Disability Studies

Educating for Inclusion

Tim Corcoran, Julie White and
Ben Whitburn (Eds.)

Disability Studies

INNOVATIONS AND CONTROVERSIES: INTERROGATING
EDUCATIONAL CHANGE

Volume 3

Scope:

Education is a dynamic and contested area of public policy and professional
practices. This book series identifies and critically engages with current responses
to worldwide changes impacting education. It is a forum for scholars to examine
controversies and innovations that emerge from patterns of inequality and social
injustice in increasingly globalised contexts. This series is particularly interested in
interrogating education through notions of social change, inequality, the movement
and displacement of ideas and people, gender and sexuality, community, disability
and health issues. Forthcoming books in this series will explore controversies and
innovations (including but not limited to):

• education and social theories/frameworks
• changing approaches to, patterns of and policies for education research
• politics and policy
• economics of education
• curriculum, pedagogies and assessment
• technology and new media
• interdisciplinary research.

Disability Studies

Educating for Inclusion

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All chapters in this book have undergone peer review.

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ROGER SLEE

INTRODUCTION

Disability Studies in Education as an Applied Project

The establishment of a Special Interest Group (SIG) dedicated to Disability Studies in Education in the American Education Research Association (AERA) in 2001 was a bold declaration of an alternative view, or more precisely, a radically different paradigm for understanding disability and disablement in education. It also signalled the determination of the founding members to rule a line under the *business as usual* approach to researching disability and education. Dissenters from the traditional special education, and axiomatically the regular education paradigm, shuffled between disciplinary groups and SIGs to present their work at AERA Annual Meetings. The absence of a Disability Studies in Education or Inclusive Education SIG was silencing critique. Typically presentations on disability studies and inclusive education were considered to be *special needs* papers. This of course was not the case. Too frequently reviewers schooled in traditional special education rated them lowly. The epistemological impasse needed to be called and structural accommodations were made. Formalising our union made good sense. Evidence of this good sense could be measured (for measure we must) through a number of indicators. The growth of interest, the quality of our publications and research projects, and the continuing commitment of people to bring scholars, educators and activists together to work collaboratively to take our work to broader audiences count in the calculus of research quality.

   Not surprisingly, in the early days, the nucleus of the seminar, symposia and roundtable participants were the usual suspects. This has changed over the years. Scholars from various disciplines are confronted by the intersection of disability and their research interests – be it gender, psychology, identity and body research, post-structuralism, critical race studies, poverty and educational underachievement and so the list goes on. The Disability Studies in Education SIG ultimately provides a platform for the assemblage of broad interests. This conference is indicative as is evidenced in the reach of the presentations and the chapters in this collection. Disability Studies in Education (DSE) is certainly an intersectional research endeavour. It draws from across a range of critical research traditions, disciplinary interests and research methodologies in the quest to advance the rights of people with disability to access and participate and succeed in education. Not all of these theoretical perspectives and research paradigms stand comfortably together on our

platform. This is to be welcomed. Tensions that spill into debates that force people to embrace doubt as a healthy part of developing knowledge are our friends. Quietly nodding uncritical agreement with each other (or nodding off) in our sessions is unhelpful. Orthodoxy, as Edward Said reminded us in his essay *Travelling Theory Revisited,* serves to domesticate that insurrectionary zeal that was the incubus for DSE.

DSE is an international research movement and this text reflects the global reach of the SIG. The awards for outstanding scholars reflect our international character. The Senior Scholar Award was conferred on Professor Athina Sideri, an eminent scholar from The University of Athens in Greece. Professor Sideri has been at the centre of disability awareness training for graduate students in education. Professor Sideri's research centre at The University of Athens brought the social model of disability to special education courses and transformed the paradigm. It is important to remind ourselves that we have much to learn from countries and languages that have not dominated this research space. Similarly Ben Whitburn, the recipient of the Junior Scholar Award, draws deeply from his research in Spain and Australia to challenge the emerging orthodoxies in our SIG. His is a timely call to broaden the theoretical mix to meet the challenge of retaining our critical sensibilities, which deal not only with changing external exigencies, but challenges ourselves. This is what our colleague Julie Allan may have had in mind when she counselled us to see inclusive education as a project on self.

If I am honest my memories of the Disability Studies in Education SIG in its early days was frustrating. It seemed more like a support group or a religious meeting than a congregation of researchers to challenge and extend the research. The meetings generated affirmations rather than debate. This appeared to this observer very different from the Disability Studies colloquia that were organised by Len Barton that culminated in the Disability Studies Conference entitled *Disability Studies: Past, Present & Future,* in Ashford in Kent in 1996. This conference was the site of a major division in disability studies when Tom Shakespeare, Jenny Corbett, Mairian Corker and Carol Thomas issued important challenges to the social model of disability. While there have been some unfortunate effects such as the personalising of the debates and some fracturing of the movement, the challenge has been essential to building a contingent and dynamic field of scholarship. The Disability Studies in Education SIG is now epistemologically more lively and poly-cultural. So now, as I think on the Melbourne gathering I feel sanguine. My only concern is what I will miss as I shuffle aside for the next and better cohort of Disability Studies in Education researchers.

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PART 1

EDUCATION – SCHOOLS

JENENE BURKE

1. NOT JUST FOR THE FUN OF IT

Children's Constructions of Disability and Inclusive Play through Spatiality in a Playspace

INTRODUCTION

In Australia, the notion of providing opportunities for children with impairments to access play in purpose-built spaces, and have fun alongside their peers and siblings, has gained momentum, translating into the development of some new and exciting 'inclusive playspaces'. Previously, very little attention or importance was given to the idea that playspaces might exclude some children and carers with impairments from shared play in community spaces. Recently, in paper titled 'Just for the fun of it' (Burke, 2013), I advanced an argument supporting the concept of playspaces that are inclusive of all children and that provide access to the experience of shared play. This paper highlighted the vagaries that apply to various attempts to ensure accessibility and inclusion in purpose-built playspaces. I concluded that inclusion in play environments should be considered an important political objective to facilitate healthy, vibrant, fair and connected communities. The reasons why children with impairments should have access to peer play in community and school spaces, however, are much more complex than merely providing access to fun and entertainment for children with impairments and their family members. When examined through a Disability Studies lens, how children construct disability and form views of those with impairments through their experiences of using in a playspace becomes an issue that requires close attention. In this chapter I explore the concept of spatial exclusion in playgrounds, from a disability studies perspective, by drawing on ideas from Armstrong (1999, 2012), Relph (1975) and Imrie and Kumar (1998) to help explain how space can be used in a playground to convey implicit messages about impairment that highlight difference, particularly, of children who use wheelchairs for mobility.

Playspaces, because of the way they are configured, spatially and physically, are likely to contribute to the creation and production of social constructions of disability and of disabled people. Armstrong (1999) insists that social groups of children can be defined by how children separately and collectively read meaning into the spatial organisation of their environments. Catling (2005) agrees, and claims that school playgrounds provide an 'explicit statement about the relative *status* [emphasis in original] of children' (p. 28). It is likely then, that a similar process of

social reproduction often applies in playspaces, with regard to how social roles and relationships are defined and understood by children and I interrogate this idea in this chapter, providing evidence from my research. In this chapter, the term 'playspaces', as defined by Woolley and Lowe (2012), refers to 'outdoor environments that have been specifically designed and designated as a place in which children can play' (p. 2). Such playspaces are recognized as being broadly accessible to the public at large and are typically found in public parks, schools, preschools and some fast food outlets.

The qualitative study reported in this chapter is drawn from a nationally funded Australian Research Council (ARC) Linkage Project (ID: LP0349365) that examines playgrounds as spaces that potentially offer all children opportunities to be included in peer play. The author was the PhD. candidate who completed the research. The ethnographic study took place from 2004 to 2009 in regional Victoria, Australia.

SOCIAL MODEL OF DISABILITY

Disability Studies, which was described by Barnes in 2004 as 'a new interdisciplinary area of enquiry' (p. 28) that is concerned with scholarly exploration emerging from the social model of disability (Barnes, 2004; Gabel, 2006; Thomas, 1999). More explicitly, the term, 'Disability Studies', according to Thomas (1999), is used to refer to those who, in studying disability 'explicitly align themselves with the social movement for the advancement of the social and political rights of disabled people' (Thomas, 1999, p. 8). Siebers (2008), moreover, agrees with Thomas and emphasises the primary political objective that is inherent within a Disability Studies perspective is 'to make disability an object of general knowledge and thereby to awaken political consciousness to the distasteful practice called "disablism"' (p. 81).

Within a social model, disability is understood as a socially constructed phenomenon due to the fact that people with impairments are put in a position of disadvantage because they must overcome barriers that are not impediments to people without impairments. They are disabled by these impediments, not by their own individual attributes (Finkelstein, 2004). A clear distinction is made between the concept of 'disability' and the concept of 'impairment'. Impairment is regarded as an individual's functional limitation. Disability, in contrast, is defined as something that has been socially created because of limitations imposed on people with impairments by features of the environment, ie, the 'disability' arises from the 'impairment'. The World Health Organisation (2002) explains that disability is viewed as a political rather than an individual issue within the social model:

> On the social model, disability demands a political response, since the problem is created by an unaccommodating physical environment brought about by attitudes and other features of the social environment. (WHO, 2002, p. 9)

Finkelstein (2001) strongly asserts that disability results from the 'nature and workings of society' that oppress people with impairments. As he explains, 'it is

society which disables physically impaired people' (p. 1). Priestley (1998) isolates theoretical and political elements of the social model that distinguish it from the medical model. The theoretical element is concerned with the study of disability barriers, policies and practices rather than with specific physical, cognitive or sensory impairments. Politically, this model draws on a discourse of disability rights, inclusion and citizenship (Priestley, 1998).

