The Metanarrative of Learning Disability

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Abstract

Over the last two centuries, learning disability has become an organising concept: a concept which has radically transformed our sense of what it means to be - or not be - a person. In this chapter, we employ a historiographic methodology to explore a metanarrative which is so powerful and pervasive that it envelops both people with learning disabilities and people without. We draw on archival evidence, our own perspectives, and those of our learning-disabled co-researchers to illuminate three tropes which persist through the metanarrative: that people with learning disabilities are vulnerable, unworthy, and requiring control.

Introduction

A metanarrative is a 'cloud of story' that displaces personal narratives and knowledges with overarching ones derived from dominant, etic discourses (Bolt, 2014, 2020). It is a globalising or totalising cultural narrative schema which orders and explains knowledge and experience (Stephen and McCallum, 1998). In this chapter we explore the cultural evolution of the metanarrative - specific tropes and stereotypes - associated with what are now frequently termed learning disabilities. Conceptualisations of, and responses to, what we now call learning disabilities have varied dramatically between cultures and across eras. It has been suggested, for example, that the Mexican Olmec tribe considered people with Down's Syndrome to be the offspring of humans and the main Olmec totem, the jaguar, and so revered them as godlike (Gonzalo & Milton, 1974; Slorach, 2014). Currently, attitudes are much more prejudicial. Contemporary Western culture tends to characterise learning disabled people as vulnerable, unworthy and requiring control. We trace the roots of these conceptualisations as far back as the mid nineteenth century, although of course they go back much further (Barnes, 1997). This was the first period of institutionalisation and

medicalisation, occurring against a backdrop of urbanization and population control, social Darwinism, scientism, capitalism, colonialism and imperialism. These conditions helped establish and sustain a dehumanising metanarrative of deficiency and deviance. This metanarrative in turn paved the way for the strategic eugenic targeting of people with learning disabilities, from antilocution to attempted extermination (Allport, 1954) - most overtly under the genocidal Nazi Aktion T4 programme yet contuining today through genetic screening and editing technologies. Definitions, descriptions and ascriptions of learning disability may be historically contingent, and yet there is one point of continuity: society remains anxious of the outgroup it creates through its shifting conceptualisations of learning disability, because the group appear to challenge the essence of what it means to be human. It is this 'inclusion phobia' that is the genuine cross-historical phenomenon (Goodey, 2015, 2017). Whether worshipped as gods or dismissed as disposable, the metanarrative of learning disability bolsters the normate subject position (Garland-Thomson, 1997): learning disabled people are always Other, never Us. They are what ordinary people are not.

In this chapter we adopt historicism as a critical analytical paradigm. Historicism recasts epistemological questioning of historical knowledge as ontological questioning, acknowledging contemporaneous sociocultural tensions to maintain a logic of enquiry when being utilised to interpret the ascription of meaning in context (Iggers 1995). Historicism assumes that every expressive act is embedded in a network of material practices, and that no discourse within that network gives access to unchanging truths nor expresses inalterable human nature (Veeser, 1989). The metanarrative of learning disability, encompassing ascriptions of meaning, as well as perceptual and attitudinal shifts, and the lived experiences of people with learning disabilities, can be argued to both express and influence cultural historiography, if this is read as a network of changeable material practices from within which these tropes ultimately arise. The intention here is to inductively analyse said tropes as reflective of the liminal spatial dialectic between culture and the shifting dynamics of its underpinning psychosocial milieu, refracted through the historiographic lens. Rearticulating the historicist discourse pertaining to sociocultural shifts in terms of concomitant cultural anxieties within this framework thus examines the psychosocial evolution of this metanarrative over the last two centuries. People who are

physically, psychologically or cognitively different have always been marginalized (Meininger, 2010). This notion of "the other" as a construction opposing the construct "the self" at its most simplistic or perhaps reductionist, pervades the literature and indeed philosophical inquiry (Brons, 2015, Jensen, 2011). Brons enquires further; framing the Hegelian dialectic of self-other self-identification and distanciation to conceptualise othering as a more fluid and complex dichotomy that could be perceived as a spectrum conceptualisation. This dichotomy comprises crude othering constructed through self-other distanciation, concurring with the commonly held notion of othering that perpetuates marginalization; and sophisticated othering predicated on an element of self-identification, whereby one perceives aspects of the self within the other, engendering empathy rather than prejudice, if not unconditional acceptance. Meininger (2010) posits a paradox, that in all periods and all cultures people who are perceived as different have also been presented as symbolic of what it is to be human. This paradox can be argued to be resolved by Brons' (2015) dichotomous spectrum construct of othering if we align Meininger's juxtaposition with its opposing loci extremis, and accepting the liminality between. The traversing of this liminal space by people with learning disabilities from the marginalization and prejudices encompassed by crude othering to the empathy of sophisticated othering, to hopefully eventually transcending othering entirely can arguably be charted via the historicist perspective, framing their metanarrative and its inherent tropes as a discourse with and punctuated by concomitant historic shifts in contemporaneous sociocultural dynamics over time.

