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14. ATTENDING TO THE POTHOLES OF DISABILITY SCHOLARSHIP

INTRODUCTION

In this chapter I sketch a picture of present-day exclusion as experienced by people with disabilities, and consider some of the activities that have been undertaken to overturn it. I consider that some of the potholes of disability scholarship can be found here: between the continued tangible experiences of people with disabilities of marginalisation and the political and social actions that are aimed at challenging their causes. I set out the basis for a methodological approach to DSE that I have been using in schools with young people with diagnosed disabilities, which might enable us to better attend to some of these matters. On the way I draw on metaphors of Spanish cooking, the stories of people with disabilities and their families, some pertinent reports and policies in the field of disability, and some of my own experiences as a person with vision impairment.

INSURING A FUTURE OF INCLUSION

The notion that we might learn from the past to ensure the future—a future in which disability is merely conceived as yet another example of human diversity—is a formidable undertaking. Through the analysis of people's experiences, potentially confronting images will assuredly appear. In the past, disadvantage among people with disabilities has been widely documented in English speaking countries (see Barnes, 1997; Oliver & Barnes, 2012 for an account in the UK; Davis, 2010; Mitchell & Snyder, 2012 in the USA; Soldatic & Pini, 2012 in Australia; Devlin & Pothier, 2006 for a Canadian perspective). Despite improvements having been made however, marginalisation is still experienced today by far too many.

   The potholes of disability scholarship can be found here—between marginalisation experienced in the present day by many people with disabilities from various aspects of social life, against the various actions that are aimed at challenging its causes. In this chapter I discuss some of these concerns, and advance a methodological approach to disability studies in education (DSE) that I have been using in schools with young people with disabilities, which might enable us to better attend to some of these matters. On the way I will draw on a metaphor of Spanish cooking, the stories of people with disabilities and their families, some pertinent reports and policies in the field of disability, and some of my own experiences as a person with vision impairment.

MULTIPLE INGREDIENTS

Let us start with food. You might be familiar with the Spanish dish called the paella. To prepare the dish, the chef has the delicate task of making rice, Mediterranean vegetables, legumes, chicken or rabbit and selected seafood work in synergy, by bathing them in the appropriate amount of broth, adding saffron, garlic and other spices, and bringing them to the boil. Ideally when ready to eat, the ingredients of the paella are not layered, stratified and working as individuals, but are mixed, amalgamated, and they work together.

You might also have heard of—even perhaps may have experienced—the notion of inclusive education. Again with an ideal borrowed from the Spanish kitchen, the educator draws on comprehensive training and sets to work in the inclusive classroom—expertly blending all ingredients—students—together regardless of diverse abilities, disabilities, cultures and backgrounds, so that they can learn from an inclusive curriculum.

The paella is then served to the table, or in the case of schooling, our kids transition from compulsory education into a society that is respectful toward diversity. It would stand to reason, then, that graduates with diverse abilities and disabilities who have benefited from this type of schooling can move freely into further education, can seek employment on a level playing field as their peers, and even pay their taxes.

However, while in Australia we pride ourselves on our diverse society—particularly our foody culture—we live in a very hierarchical social order. One in which schools and the practices of educators can constitute and perpetuate much of the inequality that reinforces broader social marginalisation. It might be presupposed that students with impairments who attend inclusive schools are included by definition. However, despite being in the second decade of the 21st century, inclusive education disservices many young people, particularly those with disabilities—both those inside, and those outside of the system.

Tangible Exclusion

I want to pause for a moment to consider the contents of an open letter published by Joel Deane (2013) on the Australian Broadcasting Corporation's now defunct online disability portal Ramp Up. Deane, a Victorian father of 12-year-old Sophie who has Down syndrome, addresses the letter to a local high school—one that he calls Discrimination High—to which he considered having his children enrolled into on their transition from primary school. Deane (2013, para 11) writes:

> Why is Discrimination High the wrong fit for our children? Let me count the ways. The first reason it's the wrong fit is that only three out of 1300 students have a disability – that's less than 0.3 per cent.

Deane (2013, para 12) continues:

> I found that figure surprising given the nearest primary feeder school ... has a large number of students with disabilities. 'Why aren't there more students with disabilities?' I wondered. Then I mentioned to two staff members that Sophie has Down syndrome and had my question emphatically answered. The automatic response from both staff members (and, in case you're wondering, this is the second reason why Discrimination High is a big nyet) was, 'Does she have funding?