Inclusion of Children in Play Contexts

Inclusion is a fundamental principle within any accessible environment and should underpin the notion of shared play and access to environments in general (Jeanes & Magee, 2012; Nind & Seale, 2009). Inclusion is seen as the major benefit and the desired outcome of accessible community playspaces, particularly for children with impairments (Dunn, Moore, & Murray, 2003; John & Wheway, 2004; Webb, 2003; Yuill, Strieth, Roake, Aspden, & Todd, 2007) however, the principle of inclusion extends to all, not just those with impairments (Beckman & Hanson, 2002). 'Inclusive playspace' has come to describe built playspaces where 'everyone belongs'; that are purpose-designed to include all members of the community (irrespective of age, ability or any other perceivable difference) in the experience of play (Burke, 2013). Inclusive playspaces aim to provide opportunities for children to play together and have fun. As this chapter will explore, such play experiences are spatially enabled by the built environment and the feelings that are engendered by those who choose to occupy it.

Goodley and Runswick-Cole (2010) caution against practices that support separate play arrangements for children according to their abilities. These authors state that:

> Play allows educational professionals to separate able and disabled children and … should be viewed critically and with suspicion…. Play is pivotal to practices that centre the normal and push disabled children to the periphery. (p. 500)

This argument highlights the oppressive nature of dominant discourses of play for disabled children where the instrumental value of play that concerned with learning and development, is privileged over the intrinsic value of play (that concerned with entertainment and enjoyment), and is not disputed in this chapter. A rarely considered and scantly researched aspect of play is how children might construct messages from their shared experiences in children's environments. Conventional playspaces are likely to exacerbate hegemonic views about impairment particularly as they cater only for those who are able to gain access.

There is some evidence that allowing children to play together in inclusive environments ensures acceptance of children with impairments by their non-impaired peers over time. Children without impairments seem to develop empathy and acceptance of difference (Stalker & Connors, 2003; Widdows, 1997). Children

in inclusive kindergarten settings in Greece and the United States were found to be more accepting of children with impairments than children in non-inclusive settings (Nikolaraizi, Kumar, Favazza, Sideridis, Koulousiou, & Riall, 2005). Marginalisation of children with impairments in conventional playspaces is well documented in the literature (Dunn, Moore, & Murray, 2003; John & Wheway, 2004; Yantzi, Young, & McKeever, 2010; Widdows, 1997; Webb, 2003).

Corkery (2004) refers to the powerful educational effects of playspaces in influencing children's attitudes and values:

> The built and social environment in which children develop will in turn influence their attitudes and values about many things…. Play environments, including playgrounds, are in the public domain and are gathering places where children are likely to have some of their initial interactions with other children who are unknown to them. Therefore these are the places where children have the opportunity to be socialised with the idea of community life, outside the more familiar domains of home and school. (p. 111)

While Corkery's comments highlight the potential of playspaces to facilitate children's social and community interactions, she does not address the impact of space on ensuring who can socialise (and who can't), neither does she attempt to consider how children might make sense of the world accordingly.

Identification with place is a socially constructed notion that is culturally defined (Armstrong, 2012; Ferri & Connor, 2006; Lupton, 2007). Ferri and Connor (2006) explain how space can be reproductive of inequality. Children construct social norms and their understanding of social positioning from their observation and knowledge of cultural practices. This includes their reading of the environment to learn and construct messages about impairment. Ferri and Connor use a school setting to explain that practices adopted by adults to manage students with impairments can contribute to children's perceptions of difference. The classroom is described as a constructed space that reflects society and which is largely formed by the 'constant struggle over who is included and who is excluded' (p. 127). The authors elaborate:

> As a microcosm of society, classrooms and schools represent the degree to which knowledge and individuals are valued… thus embedded in their very structure schools and classrooms teach explicit and implicit lessons about normalcy. For example each time a child with a perceived difference is removed from the classroom for special instruction, or isolated from his or her peers within the classroom, the student and all of his or her classmates learn an important lesson about the educational, social and cultural responses to difference… consequently, all children come to learn about norms and their own positioning, particularly in relation to others. Thus, classroom walls and more subtle divisions within the classroom act as literal and symbolic borders, assigning students to designated spaces that correspond to their perceived value in society. (Ferri & Connor, 2006, p. 127–128)

According to this explanation, children (with or without impairments) construct understandings about the social positioning and 'value' of their peers from distinctions they observe in how the school responds to difference. I emphasise, however, that it is not simply a reproductive process. It is important to note that children with impairments are active in the process of constructing their own social positioning and that of others who do not have impairments and vice-versa.

The spatial elements of a playground seem to play an important role in social production. That playspaces do not support play by some people with impairments may be reflective of deeper hegemonic socio-political positioning of people with impairments. Lefebvre (1991) suggests that perceptions of space and the way it is used are inherently socially and politically imposed. Armstrong extends this argument:

> Space is political and ideological because it is a social product, derived from power relations in society and political struggle. The repartition of space into areas, social arenas, and sites is not 'innocent', nor neutral, but reflects these social relations and political struggles. (Armstrong, 1999, p. 79)

Understandings of disability can be spatially produced and reproduced by children from their reading of the environment. According to Lupton (2009), the meaning of space is produced by the 'social relations of people within and outside it, through the ways that they use it and imagine it' (p. 112). Armstrong (2012) draws on Soja's (2010) concept of 'spatial justice' as a new means to explore 'processes of inclusion and exclusion' (p. 612), pointing out that 'questions of "justice" always have a "spatial dimension"' (p. 112). Spatial justice therefore, according to Armstrong's (2012) interpretation of Soja's work, systematically overlooks disability in discussions about discrimination and can be viewed as both an outcome and a process.

Two interrelated ideas, with reference to place, can be used to interpret children's experiences; that of 'existential space' and that of 'spatial signifiers of difference'. Lived space can be understood through existential space (Relph, 1976). The concept of existential space in this chapter is concerned with how children as members of a cultural group come to identify with playground places and to develop shared cultural identities with place. Relph (1976) describes existential space as lived space that is experienced collectively by people as members of a cultural group. Relph tells us that 'however we feel or know or explain space, there is nearly always some associated sense or concept of place' (p. 8). He explains:

> Place, in association with space, also has a multiplicity of interrelated meanings. Place is not a simple undifferentiated phenomenon of experience that is constant in all situations, but instead has a range of subtleties and significances as great as the range of human experiences and intentions. (Relph, 1976, p. 26)

I interrogate these ideas, providing evidence from my research into children's perceptions of playspace in the following pages.

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Research with Children

In 2007, Connors and Stalker put forward a conceptual lens through which to examine disabled childhoods that they called 'the social model of childhood disability'. These authors positioned this theoretical perspective at the nexus of two theoretical approaches in particular, derived from seminal words in these two fields; the social relational interpretation of disability (Thomas, 1999) and the 'new' Sociology of childhood (Prout & James, 1997). The social model of childhood disability provides a social constructionist lens through which to attempt to understand the complexities of disabled childhoods and the potentially socially oppressive nature of barriers to participation. In this perspective, passive stereotypes often associated with disabled children are rejected, as is the construction of disability as tragedy, suffering or deficit. Disabled children are viewed as a social group who are marginalised in contemporary society due to their age and perceived lack of ability and the homogenisation of children with impairments into impairment categories is avoided. This perspective steers clear of comparisons of children with impairments with 'normal' non-impaired children and seeks to demonstrate ways in which children with impairments can be consulted and active participants in research methodologies and be seen to act within children's cultures as creative agents actively constructing their playworlds (Burke, 2012). More recently several others have taken a similar theoretical stance to examine children's experiences of disablement such as Watson (2012), Tisdall (2012), Mallett and Runswick-Cole (2014) and Goodley and Runswick-Cole (2010, 2015).

The notion of interpretive reproduction can be used to explain a child's 'evolving membership in their culture' (Corsaro, 2005, p. 24). Corsaro explains:

> Children's production of peer cultures is neither a matter of simple imitation nor direct appropriation of the adult world. Children creatively appropriate… information from the adult world to produce their own unique peer cultures. Such appropriation …extends or elaborates peer culture; children transform information from the social world in order to meet the concerns from their social world… to create and participate in a peer culture at specific moments in time. (Corsaro, 2005, pp. 41–42)

Through interpretive reproduction, children actively engage with and participate in the interpretation of their worlds and cultures rather than merely imitating or internalising from encountering cultural situations. Children, like all humans, can be positioned as social agents who act independently of imposed social structure (Prout & James, 1997).

RESEARCH METHODS

In my study, data were collected from children, who compiled personal photographic scrapbooks and were observed at play in playgrounds. Of the 72 child research

participants, aged six to ten years, from four selected primary schools (three mainstream schools and one special education school), 34 children were identified as having an impairment and 38 as having no impairment. All children and schools have been referred to by pseudonyms in an attempt to conceal their identities. To gain insight into the lived experience of playspace users, data were also obtained from a series of focus group discussions with parents of children with impairments and adults with impairments, and from my field notes of observations as a participant observer in school playgrounds and other sites. Ethics approval was granted by the Human Research Ethics Committee at the University of Ballarat and the Department of Education and Training, Victoria, Australia. This study draws on a small sample of research participants, and while these participants cannot be considered representative of all children and adults (both impaired and non-impaired) who use playgrounds, it attempts to provide some understanding of the life experiences of specific child playground users with respect to their playworlds. The participants are not representative of all children and therefore the insights conveyed through this study need to be interpreted cautiously.