Methodology: A historiographic account

Owen cannot claim to be learning disabled. His first job in education was as a support worker for disabled students at his local community college (Barden, Youl & Youl, 2016). His doctoral thesis research investigated literacy practices and social media use amongst a small group of sixth form students labelled with dyslexia (Barden, 2014a, 2014b). More recently, his research has focused on the cultural history of learning disabilities (Barden, 2020a, 2020b). Steve has had an eclectic career path, initially studying human biology and medical genetics before training to become an actor and working in theatre and television, then

training as a film and television producer, all the while working as a healthcare support worker for people with learning disabilities, before latterly qualifying as a certified forensic anthropologist (Walden et al, 2017, 2018, 2020). Steve continues to work on his research interests in these disparate fields, but it is his role as a registered learning disabilities nurse and lecturer in that field with an ongoing research interest in the social history and cultural anthropology of people with learning disabilities that is foregrounded here.

We recognise that although disability studies emerges from, and seeks to speak to the lives of disabled people, research in disability studies written by and for the academy can be perceived as distant from the lives and experiences of the people it hopes to serve. We also recognise that applying the historiographic method directly to the research outlined below would produce a series of metaphoric still life images of given moments, that could be construed as both overtly subjective and arbitrary. We intend to counter this potential criticism by taking an objective view of the lived experiences of people with learning disabilities ranging in age from their early twenties to their early seventies, and facilitating comparative discussions framed around the documented experiences of their historical counterpart, Antonia Grandoni. Our methodology sought to address these concerns. We cannot claim the experiential knowledge that learning-disabled people have of the metanarrative they inhabit. However, we can bring our scholarly expertise to bear on helping to elicit and illuminate this metanarrative. Our recent joint, participatory project with learning disabled researchers helped to do just that. *Inside the History of Learning Disability* used a bespoke two-step methodology. Traditional methods and academic expertise in archival research and textual analysis were combined with a series of workshops designed to enable a group of learning-disabled co-researchers and their advocates to access, interpret, creatively respond to, and report on, the archive material. In the first step, the academic researchers accessed and selected archive material about people with learning disabilities from the UK Medical Medical Heritage Library (UKMHL). The UKMHL is an online archive of 66,000 digitised 19th-Century European history-of-medicine texts. In the second step, the academic and learning-disabled researchers worked together to explore, analyse, question and creatively respond to the archive material. During these workshops we use analytical prompts and questions alongside less orthodox techniques, sometimes facilitated by graphic illustrators, to elicit insider knowledge about

so-called learning disabilities. This knowledge was then expressed in a range of ways: spoken, written and artistic. The varied sets of knowledge and expertise each contributor brought to the project were interdependent and illuminating in developing a rich and emotive appreciation of both the history of learning disabilities and the lived experience of learning disabilities today.

Learning-disabled people today encounter systems of oppression, segregation and discrimination. Inside the History of Learning Disability examined the origins of these systems in 19th-Century Europe. To do so, it focused on narratives surrounding and precipitated by one person. Exploring, analysing and discussing the narrative presented in the UKMHL archive brought a number of other narratives out into the open; both individual narratives relating to experiences of learning disability and their relationship to the metanarrative of learning disability. The person in question was called Antonia Grandoni. She lived in Milan in the mid 19th-Century. According to Croce et al (2017: 81),

> At this time in Italy, the first institution for the education of people with intellectual disabilities opened in Aosta in 1848 for the cure of cretinism, followed in the 1884 by a structure in Rome specifically for "idiots and imbeciles". The positive reasons for these institutions rapidly diminished, and it was not long before they turned into places of segregation. By the end of the century, there was a recognizable change in society's view of disability, and in the way people with disabilities were served.

This ascriptive shift was underpinned by a contemporaneous ideology of institutionalisation and moral treatment that not only pervaded Grandoni's Italy, but the UK and the post-colonial new world of the mid-nineteenth century, under the burgeoning sociocultural influence of Edouard Seguin and his contemporaries (Wright, 2000; Chouinard, 2009; Webmeyer et al, 2017, Barden, 2020a). This ideology was characterised by its inherent dichotomy. It was on one hand couched in the biomedical positivist drive towards cure and the patriarchal religious moral imperative to care for those perceived as unfortunate, juxtaposed with the equally patriarchal desire to control and segregate those perceived as different on the other. After her death, and during her life, Antonia was perceived less as a person with all the inherent ascription of self that comes with that perception, and

perceived more as a reductionist conglomerate of diagnoses, analyses, and accounts of presentation. Her voice, her choice, and her human identity were absent from the historical record. To return to Brons (2015), she was for the most part, crudely othered. Antonia lived in an era characterised by marginalization, othering, and ultimately physical and cultural segregation for people with learning disabilities, rendering the parallels encountered within the discourse with her present-day contemporaries all the more stark.

