From 'on' to 'with' to 'by:' people with a learning disability creating a space for the third wave of Inclusive Research

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Abstract

For people with a learning disability, Inclusive Research is promoted as *the* right way to redress the hermeneutical injustice of their voices and theorising being excluded from the processes of knowledge production. This article describes the experiences and reflections of non-disabled researchers co-researching with people whose subjectivities were thought to lie beyond qualitative research. Through four stories, jointly told, we detail how those most at risk of exclusion from the academy first challenged and then took the research encounter beyond the linear, assimilative certainties of research 'on' or 'with' people with a learning disability towards the outer, cutting edges of qualitative research and an epistemology that might more authentically be said to be 'by' them.

Keywords

Inclusive Research, intellectual disability, learning disability, narrative research, participatory research

Introduction: moving from 'on' to 'with'

In an era where postmodern skepticism of the grand narratives of objective truth and universal moral authority intersect with an intellectual turn toward pluralism (Ager, 2002), and Foucault's "subject" (Kelly, 2009), there has been a newfound commitment

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to the voices of the disempowered. Perhaps inevitably, social movements like the disability rights movement have responded by also seeking to change the power relationships that historically underwrote the way they are present within the institutions of knowledge production.

For people with a learning disability,[1] Inclusive Research methods are promoted as the way for researchers to right the 'hermeneutical injustice' of failing to engage them in the development of inquisitorial frameworks that articulate their own experiences (Robertson cited in Nind, 2014). Coined originally by Walmsley and Johnson (2003), 'Inclusive Research' was intended to be an umbrella term that included a family of research approaches that demonstrated a democratising orientation towards engaging people with a learning disability as the 'initiators, doers, writers and disseminators' of research about themselves. (Bigby and Frawley, 2010: 53).

One of the claims made for Inclusive Research is, that compared to more 'rejecting' research methods, the paradigm represents a more socially just way of knowing disabled lives (Nind, 2011, 2014). For people with a learning disability, Inclusive Research is typically represented as the destination of a journey that began with their subjugation within the power-knowledge structures of a bio-medically orientated academy, but which ended with belated acknowledgment of their rightful place within research as experts by lived experience and agents of social change in their own right. More succinctly, a shift away from research 'on' to research 'with' people with a learning disability (Walmsley and Johnson, 2003; Johnson, 2009).

These assertions also reinforce and reflect a much broader political project in which the emancipatory outcomes imagined to follow the democratisation of research was but one face of a much wider socio-political movement, ignited by the Social Model of Disability.

Whilst a post-structuralist "turn" towards what Goodley (2001) coined the "resocialising of impairment" refutes the clean delineation between impairment [as biological in origin] and disability [as social in origin] (Goodley, 2001; Shakespeare and Watson, 2002), protagonists on both sides of the epistemological divide acknowledge that the ideological drivers that underwrote (and have subsequently been used to defend) the UK Social Model (Barnes, 2012; Oliver, 2013) were political by design, as disability activism coalesced around a galvanising understanding of disablism as socially constructed oppression.

Consistent with the assumption that "disability" is not intrinsically embodied, but rather locatable within the array of institutional barriers that prevent full and active participation, disabled people's exclusion from the research academy came to be viewed as yet another kind of socially constructed absence, resolvable by dismantling methodological barriers that separated disabled people from the privileged (non-disabled) enclaves of knowledge production and dissemination (Oliver, 1990, 1992). For people with a learning disability, the coincident philosophic drivers of Normalisation (a values-based set of principles asserting the need to be present in 'ordinary" spaces) and later, Social Role Valorization (which viewed achieving valued social roles as remediating the wounds of devaluation) ratcheted up pressure to create less excluding research practices within an academy responding to the clarion call of disability activists "nihil de nobis sine nobis" - 'nothing about us without us.' (Barnes, 2012).

For progenitor of the Inclusive Research paradigm, Kelley Johnson, the key questions that researchers need to keep returning to are; who is doing the research? And for what reason? (Walmsley and Johnson, 2003; Johnson, 2009). For those motivated to follow their lead, the framework Johnson developed with Jan Walmsley has provided the most widely used metric for researchers to determine whether their research falls within (or beyond) the paradigm. Included within the prescriptions for Inclusive Research are five different ways people with a learning disability ought to be methodologically present. Progressing linearly through the research performance they are: the research question must be owned (although not necessarily initiated) by people with a learning disability; research should further their interests and non-disabled people should be on their side; research should be collaborative and people with a learning disability should be involved in the research process; people with a learning disability should be able to exert some control over the research process and outcomes which should also accessible to them. (Walmsley and Johnson, 2003: 64).