Deane (2013) goes on to cite several other causes of his consternation that include the arrogances of staff through their emphases on "mainstreaming", and the existence of the Disability Discrimination Act (DDA) (Commonwealth of Australia, 1992) that has been around for a very long time, though was flagrantly ignored in this encounter. The facts and figures that Deane mentions are no doubt unsurprising to many readers. The experiences that he and his family have endured are redolent of the categorisation that sullies the lives of people with disabilities in education and beyond, despite disability rights having been enshrined in law. The medical model of disability still clearly has loads of currency while our social rights are far too often overlooked.

In a report released in 2011, PricewaterhouseCoopers (PwC) refer to Australia as "the lucky country, where most Australians have the opportunity to dream without limit" (PwC, 2011, p. 8). And indeed, the Australian cultural identity prides itself on the virtues of mateship and a fair go (Bolton, 2003). PWC draw on this argument to illustrate the gaps between this accepted wisdom of equality and its actual effects. Of 27 OECD countries, we rate dead last on the measurement of quality of life for people with disabilities. We are 21st in employment participation rates; that comes to 39.8% of people with disabilities who have a job; and as such, approximately 45% of people with disabilities in Australia live near or below the poverty line (PwC, 2011).

While the purpose of the PwC (2011) report was to leverage an argument for the implementation of the National Disability Insurance Scheme, these numbers also provide a sobering picture of how local instances of discrimination chalk up to produce national and international indicators—and it is important to bear in mind that these only take account of the recorded instances.

THE POTHOLES OF DISABILITY SCHOLARSHIP

It is also important to think about what measures we have been taking to counter the marginalisation of people with disabilities both in and out of schools and to consider where they have gotten us. It is safe to say that the social model of disability has informed policy, practice, and research in the education field. We are beneficiaries of many initiatives incited by the social model, including the United Nations Convention of the Rights of People with Disabilities (Oliver & Barnes, 2012).

In the educational sphere, Julie Allan (2008, p. 46) has described the social model as offering "an escape route from special education knowledge" that importantly

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was set up by people who have disabilities. While it has been used to challenge the barriers within society that limit the participation of people with disabilities—and certainly authoritative special education traditions fall into its scrutiny—too many instances of marginalisation continue to occur. As Joel Deane (2013) found, despite living in a diverse society, despite the cultural affinity with a fair go, and despite the presence of legal binding, inclusion in schools for some can be imperceptibly circumvented. An escape route dotted with potholes can only get you so far.

The social model decries disablement as the root symptom of inaccessible material barriers, above all the economy. But discounting the personification of impairment from social inquiry, simply because it has been lorded over by medical expertism, risks missing the opportunity to examine how we disabled people are ourselves complicit in our own inclusion and exclusion.

I liken the social versus medical model of disability debate to that other divisive political football—global warming. While climate change sceptics are steadfast to the position that the world's weather patterns have always been changing, others recognise that our actions—the reliance on fossil fuels, unsustainable farming techniques and a whole gambit of issues—contribute to the heating of the planet. For them, we are directly responsible. Meanwhile, the social model has traditionally shunned personal responsibility of disablement—directing attention instead on entrenched societal barriers.

On one hand, as Tom Shakespeare (2014) points out, people with diverse impairments are assuredly limited in some way on account of their specific conditions as well as by society. On the other hand, they can also be implicit in their own inclusion and/or exclusion. The legacy of being special: receiving a special education, making use of specialist therapies, supports and assistive technology, struggling to attain gainful employment—and so on can leave people to feel distant from the "normal" citizenry.

While of course the analysis of material social barriers to inclusion holds merit to researchers, by following this conceptualisation of marginalisation alone they can easily miss the opportunity to examine how different expressions of disability from collectives of disabled people might improve our situation. In Shakespeare's (2014, p. 9) terms, "disability is complex, it's multifaceted and it involves all of these different things." It is equally important therefore to work from within—through the embodiment of disability—as well as from without.

Embodying Disability

I embody my disability, and I have done for 30 years. While I have written about concerns I have about the dominance of special education in children's lives (Whitburn, 2013, 2014a, 2014b, 2014c), I acknowledge a particular coercive marker of difference (Allan, 1999) that was bestowed on me through specialist education that is indispensable; and that is Braille.