Antonia features prominently as a case history in Dr William Ireland's book On Idiocy and Imbecility (Ireland, 1877). Ireland presents a translation of the accounts of a Professor Cardoni, who seems to have taken an interest in Antonia while she was alive, and the report of five Italian doctors who examined her after her death. At the time, Ireland was considered an authority on the nature and treatment of idiocy and imbecility (these were clinical diagnoses then, rather than the naked pejoratives of today). Ireland's thirteen-page account of Antonia was chosen because it contains some details of her life before she was institutionalised, some description of her character and behaviour while she was institutionalised, two pencil portraits (a rare find) as well as tables and descriptions of anatomical measurements and comparisons with other "microcephalic idiots". Our intent was to work with learning disabled researchers and look beyond the documented judgements and assumptions of Ireland's medical colleagues, glean inklings of who Antonia Grandoni was as opposed to an impression of the disability she lived with, refracted through the lens of her modern-day contemporaries' own parallel and divergent personal experiences. Three distinct metanarrative tropes emerged from this process.

Three Tropes of the Metanarrative

It would be useful at this juncture to look at some of the sociocultural origins of the segregation that Antonia experienced before drawing contemporary comparisons. The rambling gothic institutions of Europe built to 'other' and contain people with learning disabilities grew from the back wards of similar institutions that marginalised people living with mental health disorders (Parmenter, 2001). Antonia Grandoni's life may well have been touched by Seguin, who had a radical and transformative impact on the perceived educability of "idiots", from the 1850s onward, predicated upon his use of intensive

sensory-motor activities in this context. Seguin adopted an unreservedly biomedical stance; taking more interest in the conditioned neuromuscular responses of his patients than in his patients themselves (Parmenter, 2001; Kraft, 1961). Parmenter goes on to posit that the influence of the medico-psychologists of the nineteenth century, including Seguin, extended throughout much of the then Western world and continued into the early twentieth century. It was only toward the end of the nineteenth century in Italy, that a more benevolent, if still patriarchal and certainly clinically positivist, attitudinal shift became apparent, as illustrated again by Croce et al (2017):

> Sancte de Sanctis, one of the fathers of neuropsychiatry in Italy, was the founder of the first kindergarten and school for children with intellectual disabilities. In his career, he introduced the first ambulatories for neurodevelopmental psychiatry (1899) and introduced the clinical practice of maintaining a file containing biographical information for each person (Cimino, 2004).

Antonia unfortunately didn't live to see this tropic shift of nascent humanist recognition of the individuality and personhood, if not citizenship as conceptualised today, of people with learning disabilities. In fairness to Ireland he did alight upon some of her reported strengths, an empathetic consideration on his part and those of Antonia's reporting physicians more in tune with Brons' (2015) concept of sophisticated othering whereby the other is allowed to share some of the qualities ascribed to the self. This apparent benevolence was far from universal however, and must also be weighed against broader cultural shifts in attitudes across much of Europe as well as the US and Australia, which identified people with learning disabilities as menacing and degenerate rather than pitiable (Barden, 2020a, 2020b).

To segue to the present day, the current postmodern neoliberal milieu that pervades Western democracy continues to foreground risk as an overarching principle informing social responses to people with learning disabilities, seated in a paradoxical dialectic with marketised dependency that argues to promote choice whilst in many ways negating it (Dowse, 2009). People with learning disabilities, if independent of their families, often live in supported living arrangements with other people with learning disabilities and are subjected to sets of rules that wider society may not be. The overt segregation that Antonia was subjected to is thus sublimated by a more nebulous, covert segregation for her modern-day

counterparts predicated on disability as commodity (Brown, James & Hatton, 2017; King et al, 2016; Richards and Flynn, 2020).

1. Vulnerable

A very significant component of the metanarrative of learning disability is vulnerability. People with learning disabilities are cast as vulnerable: needing protection from the hazards of the physical world, from exploitation by unscrupulous others, and from harming themselves. However, people who nowadays carry the label of learning-disabled are not necessarily inherently vulnerable - in our pre-industrial agrarian society they would not have been thought of as so, and they could perhaps have functioned and participated perfectly well (Barnes, 1997; Goodey, 2014; Slorach, 2014). Rather, they are trapped in a regime of truth, established during Antonia's lifetime, which depicts them as vulnerable (Barden, 2020a; Simpson, 2014). This is a powerful representation of learning disability because it circulates and so is constantly reinforced in medical discourse, popular culture, mass media and people's everyday speech; indeed, it is such a powerful and all-encompassing hegemonic as to be almost inescapable (Smith & Smith, in press). Vulnerability is then used as justification for segregation. During Antonia's lifetime notions of vulnerability and justifications for segregation and discrimination were established and reified in part through diagnostic criteria and biomedical definitions. These definitions positioned their subjects as vulnerable both to common physical dangers (Clive, in press) and to being out-competed by their fellows. As such they had a distinctly Darwinian feel and so it is perhaps no surprise this metanarrative helped feed the pseudoscience of eugenics, which sought to eliminate people deemed "unfit" - another Darwinian term - from the population. In Antonia's case, the concern over her perceived vulnerability is evident in biographical sketch which precedes the more extensive anatomical evaluation:

> She was not much later than usual in beginning to walk and speak, but her intelligence was inferior to children of her age. She, however, learned in time to do easy work in the house, and to go out of doors to buy provisions. She was fond of

> learning amorous poetry, and showed erotic tendencies. On getting older she took to wandering about, and might be seen dancing with grotesque movements to her own singing.
>
> For many years she led a wandering life, an object ofcuriosity, of pity, or of ridicule to all. At last she was removed to the hospital where she died [...] I have little doubt that, by a well-planned education in childhood, her mental powers could have been considerably increased, and her wandering and erotic tendencies repressed. Apparently she was a poor neglected creature…
>
> (Ireland, 1877 pp.106-107)

This narrative tells us that Antonia was seemingly abandoned, or at least not cared for, by her family - perhaps her brothers and sisters, mentioned earlier in the story, out-competed her for her parents' affections - and that she led 'a wandering life' for 'many years' before being institutionalised. The justification given for this course of action is that she was both neglected at home and not safe by herself in the outside world because of her exposure to ridicule. This is apparently sufficient to warrant a decision to separate her from her family and incarcerate her, condemning her to a lonely existence for the rest of her days. Moreover, her supposed 'erotic tendencies' are probably an even greater concern than her wanderlust, given Ireland's stated desire to suppress them. Again, this relates to broader eugenic concerns about promiscuity and degeneracy as well as the potential for Antonia to be taken advantage of or do things she does not understand the consequences of. The idea that people with learning disabilities should not have sexual relationships or become parents is one that is still prevalent today; still part of the metanarrative of learning disability.

Our learning-disabled researchers recognised this narrative of vulnerability and drew parallels with contemporary experiences. Their relationship to this aspect of the learning

disability metanarrative was complex. On the one hand, they appreciated the potential for exploitation, for example through sensationalist daytime television shows[1]:

Sa: Well I think that - well I know it's been axed now but - the Jeremy Kyle Show would be quite often young women, nobody knew who the father was, this kind of thing. Very vulnerable people, you could just tell, very vulnerable people. So it's a big cause for concern that, I suppose, as well.
L: We've got other ways of exploiting people-
A: But nowadays there's also that kind of idea of fandom, sensationalism and fetishism, so I think nowadays it'd be like, would she be like on Tinder or whatever, and getting like 100 likes. I don't use Tinder. [laughter, hubbub] I've got a coffee date tomorrow, that's all!
H: I think when Jeremy Kyle first started I think I saw it once and I thought "Well, how sad. You bring people on for basically Joe Public to watch and laugh at". Because it's cheap TV to get people who have problems and are vulnerable, get them on so Joe Bloggs can have a cheap laugh.
Sa: It's what they did in the old asylums, isn't it? People would come and view them.
A: Chuck tomatoes at them and stuff.
H: I saw it [Jeremy Kyle] once and I thought "That is just sick."

This exchange touches on a number of aspects of vulnerability and exploitation: media manipulation, sexual fetishism, freak shows and exhibitions, verbal and physical abuse; and how these can be traced to asylums of the kind where Antonia was held. Vulnerability to abuse and exploitation was thus clearly a concern for the co-researchers. These concerns are borne out of lived experience of learning disability and can be read as perpetuation of the metanarrative. However, other aspects of the co-researchers' insights can be read as challenges to the metanarrative. Several times, the co-researchers expressed a wish to take Antonia for a night on the town; Ireland's account tells us she was 'a good and agile dancer' as well as being 'gay and sociable' and 'fond of attracting the attention of the opposite sex.'

Sa: we talked about her lifestyle as well, that she liked to dance provocatively, and…

[1] The transcript excerpts use initials to preserve anonymity.

Cr: And she smiles

Sa: …and we talked about her sexuality and stuff, and we just joked, you know, think of describing any girl out on a Saturday night in Liverpool city centre you know [laughter] but she obviously seemed different to other people around her, and her behaviour, she was more open, more kind of, bohemian I suppose, in her own way.

[...]

Ja: Somebody mentioned that you could do the Twitter from a cell, but I'd have thought she wouldn't be in a cell today, these days. I hope she'd be out in the community. She liked dancing - maybe she'd be looking forward to Glastonbury or something! I don't know.

Part of the motivation for wanting a night out with Antonia we all began to think of her as 'one of us', belonging to our groups and being part of our lives, doing the things we do. But part of it also stemmed from wanting to resist the characterisation of learning-disabled people as vulnerable. There was recognition that a good life is one that balances challenges and risks; that protecting from risk also means protecting from success and inner growth (French & Jones, in press). And wanting a good life for Antonia was part of the broader project of rehumanising her, an objective established to counter the dehumanising narrative of Ireland's account and characteristic of the metanarrative of learning disability.