More recently, Nind (2011) has argued that being present during all phases of the research process matters in a different way to people with a learning disability. Inclusive Research is to them, she suggests, 'more centrally about the politics of inclusion' (Nind, 2011: 11), foregrounding the 'ethical rightness' of approaches to research that align with this paradigm because they seek to engage people with a learning disability in research that directly affects them.

Nind (2011, 2014) joins others in advancing the inclusive paradigm as 'right' for other important reasons too. It is, she suggests, 'epistemologically right' to mine the rich vein of 'insider' insight accessible by incorporating the voices and experiences of people living qualitatively different (disabled) lives. And 'methodologically right' to mine the qualitatively different data available by involving people with a learning disability in the processes of recruitment, data collection, and analysis. Moreover, it is also commonly asserted that including people with a learning disability enhances the validity of Inclusive Research findings by providing a window into the way people see and interpret the worlds they inhabit (Nind, 2011; Nind and Vinha, 2012), and in the way that assuming multiple social realities allows the contextual and situational to saturate subsequent disability theorising (Chase, 2017).

Often overlooked, however, is a cautionary note sounded by Walmsley and Johnson (2003) and more latterly by Bigby and Frawley (2010) and Nind (2014), about an inherent tension between the aims of the inclusive project and the institutional demands of the academy. Nind (2014), for example, suggests that the quality of co-researchers' participation and the quality of research often pull in different directions. Similarly, in explaining the need for a paradigm separate to the Participatory or Emancipatory Research methods, said to shelter beneath the umbrella of Inclusive Research too, Chapman (cited in Bigby and Frawley, 2010) argued that people with a learning disability are not in the same position to 'own' or 'control' research as other marginalized populations. In spite of their concerns, it appears as if the 'ethical allure' of methods read as an empowering turn away from subjugation has muffled a more critical assessment of the epistemological assumptions that underpin inclusive methods. (Gallaher and Gallaher, 2008 cited in Nind, 2011; Holland, 2008 cited in Nind, 2011)

Accounts of Inclusive Research are, however, replete with caveats by non-disabled researchers, owning up to the way the messy realities of transacting their research

perpetuated troubling asymmetries of power or sidelined disabled co-researchers from one or more elements of the research performance (Conder et al., 2011). Other researchers have voiced concerns about the capacity of people with a learning disability to engage in more complex research tasks too. Bigby et al. (2014b), for example, cite the concerns of Flynn (2003) and Ramcharan (2003) who argue that people with a learning disability sometimes struggle to transcend the personal in ways that uncouple their experiences from wider theorising or social policy. Relatedly, Keirnan (1999), Ramcharan et al. (2004), and Conder et al. (2011), all worry that the, sometimes scripted entrances of trained co-researchers may represent mimetic and inauthentic approximations of non-disabled methods, as likely to interrupt than to promote shared disclosure or meaning making.

Against the backdrop of these concerns, a recent reconceptualization of Inclusive Research as a shared space within which people with a learning disability and non-disabled researchers can advance 'shared and distinct purposes which are given similar attention and make contributions that are equally valid,' (Bigby et al., 2014b: 8) permits the epistemological assumptions of the paradigm to remain largely untroubled and uncontested. Whilst both partners are said to profit from the production of 'hybridised knowledge,' the understanding Bigby et al. (2014b) hold about Inclusive Research makes room for outcomes that make different value claims to be disentangled. That is, the social activism and community development that disabled people seek can be judged against a different criterion to research or theorising claiming a place within the academy.

Uncontested is that the participatory imperatives of Inclusive Research excludes harder to reach voices (Lesseliers et al., 2009; Kellett and Nind, 2011; Bigby et al., 2014b). Those missing voices include men and women whose subjectivities are communicated beyond the ordinary lexicon and those for whom embodied difference intersects with an array of other material, social and geographic marginalities. The effect of this omission is that the 'expertise' of (sometimes very) differently experienced lives of people on the fringes of the disability narrative make no contribution to the processes of knowledge production that claim to speak on their behalf (Milner and Mirfin-Veitch, 2012). Perhaps more concerning is that the (sometimes very) differently configured bodies and minds of people situated on the fringes of disability research have made no contribution to the development of Inclusive Research methods either.