The social model of childhood disability perspective endorses the utilisation of personal (micro) accounts of experiences as a way of enabling the researcher to construct and illustrate macro-level analysis (Connors & Stalker, 2003). The methodology adopted in this study provides the scope to seek insight into children's lived experiences in playgrounds. The decision to draw on the perspectives of children with impairments creates a new set of research considerations that takes into account the unique circumstances of working with children. The research, therefore, needs to engage child participants and be age and developmentally appropriate for children with a variety of participation, communication and learning capabilities. The research methods aim to elicit responses from children so that their views, feelings and ideas can be communicated, and to satisfy ethical requirements for research with participants considered potentially vulnerable both as children and as people who have impairments.

All participant children completed a photographic scrapbook project, where they were asked to take photographs of playground locations and equipment in a local community playground in response to each of 12 guiding statements (Figure 1. 'My view of the playground': Guiding statements). They later compiled their photographs into a scrapbook (some with a great deal of adult assistance) and provided written explanations for their choices. Each page in the scrapbook contained one of the guiding statements, a space for the corresponding photograph and three sentence stems that children were asked to complete: 1. This place makes me feel like this… because… ; 2. I chose to take this photo because… ; 3. I can [insert appropriate guiding statement] here because… . In follow-up interviews I discussed with each child their photo choices and their responses to the sentence stems in more detail. I also observed the children with impairments at play, both during a field trip to a community playground and in their own school playground settings. The children also indicated their feelings about their choice of the playground location pictured

in each of their photographs by adding one of three personally selected self-inking 'feelings' stamps; a smiling face ☺, a sad face ☹ and a grimacing face ☺.

Greenfield's (2003) study utilises the technique of 'photo elicitation' that has been described by C. Burke (2005) as the 'coupling of words and images allowing for interaction between the two' (p. 32). Using photo elicitation can provide the scope to stimulate responses from children, to facilitate communication with children, to triangulate with data from other sources, and as a tool to assist children to contribute their perspectives of playgrounds to the research. Photo elicitation is described by some authors as a useful way to facilitate communication with children, including very young children (Clark, 2004; Greenfield, 2003) who use limited spoken language or who have limited literacy skills; furthermore, the adoption of visual methods, in research involving the participation of children, can provide ways of engaging effectively with the children (Clark, 2004; Greenfield, 2003; Moss, Deppeler, Astley, & Pattison, 2007) by mediating and facilitating the communication between the researcher and the children (Christensen & James, 2000).

For this chapter, my field notes, children's photographic scrapbooks and focus group discussion transcripts, I reflected on the data in to try to discover structures of meaning. This process is described by van Manen (1990, p. 30) as one of six 'methodological themes' to 'animate inventiveness and stimulate insight' into phenomenological structure. Van Manen sees, 'reflecting on the essential themes which characterise the phenomenon' (p. 30) as part of the process of phenomenological research. The themes that emerged through analysis of the scrapbook data at times converged with themes drawn from my research journal

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I am looking for somewhere in the playground...

    a)   …I like to play most
    b)   …I don't like to play
    c)   …I feel safe
    d)   …I don't feel safe
    e)   …that is the best place to play with others
    f)   …to be by myself
    g)   …that is difficult for me to get to
    h)   …where I have never played but would like to
    i)   …where I want to try hard to do something
    j)   …that is fun
    k)   …where I can work hard (huff and puff)
    l)   …I can pretend

(Burke, 2012, p. 969, adapted from Greenfield 2003; 2004).

Figure 1. 'My view of the playground': guiding statements

and from the focus group discussion transcripts. In these instances I combined the data under the identified theme and then attempted to describe the phenomenon through 'the art of writing and rewriting' (van Manen, 1990, p. 30). For this chapter, I grouped pieces of text with attention to issues of access for children with physical impairments including that concerned with a particular playspace item, known as a 'Liberty Swing'. In the playspace this was the only piece of equipment where any children mentioned physical impairment even though there was also an accessible sand pit, wheelchair accessible seating and a variety of swings for a range of children in the playspace.

The playground places that children photographed and their accompanying written statements and comments provide insights into how children read and spatially construct their environment with respect to disability.

RESULTS AND DISCUSSION

I present some illustrative examples of data in two parts. First, I provide three vignettes drawn from a focus group with parents of children with an impairment from my study followed by a discussion linking the concept of existential space. Second, I offer data from the children's scrapbooks and some of my own photographs, followed by discussion about places in the particular play site that act as spatial signifiers of difference. Two of the research participants in this study are Dominic and George, both six years old and both use wheelchairs for mobility. When they visit conventional playspaces, both boys are compelled to sit and watch non-disabled children play because the equipment is inaccessible to wheelchairs. George's mother, Anita, and Dominic's mother Lisa, as participants in the research study, explain the situation in Vignettes 1, 2 and 3.

Vignette 1: George.

Kids [without impairments] can run riot. George can't access Hungry Jack's playground at all. He goes to parties there and he sits in a party room and watches other kids. (Anita, mother of George)

Vignette 2: Dominic.

I've got twins and my son [Dominic] sits there and watches his [twin] sister and you can see his little face and sometimes I've said to him, "What's wrong, mate?" and he's said, "Stupid cerebral palsy". He can't express himself but he's angry because he can't do what she's doing. She's running around. She's on the swing, she's on the slide. He just wants to be normal like everyone else. (Lisa, mother of Dominic)

Vignette 3: George.

George visited an accessible playspace and found a musical play element that was accessible from his wheelchair. Anita, his mother, describes the scene:

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> They've got the bell things… and they're great. They're big. So all my son has to do is push it and it makes a noise and he spent at least five, ten minutes just pushing these bells, pushing, pushing, hearing the different noises and he thought that it was fantastic. They were at his level for his wheelchair and other kids were playing next to him. And he had a couple [of bells] he was playing, and other kids were playing [other bells]. And he just thought it was the best thing ever. He'd never been to a playground before that had something other than just walk around it or have to get out of his wheelchair to go down a slide. (Anita, mother of George)

Aside from cultural differences between children and adults, children with impairments and children without impairments can be polarized into separate cultural groups by spatial arrangements. I use Vignette 1 and Vignette 2 to help explain this point with respect to separate play arrangements for children with impairments and the different places that they inhabit compared with their peers without impairments. George and Dominic, in the examples provided in Vignettes 1 and 2, are spatially positioned outside (or on the periphery) of the cultural play landscape of their peers it. Their membership of the cultural group, 'children', is limited by their overlapping membership of the group, 'disabled children'. Consequently they are denied spatial justice (Armstrong, 2012) because of the exclusive configuration of the playspace. When children with impairments are segregated from children without impairments by physical barriers or adult-imposed practices then they may experience difficulty sharing collective identity with place. I refer to Relph (1976) who asserts that cultural groups have been socialised 'according to a common set of experiences, signs and symbols' (p. 12).

Spatial separation denies shared cultural experiences and can lead to playground users experiencing place through either insideness or outsideness (Relph, 1976). As such, it is difficult for children without impairments to experience the place identity of the impairment-influenced culture, despite all belonging to the larger cultural group, children. For children with impairments, being able to experience place collectively as part of the broader children's social group is likely to assist in building shared cultural understanding between all children. Consequently, a strong argument for the importance of inclusion for children can be derived from such reasoning. An example of inclusion is provided by George's mother, Anita, in Vignette 3. Unlike the spatial arrangements described in Vignettes 1 and 2, in Vignette 3 George is permitted to occupy this social space and engage in a more conventional experience. A shared cultural experience is possible here because of the configuration of the built environment of the playspace. Anita further explained that the experience she describes in Vignette 3 was derived from the only example she was aware of where George, up until he was six years old, had been able to visit a playspace and actively participate in play, without watching others from the sidelines or be carried around a playspace by a carer.

Spatial Signifiers in a Playspace

The second idea associated with the lived space of the playground, is that of the role of spatial signifiers in cultural reproduction. Spatial signifiers are signs and symbols that are read from and into places by individuals within the cultural structure of society (Titman, 1994). Imrie and Kumar (1998) maintain that places can act as 'spatial signifiers of difference' (p. 385) in which exclusionary practices signal, highlight, extend, reinforce and legitimate differences between those who are impaired and those who are not. Spatial markers, when associated with certain social groups, signify difference between those who use particular spaces and those who do not (Imrie, 1996). For many disabled people, 'access to specific places is a constitutive part of how they come to be defined and recognised' (Imrie & Kumar, 1998, p. 357–358) by others. Spatial demarcations or 'spatial markers' thus produce and reproduce social exclusions.

The complexities of the built environment, and the consequent ways in which it affects disabled people's lives, are difficult to ascertain. Imrie and Kumar (1998) state that 'the configuration of the built environment is implicated, in quite complex ways, in the material circumstances, identities and daily lived experiences of disabled people' (p. 358). Imrie and Kumar (1998) draw on social constructionist theory to explain how space acts as a medium for conveying messages about impairment, asserting that social relations are 'constituted in and by space' (Imrie, 1996, p. 12–13).

A Liberty Swing as a Spatial Signifier of Difference

In this study, a Liberty Swing, pictured in Photograph 1 by one of the research participants, Riley, provides an example of a spatial signifier of difference. A Liberty

Photograph 1. Riley's photo of a Liberty Swing

Swing is a swing that was purpose-designed to allow a person to swing whilst seated in a wheelchair. It was designed in Australia and is frequently installed in large public playgrounds and special education schools. The comments provided by the children in their scrapbooks that accompanied their pictures of the Liberty Swing have been aggregated below. Of the 15 children who chose to photograph the Liberty Swing in their photographic project, they selected it under the following guiding statement categories.