2. Unworthy

The second aspect of the dehumanising metanarrative of learning disability we explore in this chapter is that such lives are barely human; that people with learning disabilities are not really people at all. As medicalisation took hold, animalization became a well-established tactic of patriarchal disability and oppression, aligned to a belief that because animals lack certain traits and abilities they exist outside our compass of moral responsibility, and are therefore fair game for domination and abuse (Taylor, 2011). This tendency to equate learning disability with non-human status is evident in Ireland's book. Here he relays Prof. Cardoni's opinion of Carlo Guiseppe Cioccio, an Italian man who lived at the same time as Antonia and also received a diagnosis of microcephalic idiocy:

> But, observes Cardona, "the smallness of the brain of Cioccio induced stupidity, idiocy, deaf muteness - in short, simply animal life ; the poverty of the brain of our Grandoni in that small size accorded to it by nature, could admit of a sensibility, an intelligence, and an education, which has not fallen much short of the average of her countrywomen."
>
> (Ireland, 1877 p105)

In this second excerpt (ibid), he quotes a Dr Adriani, one of the five Italian physicians who examined Antonia after her death:

> An examination of the brain strengthens the conclusion that microcephales do not represent a degeneration in the sense of retrogression to the organic type of certain apes, but rather an arrest of development without aberration from the typical laws of organic formation through a pathological cause.

In both cases the doctors liken their subjects to animals: Cardona in the most general and therefore perhaps dismissive terms; and although Adriani seeks to maintain a distinction between microcephalic idiots and apes, the very fact that the comparison is reported is telling. Our co-researchers were highly alert to this tendency. Their analysis of and responses to Ireland's narrative highlighted his tendency to objectify Antonia in this way, as well as how she continued to be neglected once institutionalised, even though familial neglect was part of the original justification for removing her to hospital:

Cl: Yeah, she was just judged by appearances, is what we came up with, and we picked up on one thing that it said on attachment that, you know, she attached to people who were kind to her and we thought that the very wording made us think, you know, had she been in contact with people who were unkind to her and how would she respond to them, and she would respond very differently, she was quite happy to smile at people when they smiled at her. We went along the lines of you know being on the autistic spectrum kind of thing. We thought it sounded as though she was not, had not been given many opportunities in her life and was judged by appearances, that's pretty well what we talked about.

OB: Okay, super, thank you very much. So, there's a handy little bit of summary from one group there, who would like to go next?
Sa: Can I just say that reading just that, I wouldn't surmise that she had any kind of learning disability…
St: Exactly
Sa:…if you haven't told us beforehand, she just sounds, she sounds a bit like a lab rat, really, you know, here's her measurements,
St: Exactly
Sa:… she sleeps, she does this, that's what I…that's kind of, that's how she's treated, she's treated like a subject rather than a human being. But just reading that from the paragraph, I wouldn't just think oh, this person has a learning disability at all.

As well as in these discussion, the 'lab rat' metaphor and Antonia's degrading treatment were featured in the artworks the groups produced as creative responses to the narrative presented.

The idea that a person with a learning disability is unworthy of education, opportunities, even of life itself has persisted, through the Nazi characterisation of "useless eaters", used to justify the genocidal Aktion T4 programme, to post-war characterisations of some children being ineducable, to a catalogue of abuse and neglect in "care homes" like Winterbourne View, Whorlton Hall, Yew Trees and Muckamore Abbey; and on into learning disabled people receiving inferior healthcare, dying prematurely in disproportionate numbers (LeDer, 2018) and being regarded, along with other disabled people as disposable during the ongoing Coronavirus pandemic (Wong, 2020). Again, our co-researchers had experiences which resonated with the way Antonia was apparently regarded and treated:

V: I was called a spastic
Os: I was walking home, eating my lunch, and somebody shouted you're eating like a spastic
Y: That was recent, wasn't it?
SW: That's another term that was used and we've got two people now who've had experience of that label and been called spastic
V: Another one I was called was Mongol

Y: That used to be the medical name though, when I was growing up, that's what my sister's diagnosis was; it wasn't Down syndrome, it took people a while to get used to that. Then people started using it to be mean to people and as an insult. Down syndrome was chosen because Dr Down first described it

SW: As an insult, it's racist as well as being disablist

[...]

W: R, has anybody ever called you any names that you didn't like"

Hi: I might've been called spastic once or twice

W: …and how did that make you feel?

Hi: Annoyed

Os: Dawn, when I was in school, I was called dick-head. The boys were doing the action. I'm not going to do what they did, and they said to my friend I was a frea"

W: That's terrible

V: They called me a donkey

Y: When I was little my sister punched another girl on the nose for calling her a Mongol. She didn't like that label being put on her

In this exchange, we see the tendency towards animalisation persist, as V is called a "donkey". A number of other insults are reported, all of which imply that the target is unworthy of respect or basic human decency. Moves to label people in this derogatory way are of course moves to subjugate them: to exert control. This brings us to our third and final trope.