This article seeks to address a sense of disquiet occasioned by the authors' current and past attempts to research 'with' people with a learning disability. In particular, it confronts the way a 'linear' focus on the methodological context to research can provide the illusion of inclusivity while continuing to position people on the margins of indigenous knowledge production. For the second author, the need to incorporate the 'relational rightness' of the research performance amongst the constellation of 'moral,' 'methodological' and 'epistemological' rightnesses came through Inclusive Research on self-advocacy that led to a more nuanced understanding of belonging as part of the self-advocacy experience (Frawley and Bigby, 2015). For the first author, it began with a project that sought to redress the dehumanizing way disabled co-researcher Adam Robinson appeared to experience a research collaboration that occurred more than a decade before (Milner and Bray, 2004). In the following section, we link the vestigial echoes of these research encounters to the development of a project that sought to story the lives of thirteen people with high and complex support needs. Four stories jointly told

within the Article 19 project are then drawn on to interrogate how reimagining the subject positions of those at greatest risk of being excluded by the epistemological prescriptions of Inclusive Research might lead to the co-creation of research encounters that answer the call of people with a learning disability to become representationally present in ways they might claim as their own.

Like Nind (2014) and Bigby et al. (2014b), we tap a sociological understanding of space as a container of relationships with the potential to draw social actors out (or inside) of themselves by the way that social action is structured (Foucault and Miskowiec, 1986). In particular, we explore the way storytellers with a learning disability changed the trajectory of a narrative project in ways that led us to think differently about four important epistemological questions:

- Who can be included (and who must, therefore, be excluded) as both disability researchers and/or 'participants' in research claiming a place within the inclusive paradigm?
- Whether the 'assimilation' of disabled researchers within inclusive research transforms the encounter in ways that enhance the ability of people with a learning disability to make their complex and confounding narratives more authentically their own.
- Whether allowing people to control how they are present in research through individually responsive methods advances the processes of meaning-making and indigenous theorising.
- And whether cues encoded in the missteps and resistances of people with a learning disability might be instructive of the methods they might develop as 'emic' forms of knowledge production.

'I am here:' Article 19 project

Because their subjectivities are seen to lie beyond the technologies and practices of conventional qualitative methods, people with "significant" or "profound" learning disabilities have had little or no chance to self-author their place within our historical record, nor to contest the many 'unauthorized' representations they encounter as paradigmatic truth. Theirs are, according to Atkinson and Walmsley (1999), the 'lost voices' of qualitative research.

From a human rights perspective, this silence is problematic. Situating disability rights within legal frameworks, like the UN Convention on the Rights of Person's with Disability, exposes the 50 codified rights to politically contestable discourses (Jolly, 2009 cited in Milner and Mirfin-Veitch, 2012). Who owns the meanings that give expression to rights like 'the right to full inclusion and participation in the community' (UNCRPD, Article 19), has profound implications for people subsumed within the heterogeneity of disability. The danger is, of course, that by excluding certain voices from the research canon, we unwittingly create a narrow disability script. As Jackson and Mazzei (2009: 1) note, qualitative researchers have been instructed to 'free the voice from whatever restrains it from coming into being.' Until we find ways of hearing from those most likely to be exposed to an abuse of rights like Article 19, we can make no

claim to having had a complete conversation about progress towards the realization of either universally human or distinctively different disability rights.

In 2011, a New Zealand disability service commissioned a research project to make transparent the day-to-day lives of people with high and complex support needs.[2] In the discussions (with and without disabled people) that shaped the eventual design of the Article 19 project, a decision was made to locate the research within the narrative tradition. To the forefront of the minds of those who steered the research was the academic tradition of testimonio, and in particular, the way testimonio seeks to illuminate the darker corners of oppression and disablement by giving flight to unheard voices (Chase, 2017). The hope was that by creating a publically accessible library, canvassing the social, physical and relational landscapes within which the stories of thirteen people dwelled, the project might contribute to a national conversation about the human rights status of people with high and complex support needs. All co-authors (and their allies) entered consenting (hoping even) that their story would populate the anthology. They also knew their narrative would provide a transparent link to a project report and a range of other research outcomes intended to generate meaningful social change in Aotearoa/New Zealand.

Paradigmatically sensitised to the need not to 'over-write' people's narrative, our retrospectively naïve hope, was to provide people with an opportunity to tell their own story their own way. As we would quickly discover, however, narrative has a way of pulling both story-teller and listener out of themselves and into a dialogical relationship. As is discussed in greater detail later, not only does the hermeneutical process pull those engaged into deeper relationship - obliging as it does a shared search for why a story matters (Meininger, 2009), it also exposes what Meininger (2009) described as the sometimes 'calcified' meta-narratives that shape our encounters with people and with place.