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Braille is central to both my academic and personal life. I learned to read and write braille from the age of six, when my teachers realised that I could not make sense of print with my low level of vision. Braille—once attained—is a skill that facilitated me access to the general classroom. Braille brought me literacy skills. It opened to me a world of literature and the ability to spell. I've forgotten how to write by hand—and would struggle to scribe in full my name and address in print. But I'm held back by this matter, in particular when information is not made available to me.

One of the chief concerns here is accessibility. Having access to information is key to empowering the lives of people with disabilities. Whether the skills required to gain access are special or ordinary, as citizens, disabled and able-bodied people alike personify the right to use information—though at times it feels more like we impersonate it. Stepping away from the overtone of deficit attached to these particular markers of difference is what is required to make inclusive education embrace these specialist skill sets. And I think that it can't hurt to find out from insiders—those who use Braille, sign language, and text-to-speech equipment, just to name a few—to learn how to go about this rather than relying so constantly, as has been the case, on technical rational solutions.

But of course it takes more than access to information to be included at school. I am reminded here, as a 12-year-old in my final year of primary school, a friend and I were placed in the classroom of Mrs. Collins. We were the only blind students, and the maddening sounds produced by our clunky Perkins Braille machines ensured that we would be relegated to the rear corner of the room—a location that I became grudgingly familiar with throughout my schooling (Whitburn, 2014a).

Though we had full access to our work, one fateful day we both decided to rally for change. Despite—I believe—her best intentions, unwanted attention was constantly drawn to us through her actions highlighting us as the special blind kids. We thought up a plan, and, deciding among ourselves that my friend was the better writer by hand—he had only recently lost his sight—he set to work during a lesson to compile a note. In it, I would later find out, he wrote "stop treating us like invalids", and he slipped it onto her desk as we forwarded out to lunch. Mrs. Collins did stop, and our voices were evidently heard as we were marched in front of the head of special education teacher with a sobbing Mrs. Collins to explain our behaviour. The contest had become personal, not just one of access.

ATTENDING TO THE POTHOLES

I want to change tack a little to contextualise the point of my argument to the methodology that I have been using in the field of DSE. Stories like mine above and Joel Deane's (2013) are useful. They signify a change in the construction of knowledge and the possibilities for research, by offering evidence from the inside of social and political struggles.

These ideas are not new, but they may well yet to be fully appreciated in DSE.

In my research, I like to work small. The principle aim is to conduct exploratory research—to learn how insiders experience inclusive schooling and envisage its prospects for the future (Whitburn, 2014d). Through the nuanced accounts of students with disabilities, I have learned about the multilayered precariousness of their inclusion. Seventeen-year-old Jack, for example, was blind, and he attended an "inclusive" secondary school in Queensland. Enrolled through the special education program, Jack transitioned from his local primary school to this one that was more than 20km from his house, as it was the only one within the vicinity that could provide him access to the high school curriculum. A taxi ferried him to and from school, and a teacher aide—a lady of indeterminable years supported him—and he alone—in every lesson.

Jack could read braille, and he had a laptop with screen reading software, but his computer skills were lacking. The teacher aide, for example, had to help him to perform online research. The dedicated special education teacher hadn't gotten around to teaching Jack these important skills, which would inevitably give him greater autonomy—the element that he aspired to most of all—and would liberate him from the teacher aide—another of his ambitions. I was able to obtain Jack's story through repeated interviews conducted alongside four other students who attended the same high school (Whitburn, 2014b).

Voice and Discourse in Disability Studies in Education

Voice is important. The stories that form this research are provocative when heard in the students' own words. Participants of this research each performed their own brand of analysis on their inclusion—making use of particular language that colourfully illustrated their experiences. One participant contended that personal support from paraprofessionals was like being "in mainstream with a chaperone. It's like going to a party with your parents, or something" (Whitburn, 2014, p. 153). Picking up on this term "mainstream" I asked the group of participants what mainstream school meant to them, and if they were—as they had constantly referred to it—"mainstreamed". One figured he was certainly "in some sort of stream", and his friend elaborated—declaring that his experiences of inclusive schooling were more like being on "A waterslide without any water. You get stuck half way down" (Whitburn, 2014c). The participants' comments produce powerful images. They portray the uncertainty of inclusive schooling in unexpected ways.