3. Requiring control

So far we have argued that people labelled with learning disabilities are often conceived of as vulnerable, and also as not fully human. During Antonia's lifetime there was a shift in the impact of these conceptualisations; the pity and sympathy which initially motivated the creation of asylums were replaced hostility and fear, because "idiots", "imbeciles", the "feebleminded" and "moral defectives" came to be seen as threats to the health of nations. This was an overriding concern for capitalist, empire-building Governments, who wanted populations who were fit to work and fight. Herein lie the origins of eugenics - which we

must remember was a mainstream politico-scientific movement in the late 19th and early 20th centuries, with support from, for example, the UK and US governments, before it fell out of favour following the abhorrent Nazi Aktion T4 extermination programme. T4 remains the ultimate expression of our third trope: that people with learning disabilities need to be controlled. Whether because they are seen to need protecting from risk, to a degree most other people are not, or because they represent a threat to other people, the metanarrative demands that people labelled with learning disabilities must be controlled. We can map these moves to control against Allport's (1954) scale of prejudice. Antilocution is evident in the diagnostic criteria and definitions formulated in Antonia's lifetime, and continues both in biomedical terminology - as embodied in the ever-expanding Diagnostic and Statistical Manual of Mental Disorders - and in the kind of insults our researchers reported above. Indeed, the unfortunate fact is that many diagnostic terms evolve into insults. Avoidance and discrimination are evident in moves to segregate learning-disabled people from the rest of the population in the 'archipelago of confinement': penal, medical and educational settings including asylums, madhouses, special schools, colonies, hospitals and more recently prisons, immigration and detention centres and care homes (Adams and Erevelles, 2017; Drinkwater, 2015; Foucault, 1977; Spivakosky, 2017). Many such places create marketized dependency: privatised supported living supposedly promotes choice whilst paradoxically maintaining segregation and imposing myriad restrictions. Residents find themselves living lives in the workplace of others, subjugated to available resources and "Human Resources" logistics predicated on maximising profit. Physical attacks are common, both outside such settings, and as means to control residents within them, as the continuing litany of horrendous cases like Winterbourne, Whorlton, Yew Trees and Muckamore demonstrates. The will to exterminate persists through genetic modification and screening programmes, as well as forced sterilizations.

Antonia was subject to a good deal of control, and our co-researchers reported many ways in why their lives were controlled to a far greater extent than most other people's. The very fact that Antonia was removed from her family, to prevent her 'wandering existence' tells us that the authorities felt the need to control her life, as do the attempts to suppress her 'erotic tendencies' and make her attend Church and abide by the moral code of the day, even though she was deemed ineducable:

> She had the sentiment of good and evil, and made sensible remarks upon the conduct of her companions. She was religious through imitation and habit, and behaved well in church. Every attempt to instruct her was without success.
>
> (Ireland, 1877: 107)

Similarly, our co-researchers talked about ways in which their conduct, relationships and choices were controlled - from the food they ate, to what time they went to bed or were allowed to shower, the clothes they wore, whether they were allowed boyfriends or girlfriends, to being administered medicines they knew didn't work
and even electro-convulsive 'therapy'(ECT) against their will. We present a series of transcript excerpts which help illuminate the influence of the "controlling professions" (Mitchell & Snyder, 2006). In the first, researchers in Steve's group discuss daily routines in supported accommodation:

Os: The staff say we can't have a nap in the afternoon
SW: You can't have a nap in the afternoon?
Os: We're only allowed to have granny naps if we're ill
Y: Oh really? She has just said that where she works the doors are locked at 11 o'clock and everyone's got to be in bed
W: This is not an unusual thing for people with learning disabilities
Os: In the mornings they are knocking us up
SW: In the mornings, Sh is saying that everyone has to get up between 7 and 10, have had breakfast and have showered in that time, everyone who lives there
W: So, what happened to 'this is my home'?
E: It's not their home

In this next excerpt, one researcher from Steve's group describes moves to control what people wear in their own home, something that would never happen to most people:

Os: I had a Christmas top on one morning, and the staff said what are you doing wearing a Christmas top, go and change it

SW: Was that the staff at your school or the staff at your house?
Os: The staff at the house. They say we're not to keep our Christmas top on. They'll tell R
W: What?!
D: You don't always get a choice in what you wear then?
Os: I get a choice, but if wear a Christmas top when it's nowhere near Christmas then I have to change it

The researchers also discussed repeatedly and at length controls over their friendships and romantic relationships, of which we can only present a tiny fragment here:

W: Is that the same for you Nicole? You still live at home, do your family encourage you to have relationships? Would they be OK with you taking somebody home with you?"
I: Yeah, I've already got a boyfriend.
M: If you didn't have a boyfriend, would they be happy with you taking someone home?
I: No, I don't think so
W: So it's OK for you to take your boyfriend home, but not some randomer you picked up in a pub?
I: No. But I've already found a boy!
[...]
D: My parents wouldn't allow that either.
W: ..and L you're saying there was no way your parents would ever have allowed any of it?
E: No
D: My parents would never let that happen
W: Young people these days, they go out, there's no strings attached…we're talking about relationships, yeah?
D: My mother would probably lock me up for years if I brought a random person home.

The final excerpt is harrowing as one researcher describes being subjected to ECT:

St: I, one day I suffer from what's that called that you get when you're on, oh, oh …dzh dzh dzh dzh {making buzzing noise}... Yeah, yeah, I suffered from 1, 2, 3, 4, 5, 6, 7, 8, oh god, it

was horrifying. I didn't know whether I'd be right again. I didn't believe it, well dzzzzzzz oh god, so, oh, crying duh duh duh.