Embarking on the research, two methodological challenges confronted the research team. A primary concern was how to create subjectively truthful narratives when many of the people we were working with, we knew would need to (to also borrow Tim and Wendy Booth's [1996] expression), 'loan our words.' The response of the research team was to offer a panoply of eight research methods, unimaginatively drawn from the qualitative research kit bag that storytellers could choose, adapt or reject as ways of generating the kinds of (un)conventional 'conversations' they needed to co-author a story they might claim as their own. The methods included; self-chosen personal archives, semi-structured and key informant interviews, photovoice, the objective scale of the ComQOL-ID (Cummins, 1997), an adapted version of John O'Brien's (1987) concentric friendship field and Time in Place maps that traced co-authors community presence, similar to the space-time paths pioneered by Härgerstrand (1970).

Our second methodological concern was how well would people with high and complex support needs respond to the imposed epistemology and research methods of a paradigm beyond the compass of their ordinary lives. Our response to that challenge was to begin the collaboration by supporting each person to design their own, bespoke research presence.

Thirteen continually evolving research encounters

To the thirteen disabled co-authors, their narrative emerged as the project's most significant legacy and their (physical) story its most important artifact. In a way that connects

with the second wave of feminist research, it was, the personal (and not the research process nor indeed the outcomes that spun off it) that was politically tangible. When asked about their motivation for participating in the research, we were told in many different ways, *"because I want people to know who I am."* Being able to offer readers a chance to "listen beyond their words*"* (Bertaux-Wiame, 1981; cited by Goodley, 2001) appeared to hold the hope that others might recognize a causal link between their story and an anthology flush with the everyday injustices of exclusion that accounted for their perceived invisibility. Again, although not articulated as part of the project's original design, acknowledging and responding to the imperative to be seen and heard crystalized as an unexpected and intuitively ethical design principle to the reconfiguration of methods that began the first morning co-authors met.

To collect the information needed to generate the first draft of their story, co-authors typically worked alongside each other for between three to five days. More importantly, the first meeting always began with a long discussion that traversed what each partner was hoping to gain from the project and how they might work together to accommodate the motivations each brought to the research encounter. Sometimes this was explicitly discussed with the co-author and/or the allies they chose to help them tell their story and sometimes it needed to be inferred as each story telling collaboration followed its own negotiated trajectory.

In addition to the pragmatism of learning more about the methodological elements disabled co-authors (and their allies) felt might work, it was important to the research team that this initial research encounter began with a clear understanding that it was the disabled co-author's role to orientate their writing partner to the parts of their life they felt were important. Equally important to communicate was that co-authors could shape the way the week unfolded, in ways that attended to their participatory motivations.

As is discussed later, the research team felt that this process of co-designing methods to fit the uniquely different minds, bodies and landscapes that acted as the backdrop to people's story-telling took the project's methods to the very edges of qualitative research. As a consequence, we came to appreciate what the thirteen co-authors appeared to know already. Namely that the limits of epistemological possibility were largely inked in by the knowledge-power relationships within which research is always jointly configured.

Full of beans: Richard Beale's story

To an untrained ear, Richard had a lexicon of about nine readily recognisable words with which to craft a conventional story. Beyond 'yes' (yes) and 'no' (no), Richard could communicate; 'tomorrow' (Is it happening tomorrow? or What are you doing tomorrow?), 'cappuccino' (cappuccino with cinnamon and marshmallows), 'egg sandwich' (egg sandwich or dad), 'mum' (mum) 'Over there' (used interchangeably to mean the disability service office or his community group home) and 'home' (which only ever meant Richard's family home at Hilderthorpe that remained the social and emotional hearth to his life).

Richard was also highly visible to his community. As is described in his story (Beale et al., 2012), Richard lived a highly migratory life. He could often be seen motoring (in his chair) down the wide footpaths of Oamaru where his circumnavigations were constantly

interrupted by people who would stop to ask him if he was off for his cappuccino? Or whether it would be the egg sandwich or cream cake today? Or to tease him about women.