Unanticipated voices and the stories of others are joining the chorus. And despite recent policy shifts that appear to stifle the voices of people with disabilities in Australia, such as the axing of the dedicated Federal Disability Discrimination Commissioner position in 2014 (Morozow & Osborne, 2014) and the closing of the ABC portal Ramp Up (Young & Palenzuela, 2014), these voices are gaining resonance. Indigenous activists in Australia have always relied on oral traditions of telling stories to further their causes. Richard Frankland, an Aboriginal artist activist

from the Gunditjmara people spoke recently of the peculiarity he felt when speaking inside parliament house instead of on its steps where he had so often provided voice to protest rallies (Faine, 2014).

Recent context-specific Technology Entertainment and Design (TEDx) talks given by prominent Australians have also framed alternative sensitivities. Established Australian singer, Megan Washington, used the forum in 2014 to declare that she cannot speak without a stutter—a revelation that drew mass media attention (Cheshire, 2014). Late disability activist and comedian, Stella Young, also spoke up against inspiration porn—the veneration of people with disabilities for their undertaking every day, mundane tasks (Young, 2014). More and more we are witnessing stories like these filtering into the public forum.

However, I don't want to overstate the power of voice alone as a potential paradigm changer, nor do I propose that individuals' voices are definitively significant to research. Elizabeth St Pierre (2009, p. 221) cautions that "we have burdened the voices of our participants with too much evidentiary weight. I suggest we put voice in its place as one data source among many from which we produce evidence to warrant our claims". St Pierre draws on Spivak and Foucault to build her argument that voice is constrained within the limits of discourse. We are governed everyday by policies, the actions of others and of ourselves, and thus the words we utter merely fit into the spaces provided us to speak. This is not to say that participants give false or misleading information, but that there is more at stake in a given situation that shapes their views.

As Joan Scott (1992) puts it:

> It is not individuals who have experience, but subjects who are constituted through experience. Experience in this definition then becomes not the origin of our explanation, not the authoritative (because seen or felt) evidence that grounds what is known, but rather that which we seek to explain, that about which knowledge is produced. (pp. 25–26)

I find this postconventional conception of voice constructive for DSE. If we think about what caused the students in my research to associate personal support in lessons with being chaperoned to a social event with a parental figure; or getting stuck halfway on an arid waterslide to describe attending mainstream schooling; we can analyse the larger situation to get a far more intricate picture of the discursive and material elements that colour their experiences. The concerns that these young people raise speak to matters of exclusion in policy discourse, pedagogical practices and support, social marginalisation and an acculturated emphasis on a binary of the abled-normal student versus the pathologised, disabled other (Whitburn, 2014c, 2014d).

On the other hand, I also conducted a phase of the project in Spain with 23 secondary students with diagnosed sensory, intellectual, developmental and physical impairments (Whitburn, 2014e). Here I learned firsthand when less

emphasis is placed on the categorisation of students' supposed deficits, their experiences of inclusion increased. Students reported teachers who were welcoming; who made them feel part of a community; who actively helped them to foster solid friendships; and who adapted both the curriculum and pedagogy to ensure they were included in lessons notwithstanding their specific requirements that differed from their classmates. Despite radical policy shifts threatening inclusive education in the country, any virtues of normalcy (which overwhelmed the Australian participants' experiences) appeared in Spain to be focused more on equality for all, and sharing everyday, mundane experiences of inclusion. This to me was quite astounding.

Like Spanish chefs—specialists in paella preparation—educators in the schools I visited there appeared knowledgeable about the amalgamation of diverse ingredients in classrooms. And while the mixing of diverse ingredients takes a little coaxing at times, the task is not nearly as monumental as we might think. When washed down with a glass of red wine from Spain's Rioja region, social justice can certainly be served.

CONCLUSION

To conclude, I want to return to the theme: Learning from the past—ensuring the future. It requires a commitment to reoriented action. It involves filling in the potholes of disability scholarship by using an alternative set of tools, and making people's stories available in the most unlikely of spaces—both in and out of scholarly literature.

Readers might have heard the yarn where U2 was performing a concert. After completing one of their big tunes and ushering the crowd to silence, front man Bono started rhythmically clapping his hands in three-second intervals. After a few claps he pronounced to the crowd: "Every time I clap another child living in poverty dies." A quick-witted heckler from the crowd shot back: "well stop doin' it then".

It is a humorous tale, but it also makes a poignant statement. Superficial and symbolic actions alone will not advance any cause. We need to stop simply relying on existing theories and policies, and to build on them instead to further the inclusion cause for people with disabilities. And by exploring the gory details that comprise people's stories and experiences, we might gain a greater appreciation of what is at stake.

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