Table 1. The number of children who photographed the Liberty Swing, in relation to their chosen guiding statement

Somewhere in the playground where…	Number of participants
I have never played but would like to	9
I don't feel safe	2
I don't like to play	2
I want to try hard to do something	1
I feel safe	1

Most children who photographed the Liberty Swing indicated they were excluded from using it. Examples of children's comments where they express that they were excluded are:

It looks like fun. … I wish I could go there. I don't know why I can't.

This place makes me feel like this ☹ because "nobody lets me go on it. Nobody lets anyone go in without a wheelchair. I'd like to swing on it but I can't. I would like to swing on it because it's cool. I'd swing high on it".

This place makes me feel like this ☹ because "I'm not allowed to get in there. I'm not allowed to play in there. I would like to play on this".

This place makes me feel like this ☹ because "I never went there. I have never been in here before". (This child admitted that she didn't know what the swing was for).

"It looks like fun". This place makes me feel like this ☹ because "I can't play there".

I love it. I can't get on it and I wish I could.

This place makes me feel like this ☹ because "I can't do what I want to do".

One child expressed curiosity about disability: "I'd like to know what it's like in wheelchair".

One child associated the swing with being a safe place: This place makes me feel like this ☺ because "you can't fall off".

These comments raise the question of why many of the children who say they would like to play on this swing are unable to do so. I have attempted to answer this question in the discussion that follows. Moreover, some of the children expressed negative views of disability and an awareness of the potential danger to them or getting into trouble in using the swing:

> It's a swing. It's big. It's too high and I can slip out.

> I don't like the wheelchair swing because it's for wheelchair people. It's not a good place for children. I don't feel safe here because it's dangerous. It could just start up and hit me.

> …It's a dangerous swing…

> "I'd get into trouble if I played on it". This place makes me feel like this ☹ because "I'm just dying to get on it but I can't because I might get into trouble. I want to have a swing on it. I'd like to play here because it might be really fun".

> "Wheelchairs have to play on it. It's their swing". This place makes me feel 'yucky' because "I don't like it and it makes me feel sick. It's not nice because you have to go in it if you have an accident. I don't like to play here because it's for wheelchairs and crutches".

Of 15 children who included the Liberty Swing in their photographic project, 12 children associated it with sad feelings, ☹ and three chose the 'happy feeling' stamp ☺ (Burke, 2006).

Photograph 2. A key is required to operate the Liberty Swing

Photograph 3. Sign on the gate of the Liberty Swing enclosure

Photograph 4. The Liberty Swing is located on the periphery facing away from the playground

Photograph 5. Childproof lock on the gate of the Liberty Swing enclosure

The children's comments about the Liberty Swing suggest that some research participants perceive the structural space occupied by the Liberty Swing as a place that is restricted to those who are different because they use wheelchairs. The size and physical presence of the swing (Photograph 4), the thick palings on the tall fence dividing the swing from the rest of the playground (Photograph 4), the signage restricting the area around the swing to 'users and carers' (Photograph 3), the childproof gate and lock (Photograph 5) and the swing's location on the periphery of the playground (Photograph 4), are likely to convey spatial messages to young playground users. Some of the children in this study explained that they felt excluded from this space and that only people who used wheelchairs could use this space. Thus, the children have noticed that the space is demarcated for disability and only certain types of disability. Interestingly, the swing has a fold-down seat, that enables a child to use the swing without being seated in a wheelchair, meaning that it is actually a more inclusive piece of play equipment than a conventional swing, but this is use is not promoted and no children in this study seemed to be aware of it.

From the evidence of this study, a few examples of which are provided in this chapter, it would seem that children partly construct their own and others' value and social positioning according to whether they are included in or excluded from certain playground spaces. The social value and capabilities of some children with physical impairments are conveyed through space by implicit messages about impairment in play spaces. The absence of children with impairments from mainstream play activities, and their presence in others, communicates messages to their peers from which contribute to their socially constructed notions of disability.

Another example of a spatial signifier of difference is conventional play equipment that does not cater for other than 'normal' children. The playspaces featured in Vignette 1 fit this description. Within such environments, as explained previously, the differences between those who can play and those who can't become

blatantly apparent. Alternatively, children with impairments often avoid accessing such spaces. Lack of contact in play environments of non-impaired children with their peers with impairments, according to Davis, Priestley and Watson (2004), can result in culturally deprived situations in which non-impaired children are prevented from learning about the 'true diversity' of their peer group. Furthermore, hegemonic practices that exclude people because of their impairment are normalized. Davis and his colleagues explain:

> In forming social networks and personal relationships within a disabling environment, non-disabled children learn that their social world functions without disabled people and learn not to question the exclusion of disabled people from the adult world. (Davis et al., 2004, p. 20)

Some children in this study demonstrated their understandings of disability through their comments about the Liberty Swing. These comments provide strong evidence of the social messages that children read spatially from the environment. Consider George as described by his mother playing in the 'accessible' playground that contains certain sensory equipment in Vignette 3. George plays alongside other children ringing the bells. By being permitted to occupy this social space and engage in a regular play experience alongside 'normal' children, his capabilities and his behaviour are likely to be normalised by his playmates and he is seen as being capable, and likely sees himself as capable, of participating in play alongside his peers. The playground becomes his environment too, and a shared cultural identity with place is possible for all the children included in the immediate environment. In comparison, in Vignette 2, Dominic is compelled to sit on the sidelines, unable to access the play space being utilised by other children, watching his sisters playing together. His physical presence as a spectator of play is normalised as one of absence from the play experience. He is cast (seemingly in his own eyes) as an incompetent player who is incapable of participating in peer play. The limitations of his impairment are highlighted to himself (as reported by Lisa, his mother) and, most likely, to his sisters who are engaged in the act of playing. Barriers that are often imposed on such children seem to limit their opportunities to exert their own free choice and act as creative, autonomous agents in their play.

SUMMARY AND CONCLUSIONS

A playspace is a site of the processes of social construction that occur also in the broader world beyond the playground. Central to this argument, drawing on the social model of childhood disability (Connors & Stalker, 2007), is the recognition that children with impairments have the capacity and opportunity to act as agents in their play in the playspace. Such processes can contribute to the inclusion, or alternatively to the oppression, of disabled people. In this chapter I have provided evidence of children with impaired mobility and children without impaired mobility divided into separate cultural groups by spatial arrangements. Spatial separation thus

denies spatial justice and prevents shared cultural play experiences in designated playspaces. For children with impaired mobility, being able to experience place collectively as part of the broader children's social group is likely to assist in building shared cultural understanding between all children. To redress this spatial injustice, a focus on finding ways for all children to gain access to inclusive play and opportunities for social interaction with peers must be accorded central importance over adult choices and institutional priorities imposed on children that deny them access to play.

I have drawn attention to the fact that some children in this study demonstrated their understandings of disability through their comments about the Liberty Swing. The Liberty Swing provides strong evidence of the social messages that children read spatially from the environment and can be described as a spatial signifier of difference. This is likely because of the way the swing is positioned and promoted in the playspace, rather than the actual capabilities of the swing. Exclusionary practices, therefore, signal, highlight, extend, reinforce and legitimate differences between some of those who are impaired and some of those who are not.

Considering the examples presented in this chapter, I urge the reader to consider how children without impairments might construct impairment, and how children with impairments might consequently view themselves in relation to their non-impaired peers from their reading of the way the built environment is configured. Wendell (1996) asserts that insider knowledge, if acknowledged and accepted by people who are not disabled, can contribute beneficially to the social fabric, enriching our thinking and consequently changing the way we understand each other. We may become able to embrace and understand a broad array of ways of doing and being that are not solely confined to the dominant 'ableist' adult view, but which draw on rich and varied discourses. Such a priority is vital for all children, not just those with impairments. Being denied opportunities to learn about and experience the true diversity of their peer group can thus result in play deprivation for non-impaired children. Importantly, from a disability studies perspective, some children with impaired mobility are unable to access spatial justice. Furthermore, within a play environment bereft of children with impairments, the subsequent social messages that non-impaired children receive may lead them to accept social segregation for people with impairments as a 'normal' part of life and the consequent devalueing of disabled people.

Play, as a major social institution, influences the shaping of society. By gathering in playspace environments, children who do not necessarily know each other learn about others, social values and the communities in which they live. This cultural learning is an important by-product of a child's play experience and emphasises that inclusive play is not just about children experiencing fun and pleasure from such activities. It is important that practices are adopted that enable children with impairments to be independent, welcomed and included as equals in children's environments such as playspaces.

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2. TEACHERS' AIDES' PERCEPTIONS OF THEIR TRAINING NEEDS IN RELATION TO THEIR ROLES IN STATE SECONDARY SCHOOLS IN VICTORIA

INTRODUCTION

Inclusive educational policies have led to an increase in employment of teachers' aides (TAs) to support students with disabilities in schools. Research that has investigated the roles of TAs in schools has reported that TAs are often employed with little or no training. This study used an online questionnaire to examine TAs perceived training and professional learning needs for performing their roles in state secondary schools in Victoria. One hundred and sixty-three TAs completed the anonymous on-line questionnaire. The study examined a range of issues related to TAs knowledge and skill levels, and training and professional learning. The results from the study showed that the majority of TAs in state secondary schools in Victoria (1) consider they have substantial knowledge regarding work related items; (2) have had training or have no need for training in work related items; (3) consider they are well prepared to effectively perform student related tasks; and (4) have had training or have no need for training in student related activities.