In the course of orientating his writing partner to his life, Richard and his research partner realised that all of his less ambiguous articulations represented ways for him to generate the migrations he regularly took. This realization led in turn to an unexpected and intuitive outsider discourse analysis in which each word's purpose and Richard's reading of the destinations that represented his entire vocabulary were unpacked. Within his story, the various ways Richard experienced the cardinal spaces of 'home' and 'over there' were juxtaposed, which became his way of 'talking back to' a life bent to the customs and routines of (misnamed) community group 'homes'(s). That part of Richard's narrative begins:

'At Home,' there is a plate on an open gate at the top of the drive that announces Richard as belonging to the social landscape of his community. 'Over there,' a sign at the entrance instructs visitors to keep the gate shut for the safety of a resident.' (Beale et al., 2012: 1).

Why don't you come to my place? Scott and Graham's story

Scott and Graham McDonald are brothers. They share the same family home, forty winding kilometres south of Rotoroa and a couple of corrugated turns on from the Reporoa turnoff. They also share a rare genetic disorder (Cohen's syndrome) – but little else. Graham is urbane and would like to become a model and Scott 'has the mind of a farmer' (McDonald et al., 2012c).

For both young men, Cohen's syndrome is meaningless as a form of social knowing. Instead, they are both defined by their passions. For Scott, it is his love of farming, obsession with farm machinery and his remarkable memory for the specification details of farm equipment extracted from the rising tide of catalogues in his wardrobe that local distributors send (McDonald et al., 2012c).

Within an hour of our first meeting, Scott wordlessly pulled his writing partner into his place by insisting on a walk. In effect, Scott's first reaction was to guide his co-author towards inscriptors of personhood coded within the landmarks they 'bimbled' through that morning – unexpectedly and intuitively approximating the walking methods pioneered by Anderson, (2004) and Moles (2008) or the 'Go-Along' method developed by Castrodale (2018) as a way of accessing and attending to spatially locatable narrative. In being forced to 'get in step' with Scott, his writing partner became aware of the alternative ways he and his mum read the same community spaces. To Scott's mum Jane, places were sites to conduct an almost unconscious interrogation of their potential to seed new relationships. And for Scott they represented an opportunity to relieve his unquenchable impulse to shake peoples' hands and to ask them if they owned a chainsaw? . . . and if it was a Husqvarna 120i?

The walk that Scott insisted on taking opened Scott and Graham's story. A narrative that he and his family used to 'talk back to' the way people with a learning disability become relationally dislocated by understanding the purpose of support as being to connect people to places and not people to people.

Stepping stones along my journey toward independence: Angela Griffin's story

Another method offered as a possible way for disabled co-authors to locate themselves was by generating Time in Place maps. Centred on each co-authors home, the three-dimensional maps plotted where and for how long each person was present in all of the community locations they visited between 9 a.m. and 9 p.m. for one week of their lives. Reflecting on the tracings left by each person's map entangled writing partners within an evolving dialogical relationship in which each took turns as surprised witnesses, speculative theorists and ultimately characters within the resultant narrative.

Within the body of her narrative, Angela's story captures her writing partners surprise that she did not experience her inability to get beyond her flat for more than four hours a week as socially isolating. In the braided conversations that punctuate the story, Angela responds to the question, 'How well do you know Oamaru?' by saying she '[knew] it very well.' When asked 'How well does Oamaru know you?' however, the text records Angela as saying, 'Most places I go absolutely no one knows me.' (Griffin and Milner, 2012).

As the narrative unfolds, Angela goes on to explain that within the context of a life spent trying to escape the dehumanising cadences and social conventions of different forms of institutional 'care,' her newfound ability to invite others into the daffodil yellow of her small flat meant that to Angela, her community now came to her.

Whilst not part of the original design, this unexpected and intuitive narrative form approximated the ground-breaking ethnographies of Behar (1993), allowing co-authors to enter what Tedlock (2012) colourfully describes as the polyphonic border-zones of creative non-fiction.

Frog: Chris Lucas's story

Half of the co-authors who contributed stories to the Article 19 project chose not to diarise their time in place. Given the way their bodies worked, the method was often impractical. Chris however, rejected Time in Place mapping for another reason.

Chris was a man who valued independence and wanted to communicate his sense of being unshackled from the routines and social practices of disability support. 'People always ask me what I am going to do tomorrow, but I always say I don't know because I don't,' (Milner and Mirfin-Veitch, 2012: 77) he told his writing partner. Of the thirteen co-authors, Chris was the only person to have a job. Chris collected mail from three local businesses and delivered it to the post office. Contributing to his community this way was important to Chris but he also liked the job because the loose employment arrangement meant it was something he could do with the autonomy and unpredictability he courted.

Chris also loved body art, most of it themed around his nickname 'Frog.' To Chris, his inkings appeared to represent another way of wearing his autonomously defined identity – this time on his skin.