Ja: This is in recent times Stella, this isn't so long ago.

An: ECT, ECT

Jn: ECT'll do it yeah.

H: They were gonna do it on me but didn't

St: Yeah. I got this when I was younger, 18-19, really, really go on, in my head. I lost conscious of the oh, and then a month time, it was for me to go again, I dreaded that, dreaded, I cried, really, and don't get me wrong, it is abomination of that to happen, I spoke out about that, but every day, oh I felt frightened because only for the 8 and finish, oh my god der der der der der duh. I got energy back in myself, I got the, you know what I mean, I got, I was elated to not have this treatment.

Both the transcripts and the account of Antonia's life amply demonstrate both the degree and the various ways in which people labelled with learning disabilities are subject to control, stemming from their persistent conceptualisation as an outgroup.

Conclusion

From the meta-analytic vantage point of the historicist perspective then, we see a shift in the meaning ascribed to what it was to be a person with learning disabilities in Antonia's time, concomitant with an associated attitudinal shift on the part of Western society responsible for their othering. The atavistic and irredeemable 'idiot that must be segregated' trope had been superseded by a more benevolent, if patriarchal and overwhelmingly positivist 'idiot that must be conditioned to resemble the perceived norm whilst remaining segregated' trope that circulated among at least some of the medical profession, at the same time as eugenics was gaining ground as mainstream politico-scientific movement. It was this shift from crude to sophisticated othering, to draw once more upon Brons (2015), that may have prompted the recognition and documentation of some of Antonia's personal strengths, if not going so far as to document Antonia's actual personhood. Antonia was not entirely rejected by the society in which she lived but she was

never entirely accepted either. A perception of the world that, as outlined in this chapter, is still all too familiar to people with learning disabilities today. As our analysis demonstrates, the tropes of vulnerability, unworthiness and requiring control are still very much in operation. The metanarrative may at times seem inescapable, and yet there grounds for cautious optimism. It may indeed be possible to transcend narrative othering through embracing and appreciating the insider knowledges and perspectives that people living with learning disabilities bring, and continued advocacy work. Our co-researchers spoke, for example, of generational shifts in parental attitudes towards relationships, with younger people in our groups reporting more choice and freedoms than their older counterparts. However, our teams also recognised that learning disability communities can often be quite insular - and this is, of course, itself a manifestation of the metanarrative. The real challenge is to shift attitudes outside learning disability circles and networks; not just in disability-related communities, but in culture more broadly.

References

Allport, Gordon W. (1954) The Nature of Prejudice. London: Addison-Wesley.

Barden, O. (2014a). Facebook levels the playing field: dyslexic students learning through digital literacies. *Research in Learning Technology*, 22, 18535. http://www.researchinlearningtechnology.net/index.php/rlt/article/view/18535#alm

Barden, O. (2014b) "*Winking at Facebook: capturing digitally-mediated classroom learning*" E-Learning and Digital Media 11 (6) http://www.wwwords.co.uk/rss/abstract.asp?j=elea&aid=6117&doi=1

Barden, O. (2020a). A Cultural History of Learning Difficulties in the Modern Age. In Snyder, S. & Mitchell, D. A Cultural History of Disability in the Modern Age. Bloomsbury.

Barden, O (2020b). Demanding Money with Menaces: Fear & Loathing in the Archipelago of Confinement. *Journal of Literary & Cultural Disability Studies*, 14 (1) 91-108

Barden, O., Youl, W. and Youl, E.J., (2016). Including adult learners from diverse cultural backgrounds. In: Fehring, H. & Rodrigues, S. (Eds) Teaching, Coaching and Mentoring Adult Learners: Lessons for professionalism and partnership, p.60.

Barnes, C. (1997) A Legacy of Oppression: A History of Disability in Western Culture. In Barton, L. & Oliver, M. (Eds) 'Disability Studies: Past Present and Future' Leeds: The Disability Press, pp. 3 – 24.

Bolt, D. (2020) The metanarrative of disability: Social encounters, cultural representation and critical avoidance, in N. Watson & S. Vehmas (eds) Routledge Handbook of Disability Studies: Second Edition, Abingdon: Routledge.

Brons, L., (2015). Othering, an analysis. *Transcience. A Journal of Global Studies*, 6(1), pp.69-90.

Brown, M, James, E and Hatton, C. (2017), A Trade in People: The inpatient healthcare economy for people with learning disabilities and/or Autism Spectrum Disorder. University of Lancaster: CeDR Briefing Paper 2017:1. Available from: http://wp.lancs.ac.uk/cedr/files/2017/06/A-Trade-in-People-CeDR-2017-1.pdf [Accessed 27.6.17]

Clive, R. (in press) Panarchy 3: River of the Sea. *Journal of Literary & Cultural Disability Studies*, forthcoming

Garland-Thomson, R. (1997). Extraordinary bodies: figuring physical disability in American culture and literature. New York, Columbia University Press.