BACKGROUND

Inclusive education provides for the rights of individuals and refers to the placement of students with disabilities into regular schools (Bourke & Carrington, 2007; Oliver & Barnes, 2010; Rioux & Pinto, 2010; UNICEF & UNESCO, 2007). Inclusive education has led to a rapid increase in the number of TAs employed to assist with the placement of students with disabilities into regular classrooms alongside their peers (Carrington & Holm, 2005; M. Giangreco & Doyle, 2002; Subban & Sharma, 2006; Takala, 2007). However, while TAs are the preferred option for supporting students with disabilities in the classroom, researchers have questioned the use of untrained or underskilled TAs in supporting students with the most need in schools (Angelides, Constantinou, & Leigh, 2009; M. Giangreco & Broer, 2005; M. Giangreco & Doyle, 2002; Inclusive Education Network, 2006; Webster et al., 2010). Furthermore, while researchers question the use of undertrained TAs, it may be constructive to posit a further question, what are the perspectives of the TAs themselves regarding their

preparedness to perform their roles? The purpose of the study outlined in this chapter is to develop an understanding of the preparedness and training of TAs from the TAs' perspective. There is growing research literature that suggests that TAs are unprepared for their role in supporting students with disabilities through a lack of training or a lack of clarity in their role (e.g., Angelides et al., 2009; Mansaray, 2006; Webster et al., 2011). However to date, there is a dearth of information regarding the TAs perceptions of their role and the training they have performed to address the array of work related items and student related tasks inherent in their role. By researching the TAs perceptions the study gives agency and relevance to the TAs own voices and experiences. The study endeavours to provide an understanding of, and direction for, better-informed utilization of TAs as support personnel for students with disabilities within the secondary school environment.

Work Related Items

The evolution of inclusive education has created issues for mainstream schools (M. Giangreco & Doyle, 2002; McNally, Cole, & Waugh, 2001). As a result, TAs may become central to the process of implementing the policies and practices of inclusive education in schools. Inclusive of their role in supporting students in the school setting TAs need to know about the guiding principles that impact their working environment, for example, school and department safety policies and legal obligations (Dymond, Renzaglia, Gilson, & Slagor, 2007; Etscheidt, 2005; Pearce & Forlin, 2005; The Senate, 2002). Riggs (2005) held a workshop with 35 TAs to discuss what teachers should know when working with TAs. From the study Riggs (2005) noted that while TAs may have experience with students with disabilities in the community, TAs who attended the workshop had no experience in the classroom prior to working in the role. This infers that the TAs required an understanding of working within the culture of a school. Hudson et al. (2010) undertook a small-scale study in Queensland, Australia, to explore practices and strategies for mentoring potential teacher aides (PTAs). The study results indicated that PTAs require knowledge of school culture and infrastructure that would aid the PTA's work practices. Researchers have also noted the need for TAs to be trained in communication and management skills for working with other adults in learning situations, particularly in secondary schools where TAs work with a range of teachers who may have varying experiences in working with and monitoring TAs (Angelides et al., 2009; Etscheidt, 2005; M. Giangreco, Yuan, McKenzie, Cameron, & Fialka, 2005; Howard & Ford, 2007; Logan, 2006; Norwich & Lewis, 2007; Wilson & Bedford, 2008). However, it may be inferred that TAs who have little or no training, and are not supported by a mentoring type program may not be aware of or understand the rules inherent to working in a school community. While a number of studies have addressed issues related to the role of TAs in supporting students with disabilities in secondary school settings there are a limited number of studies that examine the TAs perspective. Further research is needed to give the TAs

agency and recognition when examining the knowledge TAs possess when working in schools with students with disabilities.

Student Related Tasks

In working with students with disabilities TAs can be responsible for physical, educational, and emotional support of students with disabilities. Their roles are diverse requiring a level of competency across a multi faceted range of student related tasks (Angelides et al., 2009; Carroll, 2001; Dymond et al., 2007; Egilson & Traustadottir, 2009; M. Giangreco & Broer, 2005; Griffin-Shirley & Matlock, 2004; Inclusive Education Network, 2006; Logan, 2006; Ministerial Advisory Committee: Students with Disabilities, 2005; Pearce & Forlin, 2005). Researchers suggest that TAs can make valuable contributions in promoting participation and social awareness among students with disabilities (French, 2003; Henley, 2010). Conversely, the presence of a TA can result in limited use of the student's strengths and may possibly create unnecessary or unhealthy 'dependency and learned helplessness' (Egilson & Traustadottir, 2009; Griffin-Shirley & Matlock, 2004, p. 129; Logan, 2006). For example, Whitburn (2013) in reporting the outcome of his small-scale study of 5 secondary school vision impaired students in Queensland, noted the students spoke of 'the embarrassment that they (the student with a disability) often experienced because of their supposed dependence on the support personnel' (p. 155). Whitburn suggests that TAs be encouraged to provide facilitative (light) services and avoiding inhibitive (heavy) services to accommodate the student's inclusion into the school. Other research studies suggest that TAs need the knowledge and skills to be able to differentiate between support and overreliance (Blatchford, Russell, Bassett, Brown, & Martin, 2007; Egilson & Traustadottir, 2009; M. Giangreco & Broer, 2005; Mansaray, 2006; Takala, 2007). However, less is known about the frequency in which TAs perform these tasks, their knowledge and skills, and the training TAs may have undertaken to perform the tasks effectively.

Training

In Victoria, Australia, TAs do not require a qualification to be employed. The Victorian Auditor General's Report (2012) stated that TAs were selected for employment 'firstly on 'personality fit' and then experience' implying that training assumed a lesser level of importance when employing TAs (p. 29). The Australian Senate (2002) reported that as TAs are often employed with little or no training the quality of program delivery may be compromised. Similarly, a number of Australian studies have reported the need for training for TAs (Howard & Ford, 2007; Ministerial Advisory Committee: Students with Disabilities, 2005; The Senate, 2002; Wilson & Bedford, 2008). Wilson and Bedford (2008) state that there appears to be significant confusion in terms of the skills required, knowledge attained, potential levels of responsibility, and the role of TAs in the school

structure, which ultimately impacts on the training requirement of TAs. In Australia the range of needs of the students, the expected role the TA and the expectations of the stakeholders could all impact the knowledge and skill required for a TA in supporting a student with disabilities. However, the number of studies based on the Australian school system is limited. Furthermore, there are there is a dearth of studies that explore the TAs perspectives of their training and professional learning experiences. By using a quantitative questionnaire to explore the TAs perspective of their training and professional learning needs a broader understanding of the TAs knowledge may emerge.

This chapter reports key findings of a recent quantitative study conducted with TAs working in mainstream state secondary schools across Victoria, Australia. This purpose of the study that informs this paper was to explore TAs' perceptions of their knowledge and preparedness for supporting students with disabilities across a number of common work related items and student related tasks in state secondary schools in Victoria. The study also examined TAs training needs related to these tasks. Specifically, this study sought to investigate the following four aims: (1) the TAs level of knowledge of the listed work related items, (2) the level of training needed to understand these work related items, (3) the level of preparedness of TAs to perform the listed student related tasks, and (4) the level of training needed to perform the student related tasks.

This chapter draws on some of the results of this study to argue that it is relevant to explore TAs perceptions of their preparedness and training to perform work related and student related tasks to provide a better understanding of the role TAs perform in supporting student with disabilities in the mainstream secondary school environment. The results of this study show that in general TAs perceive they have the knowledge and skills to understand and perform their role in supporting students with disabilities in mainstream schools in Victoria. The TAs in this study considered that they had training that enabled them to work within the guidelines of an inclusive school environment, and to perform the listed student related tasks to support students with disabilities in the secondary school environment. Knowing more about how TAs perceive their knowledge and understanding of their role may enable schools to be better positioned to make informed decisions about the policies and deployment of TAs in supporting students in the inclusive secondary school. Furthermore, schools may use this knowledge to plan and support training regimes to better prepare TAs for their role within the school environment.

RESEARCH DESIGN

Data for this research was collected using an anonymous on-line questionnaire. The questionnaire sought to investigate TAs' educational background, knowledge and skills related to specific tasks undertaken as part of their role, and the TAs' training related to these tasks.

Data Generation

Questionnaire. Having received ethics approval from the Victorian Department of Education and Early Childhood Development (DEECD), 374 principals from 299 secondary school (Years 7–12) campuses in the state of Victoria, Australia were invited to approach their TAs to participate in the study. Principals were asked to forward an invitational email to the TAs in their school who supported secondary students with disabilities. There were no criteria that excluded any TAs from participating in this research.

The research instrument was a questionnaire aimed to collect data about TAs' knowledge and training from a TAs' perspective. The questionnaire was distributed on-line to enable information to be gathered from many individuals from a large sample population across the state of Victoria. This method of quantitative research enabled the collected data to be measured and trends assessed to provide a clear picture of TAs' perceptions of related tasks and training within their role. The questionnaire was developed on the basis of a review of the literature. In particular, the work of Giangreco (2002) and Carter (2010) informed the development of many of the items included in the questionnaire relating to TAs' knowledge and skills, the specific tasks that TAs are often reported to perform daily, and specific needs for further professional learning in supporting students with disabilities. The anonymous questionnaire consisted of 28 items that included tick-the-box, nominal, and open-ended questions. This chapter presents the items relevant to TAs work related skills and student related tasks. Seven items gathered demographic data about the participants, For example, age, length of service and number of schools worked in (see Table 1). Participants were also asked to indicate their educational level. Items 15 to 18 sought to explore TAs weekly work schedules including the school setting they work in, the number of students with disabilities, the number of teachers that they work with, and the number of subjects they assist students in (see Table 1). Participants were also asked to indicate the settings in which they supported students. Items 23 to 26 investigated teacher aides' level of knowledge and skill in carrying out many of the tasks related to working as a TA. For example, in item 24 participants were asked to rate their level of preparedness to perform 18 listed student related tasks on a Likert scale of very prepared, moderately prepared, little prepared and unprepared.