Chris's writing partner was one of the few people that Chris had permitted access to the private social world of the tattoo parlour. He had pre-arranged the session because it was important to Chris that his story capture that within the parlour, his differently articulated body disappeared with a community who recognized a man simply seeking to add to his

profoundly personal collection of body art. 'I know him really well and he knows [my] body. That is important. He knows who I am and he knows how I move' (Milner and Mirfin-Veitch, 2012: 88). Knowing who he was in the stillness and silence of inking was more instructive, Chris felt, than exposing how he moved in the, sometimes discriminatory spaces and migrations, he was forced to take because his community group home closed between 9.30 a.m. and 3 p.m. To Chris, placing himself visually within his narrative within images that captured motionless time was his way of 'talking back to' the way imposed qualitative methods expose people to renderings that bare no relationship to their subjectivities.

Research as spaces of subjectivised invitation

Inclusive Research methods emerged as ways of 'inviting' disabled people to contribute to the academic discourse about themselves. In seeing participatory research as 'spatial practice,' however, Thomson, cited in Nind (2014) makes a clear distinction between two different kinds of spatial invitation. 'Closed [research] spaces' and 'claimed and/created spaces in which participants create new power and possibilities.' (Nind, 2014: 7).

Within the body of Inclusive Research, many examples can be found of innovative and creative ways that co-researchers have found to collect (Bigby et al., 2014a) analyse (Nind, 2011; Holland et al., 2008 cited in Nind, 2011; Nind and Vinha, 2012), and present research data, (Goodley and Moore, 2000; Rice et al., 2015) re-define roles (Woelders et al., 2015) and even to challenge major quasi-methodological frameworks like the Quality of Life Construct (Conder et al., 2011).

The creativity obliged by people with a learning disability participating in research ought not, however, to obfuscate that the price of their admission into the academy has been to acculturate to a pre-scripted paradigm. Both explicit and implicit rules and conventions have continued to underwrite an assimilative assumption that Inclusive Research is best realised by training/supporting/educating (or collaborating) with people with a learning disability in ways that approximate us. In this sense, the very architecture of the Inclusive Research methods reflects deeply embedded assumptions about the embodied 'otherness' of learning disability and the biological (rather than sociological) origins of learning dis/abled in/competence.

When viewed as assimilative research space, the journey people with a learning disability have taken towards inclusive methods might more accurately be characterised as a migration from 'incompetent' to 'imperfect' knowers. More recent reconceptualisations of Inclusive Research as involving a symbiotic encounter between social actors bringing different skills but seeking outcomes that make different and divergent value claims (Bigby et al., 2014b) triages co-researchers down the dividing line of methodological imperfection. That is that it is legitimate for academics to carve off elements of the research collaboration that fit with the epistemologies (and vested interests) of the academy from other less valid, less reliable and atheoretical forms of knowledge production. Rather than de-privileging or depowering professional ontology, this conceptualisation of Inclusive Research may represent a subtle re-inscription of relational power that makes the spatial invitation demanded by the praxis 'nothing about us without us' but which continues to appropriate disabled people's experiences and theorizing by continuing to position them as 'other'.

Writers who interpret Foucault tell us that it is the power/knowledge complex of discourse that circumscribes the range of possible ways we constitute ourselves as subjects. A process he neologically coined 'subjectification' (Heller, 1996; Kelly, 2009). Foucault argues that the subject's ability to speak and act is bounded by the discourses through which her/his subjectivity is constructed. Like Heidegger, Foucault viewed subjectivity, on the one hand, as "always already," in the sense that we are always and already situated with concrete activities and ways of acting that are woven into the structure our perceptions (Kelly, 2009).

Asserting that the paradigm of Inclusive Research represents a changed and 're-righted' social position for people with a learning disability ought, therefore, to invite deeper reflection about the extent to which any real change has occurred within the discourses through which power finds expression. Learning more about the subject positions of those entangled within the research performance is doubly important when we consider that the 'rules' of this newer epistemological dance have almost entirely been choreographed within the same institutions the proponents of Inclusive Research methods hold responsible for their original methodological subjugation. What we have yet to ask ourselves is, how many of the formally dehumanising practices and technologies have been carried forward as 'always and already' within the reproducing social spaces of more contemporary research encounters.

People's capacity for self-articulation is the second way that Foucault suggests we constitute ourselves as subjects. In unpacking Foucault, Kelly (2009: 89) argues that subjects create themselves 'like pearls around foreign particles of power' through the complex and reciprocal processes of hegemony and counter hegemonic resistance.