Cimino, G. P. L. (2004). Sante de Sanctis tra psicologia generale e psicologia applicata. Milano: Franco Angeli.

Chouinard, V., 2009. Impairment and disability. A companion to health and medical geography, pp.242-257.

Croce, L, Di Cosimo, F and Lombardi, M (2017). "A short history of disability in Italy." In The Routledge History of Disability, pp. 70-93. Abingdon, OxonRoutledge.

Dowse, L., 2009. 'Some people are never going to be able to do that'. Challenges for people with intellectual disability in the 21st century. *Disability & Society*, 24(5), pp.571-584.

Mapley, H. (2016) 'Culture as Pharmakon': Representation, Social Encounters, and Discourses of Disability. *Considering Disability Journal,* 1012.

Goodey, C.F. (2015), "Why study the history of learning disability?", *Tizard Learning Disability Review*, 20 (1,) pp. 3-10.

French, J. & Jones, L. (in press) Recipe for a Good Life. A Self-Advocate's Perspective on Curating the 'Good Life' to Explore Happiness and Living Well. *Journal of Literary & Cultural Disability Studies*, forthcoming

Gonzalo, R. and Milton, G., 1974. Jaguar Cult-Down's Syndrome-Were-Jaguar. Expedition, 16(4), p.33.

Hacking, Ian. (2002) Historical Ontology. London: Harvard UP..

Iggers, Georg G. (1995). “Historicism: The History and Meaning of the Term.” *Journal of the History of Ideas* 56 (1) pp. 129–152.

Iggers, G.G., 1995. Historicism: the history and meaning of the term. *Journal of the History of Ideas*, 56(1), pp.129-152.

Ireland, W.W. (1877). On Idiocy and Imbecility. J.A. Churchill: London.

King, E., Okodogbe, T., Burke, E., McCarron, M., McCallion, P. and O’Donovan, M.A. (2017). Activities of daily living and transition to community living for adults with intellectual disabilities. *Scandinavian journal of occupational therapy*, 24(5), pp.357-365.

Kraft, I., (1961). Edouard Seguin and 19th century moral treatment of idiots. *Bulletin of the History of Medicine,* 35, p.393.

Meininger, H.P.,(2010). Connecting stories: A narrative approach of social inclusion of persons with intellectual disability. *Alter*, 4(3), pp.190-202.

Mitchell, D.T & Snyder, S. (2006). “Regulated Bodies: Disability Studies and the Controlling Professions,” in D. Turner & K. Stagg (eds.), Social Histories of Disability and Deformity: Bodies, Images, and Experience, 1650-2000. London: Routledge, 2006: 175-189.

Simpson, Murray K. (2014), Modernity and the Appearance of Idiocy: intellectual disability as a regime of truth. New York & Lampeter: Edwin Mellen Press

Parmenter, T.R., (2001). Intellectual disabilities-quo vadis. In: Albrecht, G L, Seelman, K & Bury, M2001, *Handbook of disability studies*, SAGE Publications, Inc., Thousand Oaks, CA, pp.267-296.

Richards, L. and Flynn, S., (2020). Barriers to and complexities of supporting paid work for adults with learning disabilities. *Learning Disability Practice*, 23(4).

Slorach, R. (2016). A Very Capitalist Condition: A History and Politics of Disability. London: Bookmarks Publications

Smith S. & Smith K. (in press) Down Syndrome as Pure Simulacrum. *Journal of Literary and Cultural Disability Studies.*

Taylor, Sunaura (2011), Beasts of Burden: Disability Studies and Animal Rights. *Qui Parle*, 19 (2), 191-222.

Walden, S.J., Evans, S.L. and Mulville, J., (2017). Changes in Vickers hardness during the decomposition of bone: Possibilities for forensic anthropology. *Journal of the Mechanical Behavior of Biomedical Materials*, 65, pp.672-678.

Walden, S.J., Mulville, J., Rowlands, J.P. and Evans, S.L., (2018). An analysis of systematic elemental changes in decomposing bone. *Journal of forensic sciences*, 63(1), pp.207-213.

Walden, S.J., Evans, S.L., Mulville, J., Wilson, K. and Board, S., (2020). Progressive dehydration in decomposing bone: a potential tool for forensic anthropology. *Journal of Thermal Analysis and Calorimetry*, pp.1-8.

Wehmeyer, M.L., Shogren, K.A., Singh, N.N. and Uyanik, H., (2017). Strengths-based approaches to intellectual and developmental disabilities. In Shogren, K.A., Wehmeyer, M.L. and Singh, N.N., 2017. (Eds) *Handbook of positive psychology in intellectual and developmental disabilities*. Berlin: Springer: pp. 13-21)

Wong, A. (2020) I'm disabled and need a ventilator to live. Am I expendable during this pandemic? Vox April 4th. Available here: https://www.vox.com/first-person/2020/4/4/21204261/coronavirus-covid-19-disabled-people-disabilities-triage Accessed 22.7.20

Wright, D., 2000. Learning disability and the new poor law in England, 1834–1867. *Disability & Society*, 15(5), pp.731-745.