The anonymous on-line questionnaire responses were collected using Survey Monkey across a six week period. The overall return number of responses was 163. Statistical analysis and descriptive analysis were used to summarise the participants' demographic data. The demographic data included gender, age, years of experience, number of schools worked at, classroom support data and the participants' level of education. Statistical analysis and descriptive analysis were also used to summarise the teachers' aides' item-level responses across the three themes of work related items, student related tasks and training.

Participants. Participants were asked to provide basic demographic data. Table 1 shows the results of these items.

Table 1. Participant demographics and weekly work schedules

Participant results				Characteristics			
	Gender	*Age*	*Years of experience*	*Number of schools*	*Number of students per week*	*Number of teachers per week*	*Number of subjects per week*
Majority results	Female 94.4%	50–55+ 68.3%	2 months – 32 years mean = 9.9 years	1 – 8 mean = 2.3 schools	4 – 6 38.7%	5 – 8 60.8%	5 – 8 63.2%

Note. Percentages are based on the number of participants who provided information for each item.

Participants were also asked to provide information on their level of education. Results showed that 83.9% of participants had completed year 12. There were 67.5% of participants that had completed post school training at Certificate, Diploma, Undergraduate or Postgraduate level. A number of participants (33.1%) had completed Certificate level education that included nursing, hairdressing, typesetting, horticulture and art. Nine of the participants responded that they were currently studying either a Certificate or undergraduate degree. Five of these participants noted that their studies were in Education. Eighteen of the participants (11%) indicated they had worked as a teacher. The average time as a teacher was 12 years but the majority of responses were in the range of 14 years or less.

Participants were asked to indicate the settings in which they worked with students with disabilities. The results showed that the majority of TAs typically work with students with disabilities in or mostly in general classroom settings (68.0%). The majority of participants worked evenly between working in groups or one-to-one with the students they support (93.1%).

RESULTS

Work Related Items

Level of knowledge. The questionnaire included two items related to the work related items. The first item asked participants to rate their level of knowledge across 13 work related items. The results were grouped and tallied into substantial/ moderate knowledge, and some/no knowledge. The results show that the majority of participants indicated that they consider their level of knowledge to be in the substantial/moderate range (89%). This indicates that TAs consider that they have

an understanding of the work related items that impact their role in working as a TA supporting students with disabilities. Table 2 shows the results for this item.

Training and professional learning. Item 26 asked the participants to indicate whether they had received training or had no need for training across the listed 13 work related items. In responding 'no need' for training teachers' aides may have been indicating that they had received adequate training in the selected item or they may have been indicating that the selected item was not relevant to their current role. Participants were also asked to rate their need for additional training in these areas. The results were grouped and tallied into two categories: 'had training or no need' for training; and 'need for training.' Table 2 presents the responses from the participants to this item.

Table 2. Overall ratings of work related items

Work related items	Level of knowledge		Training or professional learning	
Knowledge standard	*Substantial/ Moderate knowledge (%)*	*Some/No knowledge (%)*	*Had training or no need (%)*	*Need for Training (%)*
Communication skills	96.4	3.6	80.0	33.3
Your role as a teachers' aide	96.3	3.7	83.6	30.3
Ethical practices relating to confidentiality	94.4	5.6	81.5	29.5
Basic educational terminology	92.6	7.4	74.8	37.8
Effects a disability can have on a student's life	91.1	9.9	69.5	44.7
Students' rights and responsibilities	90.2	9.8	73.7	39.4
Demands of various learning environments	90.1	9.9	58.3	49.3
Basic instructional and remedial strategies	88.3	11.7	59.1	51.7
Rules and procedural safeguards related to students' behaviour	87.8	12.2	60.9	47.7
Purpose of programs for students with disabilities	87.2	12.8	66.2	43.9
Families' rights and responsibilities	86.1	13.9	66.6	43.3
Your legal rights and responsibilities	84.8	15.2	68.0	44.0
Your role in implementing an IEP	74.3	25.7	52.7	56.1

The participants (69%) indicated they had received training or acquired the knowledge and skills to perform the 13 work related tasks. This implies that the majority of TAs considered that their training or experience gave them the knowledge and skills to understand their role as a TA in supporting students with a disability in a state secondary school in Victoria. In 9 of the listed knowledge standards the difference in results indicated that the 'no need' for training is substantially higher that the 'need for training' (35.3%) (see Table 2). There were three work related items where the difference in the training results were around 10% (9.9%) where TAs indicated that the 'need for training' was similar to the 'no need for training' (see Table 2). The work related item 'your role in implementing an IEP' is the only item that shows the 'need for training' to be higher than the 'no need' across the 13 items (–3.4%). This indicates that there are work related items relevant to the role of the TA in which the TAs may have less than adequate knowledge in or understanding of; thereby indicating that training could be beneficial for these work related items.

A number of participants indicated they had participated in training but also indicted they would like more training in some of the listed items. The overall participants' response for needing training in the work related items was 42%. This result may indicate that the participants consider they have adequate knowledge of the work related item but would like more knowledge. For example, participants responded 59.1% to 'had training or no need' to the item 'basic instructional and remedial strategies' and also responded 51.7% for 'need for training'. This indicates that a number of the TAs working in the secondary state school system in Victoria consider they need additional training in these work related areas. Similarly, it may indicate that the training available to TAs does not address these items or that training for these items is not available.

Student Related Tasks

The questionnaire included three items related to the student related tasks. The first item asked participants to rate the frequency of performing student related tasks. The second item asked participants to rate their preparedness to perform 18 student related tasks when working with students with disabilities. The third item asked participants about their training related to the 18 student related tasks.

Frequency of performing student related tasks. Item 23 invited participants to indicate how often they carried out particular activities in their work as TA. Tasks that participants chose as NA may not be applicable to their understanding of the role they perform, for example 'write lesson plans'; or they may not be applicable to the students they are currently supporting at the school, for example 'provide health care assistance.' NA may also mean that TAs may have, or could, perform these tasks depending on the needs of the students. Similarly, the participants may

have responded 'never' because the activity has not currently been allocated to them or because of the different expectations of the schools they currently work. Table 3 presents the majority responses from the participants to this item. The figures in the frequency section of Table 3 represent the sum of the responses to the NA and 'never' tasks.

The majority of participants indicated that five of the activities listed were undertaken on a daily basis. Three activities were performed on a weekly or termly basis. In total there were 6 tasks that the majority of participants indicated NA/ never because they are not currently performing these tasks with the students they support or because they consider these are tasks that are not applicable to their role in working as a TA supporting students with disabilities in mainstream secondary schools. Three items were not included in the questionnaire frequency item. In retrospect the information that may have been provided could have added depth to the understanding of the role of the TA in supporting students with disabilities in mainstream secondary schools in Victoria.

Preparedness to perform student related tasks.   Item 24 of the questionnaire related to TAs' preparedness to work with students with disabilities. The responses were grouped and tallied into three categories: very prepared; moderate/little/unprepared; and NA. Table 3 presents the participants responses to this item.

The majority of participants indicated that they were very prepared (45.7%) to support students with disabilities across the 18 listed student related tasks. In particular participants indicated they were very prepared (62%) in 10 of the student related tasks they considered applicable to their role in supporting students with disabilities in mainstream secondary schools. This implies that TAs consider they have the knowledge and skills to undertake these student related tasks. One task 'provide health care assistance' was also rated in the very prepared category (35.3%) despite it being a task that the majority of TAs (53.3%) considered was NA/never part of their role. This implies that the TAs in this study were not participating in this support role at the time of completing the questionnaire or have never performed this task. However, it may be inferred that a number of TAs considered that if they were required to provide health care assistance to particular students they have the knowledge and skills to perform the task.

There were three tasks that the majority of participants indicated were moderate/ little or unprepared for (41.3%). These tasks included 'implement behaviour management programs', 'working with students who have refuge backgrounds' and 'working with students from diverse cultural and religious backgrounds'. The results indicated that a number of participants (24%) considered these roles to be NA/never. The participants may have responded NA/never to the two tasks regarding the students' backgrounds because the students they are supporting do not fall into these categories or the schools they work in have a limited number of students from different ethnic or religious backgrounds. Similarly, the behavioural

Table 3. Overall ratings of student related tasks

Student related tasks	Frequency of task performance	Level of preparedness			Training or professional learning	
Tasks	Majority of responses Frequency (%)	Total very prepared (%)	Total moderate/little/ unprepared (%)	NA (%)	Had training or no need (%)	Need for training (%)
Assist single students in class	87.1 Daily	86.5	13.5	0.6	92.3	28.3
Liaise with teachers	80.8 Daily	89.0	9.6	0.0	86.7	23.2
Work with multiple students in a class	72.4 Daily	76.1	22.8	0.6	85.6	30.8
Facilitate social relationships amongst students	47.7 Daily	45.9	32.6	18.2	57.2	52.4
Modify a student's work program	46.8 Daily	51.6	38.1	10.3	66.5	47.4
Prepare instructional materials	28.5 Weekly	37.5	33.5	27.0	63.4	44.5
Liaise with parents	25.4 Weekly /Termly	64.7	22.9	11.8	75.8	32.0
Attend PSG meetings	64.7 Termly	72.3	20.0	7.1	82.4	27.4
Write lesson plans	77.1 NA/never	17.4	24.1	50.3	64.5	40.3
Provide therapy assistance	75.5 NA/never	19.7	29.3	40.8	52.6	51.3
Write reports	70.0 NA/never	25.0	22.3	48.6	70.1	34.7

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Administer student assessments	69.4 NA/never	19.5	31.5	44.3	63.1	42.3
Provide health care assistance	52.3 NA/never	35.3	34.0	28.7	65.1	46.0
Complete administrative paperwork	37.7 NA/never	46.7	26.0	24.7	68.5	40.5
Implement behaviour management programs	32.7 NA/never	33.8	40.4	25.8	53.1	55.1
Using appropriate technology to assist student learning	ND	49.7	43.3	3.2	49.3	62.0
Working with students who have refuge backgrounds	ND	21.2	41.1	26.5	46.2	56.5
Working with students from diverse cultural and religious backgrounds	ND	32.0	42.5	19.6	66.2	59.9

Note. ND: No Data   NA: Not Applicable

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management role may not have been allocated to the TA, or their student does not fall into this category. The TAs may have indicated NA/never because of the different expectations of the schools they currently work in.