Through the auto-ethnographies of Lesseliers et al. (2009) and Woelders et al. (2015) we have some understanding of the subjectivities of non-disabled researchers seeking to walk Nind's (2014) tightrope of research that neither exposes nor excludes people with a learning disability within the prescriptions of the 'inclusive' paradigm. To date, however, we have little more than a coloniser's understanding of the way people with a learning disability experience the research encounter. As a consequence we cannot – nor should we – answer the question, 'what would an emic epistemology look like if people with a learning disability had the opportunity indigenous researchers have had to shape what happens when strangers meet within the research encounter?'

If we are serious about our democratizing intent not becoming just another form of discursively organized colonization, we argue that a similar investment in understanding (and responding) to the subject positions of our partners in the research performance ought to become the foundation principle of relationally reconfigured research methods. In doing so, we align ourselves with Goodley and Runswick-Cole's (2016), who issue an invitation to draw on the radical potential of people with a learning disability to 'disrupt, shake up and interrogate(s) the normative' by approaching us from the other side of the dis/ability binary. And with Delueze and Guittari (1987) who also argue that attending to the ontologies of the 'imperfect' and 'unknowing', represents the best way of gaining access to the inventiveness and creativity required to transcend the limitations of pedagogical certainty.

For inclusive researchers, becoming more open to the (im)possibilities of renegotiated subject positions might yield, new and more fluid research methods, new modes of representation that resonate within the cultures from which stories have been drawn, and the

elevation of new and unfiltered voices and theorizing. More importantly, it may offer the possibilities that come with new and more human ways of being and becoming together.

Research as spaces of possibility: reciprocally responsive research methods

> We have taken freedoms away from human beings, not because one culture oppresses another, but because we have lost the imagination of what 'sight' meant. It is important to re-establish the question, how do I have to be as a human being in order for others to be free? . . . Freedom is not freedom from something or to achieve something. It is freedom to be present with. (Bishop, 2007).

We short-titled the Article 19 research project 'I am here,' It is the recursive response to a traditional South African greeting (Sawubona) that opens with the greeting, 'I see you.' In his explanation of the greeting, Orland Bishop tells us that it is derived from an older proverb, 'A person is a person because of people,' reminding us that we are all pulled into existence when people see us in a way that we might answer, 'I am here' (Bishop, 2007).

Because of the way disability theory has conceptualised the journey to inclusion, the social typology of the 'stranger' has often been invoked to describe the 'otherness' of people with a learning disability. A spatially present but socially absent archetype of disablism or representation of people as the victims of a wider structural failure to acculturate to the cultural spaces and institutions of the economically, socially (and academically) powerful. But this is not the way the social typology was imagined by German sociologist and philosopher Georg Simmel (1908). To Simmel, the stranger had a critical role to play in society by gifting others the 'wonder and shock' of new ontologies. It is the stranger, Simmel (1908) concluded, who challenges and contests moribund and unethical ways of thinking and the 'others' amongst us who are always the drivers of significant social (and epistemological) change.

As a consequence of the tools and technologies of qualitative research being of limited use, either to the researchers who brought them or to co-authors described by Atkinson and Walmsley (1999) as the 'ultimate other,' the people who meet through the research performance of the Article 19 project had no option but to enter a transformative third space as equally dis/abled. For their part, the thirteen co-authors with a learning disability welcomed and guided their writing partners into the homes, relationships and experiential landscapes within which they felt their stories were locatable, challenging and contesting the preference of a colonising epistemology for the bright line of relational separation.

By blurring the lines of social distance, co-authors potentiated unscripted and ever-changing ways for writing pairs to get to know each other. In Deleuzean speak, the lines of inquiry that shaped the stories of dis/abled story tellers continually fractured along unexpected and intuitive lines of flight as people reimagined themselves within their own and each other's life narrative (Deleuze and Guattari, 1987). Spreading outwards from an 'unimaginative' smorgasbord of conventional methods, writing partners nomadically wandered across a panoply of different ways of co-creating their story. In thirteen separate journeys, dis/abled co-authors were at liberty to take their dis/abled writing partners to the outer, cutting-edges of qualitative research methods, similarly challenging

and contesting the way they are constructed as less useful generators of knowledge or 'imperfect' transactors of qualitative inquiry.

