectories and political ambitions: a goal that I think would be shared by many in and outside of APA.

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