Participants indicated that there were 4 of the listed tasks that were NA/never to their current role (46%) (see Table 3). Despite the NA/never rating to these 4 tasks by the majority of the participants, some participants (20.4%) rated their preparedness to perform these tasks as very prepared.

Training and Professional Learning

Item 26 asked the participants to indicate whether they had received training or had no need for training across the listed 18 student related tasks. In responding 'no need' for training TAs may have been indicating that they had received adequate training in the selected task or they may have been indicating that the selected task was not relevant to their current role. Participants were also asked to rate their need for additional training in these tasks. The results were grouped and tallied into two categories: 'had training or no need' for training; and 'need for training.' Table 3 presents the responses from the participants to this item.

Overall the results show that the majority of participants (67.2%) indicated that they had 'had training or no need' for training across the 18 listed student related tasks. Participants responded that for 15 of the student related tasks the 'had training or no need' for training rating (71%) was higher than the 'need for training' category (40.1%). In these 15 tasks TAs considered that they had sufficient knowledge and skills to be able to perform the tasks allocated to them. The result implies that through training or experience TAs have broad levels of understanding of student related tasks that may be assigned to them in secondary schools in Victoria. Some of the tasks had a lower indicator score in the 'had training or no need' tally. This may be because the TAs did not need the training or professional development to address this issue at the time of completing the questionnaire or task the may not be relevant to the students they have, or are currently supporting, for example, 'provide therapy assistance.' Whether through training, professional learning or experience TAs indicated that they felt they were prepared to perform the listed student related tasks with understanding.

As shown in Table 3 the there were only three tasks that TAs indicated that their 'training needs' were higher than the 'had training or no need' for training. The three tasks were 'using appropriate technology to assist student learning', 'working with students who have refuge backgrounds' and 'implement behaviour management programs'. As previously discussed, the responses from the TAs regarding student backgrounds may have impacted this result. Similarly, it could be inferred that TAs would like training in these areas but they may have limited access to such training or training courses to address these tasks may not be available. Moreover, as the role of TAs is dynamic the TAs may not have had training in the listed task as it was not in their job description or they did not consider it was part of their role, however the

TAs could now consider it would be appropriate to have training in these tasks. For example, the need for training response to 'using appropriate technology to assist student learning' may be a result of the increase in the use of technology in schools. Likewise, the need for training in the item 'implementing behavioural management programs', may be a reaction to an increase in the potential for TAs to be allocated this task.

DISCUSSION

Examining the perspectives of the TAs is important as it provides a basis for understanding their perceived ability to perform their role in supporting students with disabilities in an inclusive educational setting. Similarly, by examining TAs' perceptions of their role the results may be used to inform decisions regarding the deployment of TAs within the inclusive support structure of the school. This study addresses the gap in the literature by exploring the TAs' perspective of their knowledge and training in supporting students with disabilities in mainstream secondary schools.

Work Related Items

This section of the study explored the TAs' perceptions of their knowledge of work related items. Work related items refer to the guiding principles of working within the school setting. The findings of this study showed that TAs considered they had considerable knowledge of work related items relevant to supporting students with disabilities within an inclusive school setting. The result is that TAs, by being assigned to support students with disabilities in mainstream schools, can be pivotal in interpreting and performing inclusive practice. Their daily work entails enacting inclusive strategies and programs through putting 'the theory into practice'. However, despite the knowledge and understanding TAs consider they have of the needs of individual students they support; TAs may not receive support within the school to uphold their responsibilities in performing their roles. This may be especially so within the political climate and culture of the school where TAs consider that members of the school often think TAs are not skilled and lack a level of education, which can often be reflected in their lower standing in the school hierarchy.

Student Related Tasks

This section of the study explored the TAs' perceptions of their knowledge and skills of student related tasks. Student related tasks refer to the tasks involved in supporting students with disabilities within the inclusive school setting. In this study TAs considered they were very prepared to perform daily tasks that were related to supporting students in the classroom. This implies that the majority of TAs consider they are sufficiently prepared to perform the tasks they frequently perform.

Similar to Carter et al. (2009) the results did not specify whether this was because TAs were assigned to tasks they were more prepared to perform or whether they were competent in tasks they regularly performed. However, consideration should be given to the findings that participants had been working as TAs for an average of 9.9 years therefore it could be inferred that on-the-job experience provided the knowledge and skills to enable TAs to rate themselves as more than adequate in performing these tasks. Additionally, although small in number, eighteen of the participants (11%) indicated they had also worked as a qualified teacher, implying they have a high level of preparedness to perform their role.

The findings of this study show that TAs consider they have the knowledge and skills to assist the students they support to achieve their individual educational goals. This implies that TAs have gained skills or knowledge related to these tasks through experience, training and/or professional learning. However, while TAs see themselves as very prepared to perform this role, external evaluators question the TAs pedagogical competence in performing these tasks (e.g., M. Giangreco, 2003; Webster et al., 2010). For example, as reported by Webster et al. (2010) from the outcome from the DISS project in the UK, students receiving most TA support made less academic progress than similar students who received little or no TA support. This finding implies that the allocation of a pedagogical role to TAs supporting students with disabilities has a negative impact on students' academic outcomes. Such findings further question the allocated roles and training of the TAs within the mainstream school setting.

The study indicated there were some student related tasks that some TAs considered they were less than prepared to perform. This implies that these TAs may need to gain knowledge and skills through training or professional learning in some areas related to their roles as TAs. It may also indicate that training or professional learning is not available, for example, there is no training/courses that address these issues; or is not accessible to these participants. Also funding, time release or distance may inhibit the TAs accessibility to any relevant training. Similarly, TAs may have indicated they are less than prepared to perform these tasks as they are not supporting students with these needs at the time of completing the questionnaire, for example 'provide therapy assistance'; or the participants may not consider the task is applicable to their role as a TA, for example 'write reports'.

Training

This section of the study investigated TAs' perceptions of their relevant training and training needs regarding the listed work related items and student related tasks. The study also examined the TAs educational levels. The results of this study indicated that the majority of TAs (67.5%) have had post school training. Despite TAs having post school training it may be inferred, as Riggs (2005) found, that they had no experience of working in the school setting prior to working as TAs. Teachers' aides who had no preservice training or formal training may have learnt about their allocated

tasks through mentoring programs or through trial and error. However, while Salas-Velasco (2007) reports that adequately educated workers require a shorter period of job training than do under-educated graduates, Carroll (2001) contends that the quality of the instructional services provided to TAs is directly related to the training they receive. This implies that TAs who have post school training are quicker to learn the skills required in performing their role, however the type of learning could create concern for some TAs. For example, not only does on-the-job training take time, the type and quality of training the TA receives is dependent on the knowledge and skills of the supervising personnel (Carroll, 2001; Carter et al., 2009; Devlin, 2008; Ghere & York-Barr, 2007). The outcome may be that TAs are working with limited knowledge of the guiding principles relevant to being employed in schools; or they may be supporting students with disabilities with inadequate knowledge of the individual needs of the students they are assigned to.

The findings of this study showed that the majority of TAs had received training or had no need for training in the listed work related items and student related tasks. The results imply that TAs have accessed training or have gained knowledge through experience to perform their role. However, despite the TAs perception of their training levels, a number of researchers question the validity of some of the roles being allocated to TAs (Angelides et al., 2009; M. Giangreco & Doyle, 2002; Gibson, Paatsch, & Toe, 2014; Inclusive Education Network, 2006; Webster et al., 2010). The findings of the current study showed that there was as a divergence in the tasks allocated to TAs across different schools. This may indicate that there are different expectations within different schools or it may also be interpreted that TAs are being given tasks that should fall within the responsibility of certified teachers and the school administration. It could also imply that the tasks allocated to TAs may be reactive in addressing the needs of the students with disabilities in the classroom. It may be interpreted that schools could manipulate TAs roles to address different issues that arise in supporting these students, rather than allocating these responsibilities to fully qualified teachers or specialist staff. The outcome of allocating these tasks to TAs could have legal implications for the school (Etscheidt, 2005). Moreover, it should also raise questions as to the allocation of these tasks to undertrained TAs. This may be resolved by TAs participating in a regime of formal training that could provide them with the knowledge to clearly understand their role and responsibilities in supporting students with disabilities in an inclusive school setting. For example, a preservice training course, formal induction training, or mentoring programs could enable TAs to access the knowledge recommended as they start their careers. Furthermore, formal training could establish unambiguous role definitions for TAs. By formalising the TAs' role definition all members of the school community would be able to work towards accessing and understanding the explicit roles of the TA and the potential for misuse or overuse of TAs in the school may be avoided.