Richard, for example, orientated his writing partner to a less conventional discourse analysis, engaging them both in a dialogical exploration of the meanings embedded in but two words lifted from his skinny lexicon. Scott, on the other hand, insisted on walking methods as a representational modality that fit with the uncaged gregariousness and energy of a man at risk of being of being understood as having Cohen's syndrome. Intuitively, Scott yanked his writing partner into the social and physical landscapes that encoded a narrative he didn't have words enough to describe. Even the way Scott and his family chose to write their story as one interlaced narrative, disrupted the trope of 'voice' belonging to an individual (Goodley and Runswick-Cole, 2014). In addition to reflecting the reality that people with a learning disability often answer back with distributed voices, their storytelling also acknowledged that for Scott and Graham, dis/autonomy and dis/independence were relationally situated within the assemblage of people that together supported their expression (Goodley and Runswick-Cole, 2014). Angela, on the other hand, invited her writing partner into the daffodil yellow of her home and a place within the narrative of an equivalently polyphonic story. And Chris steered his writing partner away from methods that, to him, provided a disabling counterpoint to a life spent resisting the assumptions and prejudices of others.

Similarly, by beginning the encounter by, 'doing what we (could) whilst leaving a place for what we (could not) envision to emerge' (Lather, 2009: 21) dis/abled writing pairs opened a space for new voices and new modes of articulation to infuse the research encounter.

Not only are people with a learning disability still waiting to hear their unedited and unexplained voices within the biblitheca of the academy, those who argue that they have a place are required to demonstrate nimbleness within the minefield of critical disability theory and a grasp of problematized constructs like subjectification and narrative authenticity. As a consequence, academics, by self-created self, find themselves with little option but to draw on the othering and completely inaccessible vocabularies of Foucault and Deleuze and Goodley and Lather and now ironically, Milner and Frawley.

If instead we approached the research encounter with humility enough to hear the 'unknowing' voice, we might expand the horizons of theorizing in ways that make room for the seemingly unassimilable vocabularies of people with a learning disability too.

For example, people with a learning disability are commonly accused of lacking theory building capacity. Some have argued that the inclination they have to use their own lives as their reference point for new information makes it difficult for them to see connections to larger meta-theories or to generalise beyond their own experiences (discussed in Nind, 2011). Such an understanding misrepresents the potency of the personal as a site of knowledge generation and activism. It also exposes the difficulty researchers sometimes have in stepping beyond their narrow library of paradigmatically privileged stories.

For example, Angela's seemingly simple observation that the migrations that patterned Richard (and Chris's) weeks might also be explained by their inability to invite people into the sacred space of 'home' (Griffin and Milner, 2012) carries seeds of theorising that connect the meta-theories of human development (Ainsworth and Bowlby, 1991) with the recent 'mobility turn' (Sheller, 2014; Castrodale, 2018) and our attempts to theorise the human journey towards 'belonging' (Hall, 2010). Angela's observation is

not atheoretical. It reflects the same (ordinary) imperatives, to make her world more predictable, known beyond herself and socially just that drive institutional theorising.

Moreover, Angela's postulate that people migrate in search of relational proximity asks an important methodological question too. How might we invite people with a learning disability into the institutions and sacred spaces of the academy in ways that they might also experience the freedom to be present with.

In the Article 19 project, we found it in the gravitational pull of a less-hierarchical, humanised third-space, within which thirteen disabled co-authors invited their writing partners to be present in ways imaged by the gift of Sawubona. Recognising that real power lay in defining the codes of conduct that strangers employ to pull each other into existence, the people the first author met through the Article 19 project and second author met in trying to reach a more nuanced understanding of self-advocacy demanded that their research partners abandon the constraining social construction of a disconnected and objective observer by inviting them into the relational and material landscapes within which the research relationship was unfolding. Human first in ways that began to allow both co-researchers to say and to answer, 'I see you.' 'I am here.'

To those whose lives intersected through the Article 19 project, re-establishing Orland Bishop's' (2007) question, 'how do I have to be as a human being in order for others to experience the freedom to be present with? necessarily involved entering into relationships in which either and both partners could, as Goodley and Lawton (2005) imagined, interchangeably be and become; learner/educator, transformer/transformed disabled/able – story-teller/listener. It is within this relational space that we think thirteen narrators, previously constructed as less valid creators of knowledge, may have taken a tentative step beyond research 'on' or 'with' to more authentically research 'by' themselves.

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Notes

1. 'Learning disability' and not 'intelletual disability 'has been adopted because it is the preferred referent of the New Zealand national Self Advocacy Organisation, *People First*.
2. The Article 19 project received ethical approval from the New Zealand Health and Disability Ethics Committee.

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