Although the pragmatic reasons for employing TAs are predictable, the effects of the presence of a TA on student independence, social interactions, behaviour, and

academic achievement are still challenges for many within the school community (French, 2003). Despite concerns by researchers, this study found that TAs consider they have the work related and student related knowledge and skills to support students with disabilities in the mainstream state secondary school. However, the implicit confidence of TAs to address the issues that impact students with disabilities in the regular classroom may adversely affect the students they are there to support.

LIMITATIONS

The findings from this present study represent a sample of TAs who: (1) were forwarded the questionnaire by their Principal; and (2) were willing to participate in the questionnaire. The sample was drawn from a single state in Australia and therefore the results may not be reflective of the views of TAs in other states or regions that employ TAs. This study relied on the perceptions of the participants, with no verification of their experiences through observation, nor through the perceptions of other stakeholders such as schools staff including teachers, parents, and students. Despite the limitations of the current study, the information gained offers insight into the perceptions of TAs regarding their knowledge and skills in supporting students with disabilities in the mainstream secondary school system.

CONCLUSION

The Australian Senate (2002) recommended that all TAs working with students with disabilities should be qualified in special education from an accredited TA training course. The type of training TAs undertake can impact their learning. For example, whether the TAs' training course has been designed to give a broad overview of the knowledge and skills that may be relevant to their roles in the schools they are employed by; or whether the courses are directed to the needs of practicing TAs involving more comprehensive training focussing on areas including behaviour, learning styles and needs, and communication. Similarly, whether one course can provide sufficient knowledge to TAs to perform a myriad of tasks across a myriad of schools may be debatable. However, by giving TAs understanding and confidence regarding their role in supporting students with disabilities they are more likely to seek out professional learning to understand and provide support to address the differing needs particular to each individual student. Furthermore, understanding the particular needs of each student may encourage TAs to provide, as Whitburn (2013) describes, facilitative (light) services and avoid inhibitive (heavy) services to accommodate the student's inclusion into the school. Formal training for TAs could establish unambiguous role definitions and avoid what Giangreco et al. (2006, p. 216) call the 'training trap' where teachers and special educators relinquish even more instructional responsibilities to TAs based on the notion that 'now they are trained'. TAs should not be expected to be the expert in all fields of curriculum

but should be capable of providing the physical, social and educational support to students with disabilities to facilitate learning and be an active member of the school community. A clear definition of the role and its boundaries would support TAs and schools to maximise the benefits of TAs support for students with disabilities.

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KATE HOLLAND

3. CELEBRATING THE VOICES OF STUDENTS WITH HEARING IMPAIRMENTS IN NEW ZEALAND SECONDARY SCHOOLS

INTRODUCTION

Disabled children and young people worldwide have rights to inclusion and equal treatment enshrined in national legislation and international conventions. Yet they often remain left out – from generic children's research, from policy-making about children's services and, in their everyday lives, from inclusion in friendship groups and social and sporting activities. (Stalker, 2012, p. 173)

As Stalker (2012) explains, despite all children and young people's rights being recognised in legislation and policy, these rights are infrequently enacted in reality. Traditionally, the voices of parents, educators, and medical professionals have replaced those of children and young people. Even with the recent surge in student-centred research, many texts omit the voices of students with disabilities, instead privileging other forms of diversity such as class, ethnicity, or gender (Barton, 2009; Fitzgerald, 2009; Fitzgerald, Jobling, & Kirk, 2003; Suomi, Collier, & Brown, 2003).

Cognisant of the aforementioned gap, in this chapter I share the stories of two students with hearing impairments who attend New Zealand secondary school. Fourteen year-old Kelly, and twelve year-old Cody (pseudonyms) demonstrate that, while their voices are not often listened to, they have valuable, insightful knowledge about their own education experiences and how these relate to wider educational discourses. Kelly and Cody highlight discrepancies between educational policy, legislation, and practice in mainstream New Zealand secondary schools. The stories they chose to share garner insights into the effects of New Zealand's educational climate and provide an alternative way of thinking about what it means to be 'hearing impaired' in New Zealand education. Overall, Kelly and Cody's voices demonstrate that despite inclusive policy and legislation, discourses of neo-liberalism and special education can threaten the education of students with hearing impairments in New Zealand secondary schools.

LEGISLATION AND POLICY CONTEXT

The right for all students to access and be included within education has long been acknowledged. Internationally, the Universal Declaration of Human Rights (1948), the United Nations Convention of the Rights of the Child (1989) and the United Nations Convention of the Rights of People with Disabilities (2007) state all people are entitled to an equal and fair education where they are supported, included, and respected.

The rights enshrined by this international legislation are reinforced specifically within New Zealand's education policy. The 1989 Education Act pivotally acknowledges the rights of *all* children to access education. This is further reinforced in section 57 of the Human Rights Act, which states that every child has the right to education, and that it is unlawful to exclude or remove students from their educational context on the basis of disability (Human Rights Commission, 1993). Also, the New Zealand Disability Strategy states that 'all children, youth and adult learners will have equal opportunities to learn and develop in their local, regular educational centres' (Objective 3, Ministry of Health, 2001). In other words, every student is to be recognised, accepted, and included within education.

The current New Zealand Curriculum states that practices within all New Zealand schools should be 'non-sexist, non-racist, and non-discriminatory; it ensures that students' identities, languages, abilities, and talents are recognised and affirmed and that their learning needs are addressed' (Ministry of Education, 2007, p. 9). The inclusion of all students is not merely a passing comment in this document, but an ongoing priority for the New Zealand education system (Ministry of Education, 2014). The most recent Ministry of Education Statement of Intent (2013) prioritises the education of students with 'special educational needs' and reinforces the aim of a fully inclusive education system.

As these conventions, legislation, and policies attest, all students are to be valued, respected, and included. Yet, the mere presence of such documents suggests that for some students, their rights are at risk. The need to have their rights explicitly stated indicates that these rights are not automatically realised and that barriers exist that prevent young people with disabilities (including those with hearing impairments) from enacting their rights (MacArthur, 2013). Further, despite students' rights being well documented, Quennerstedt (2009) argues that many New Zealand schools fail to respect this right for some students. Instead, students are often excluded from decision-making about their education and are limited in the opportunities available for them to learn alongside their peers (Human Rights Commission, 2009; IHC, 2014; Quennerstedt, 2009). Such injustices are well documented by the Human Rights Commission, which notes, 'education-related complaints from or on behalf of disabled students continue to be amongst the most frequent groups of complaints' (Human Rights Commission, 2008, Section 2.7.9). As a result:

Disabled students continue to be seen as 'other', and therefore as problematic for the education system, the school and the individual teacher. Disabled

students remain the object of policy rather than the subject of their own education. (Human Rights Commission, 2009, p. 17)

Thus, while a student's education context may seem equal, fair, and inclusive on paper, there appears to be major discrepancies between policy and practice. In this chapter, I refer to two particular concerns with the New Zealand education system, which could threaten these rights: the effects of neo-liberalism, and the discrepancy between 'inclusion' and special education.

NEO-LIBERALISM AND NEW ZEALAND EDUCATION

Education in New Zealand is increasingly regarded as a commodity and cited as becoming overly neo-liberal (Pope, 2013; Shore, 2010). Families are encouraged to choose the best 'product' for their child, resulting in a highly competitive marketplace driven by education outcomes that focus specifically on numeracy and literacy (Armstrong, 2003; Ballard, 2013; Gordon & Morton, 2008; Higgins, MacArthur, & Morton, 2008; Kearney & Kane, 2006; Millar & Morton, 2007; Morton, Higgins, MacArthur, & Phillips, 2013; Pope, 2013; Wills, 2006; Wills & McLean, 2008). A specific focus on measurable, educational achievement has also been cited as causing value to be ascribed, not only to particular schools, but also to particular students (Kearney & Kane, 2006). This is largely dependent on what resources are required for them to achieve educational success and how students are sorted and stratified by their perceived educational potential (Willis & McLean, 2008). For example, Higgins et al. (2008) explain New Zealand children and young people are measured in terms of their potential to produce certain educational outcomes and how much time, funding and support is required to assist them to reach these outcomes. The competitive, market based education context (Shore, 2010) and the pervasive assumptions that students with hearing impairments are educationally less able and in need of a higher financial investment than their able bodies peers (Kearney & Kane, 2006; Macartney, 2009), greatly conflicts with the tenor of legislation and policy which recognises every child's right to education without discrimination.

Neo-liberal thinking has also been criticised as being for particular students who fit the mould of the educable individual. As Kearney and Kane (2006) mention, certain students are seen as giving less return for education investment than others. The lingering presence of special education within a theoretically 'inclusive' setting such as New Zealand sees resources automatically ascribed to those who fit the educational setting (Armstrong, 2003), meaning others, such as those with hearing impairments, must fight for their educational requirements. Therefore, despite inclusive sentiments, there appears to be conflicting and inconsistent governmental perspectives regarding the place of students with hearing impairments in New Zealand educational institutions (Higgins et al., 2008). The terms 'inclusive education' and 'special education' are used interchangeably, signalling a lack of understanding of the underlying beliefs and values for special and inclusive education (Brown, 1997;

Higgins et al., 2006; Higgins, MacArthur, & Rietveld, 2008; Morton et al., 2013) and creating an opportunity for neoliberal thinking to mature and develop.

Ainscow (2007), Ballard (2004), and Slee (2001a) agree that inclusion is the recognition and valuing of the diversity of all students, and their rights to education. It is about valuing all students' 'presence, participation and achievement' in the mainstream classroom (MacArthur, 2009, p. 14). Inclusion is also a process of examining and removing barriers – rather than viewing students' 'educational failure' as the result of 'characteristics of individual children' (Ainscow, 2007, p. 3). Barton (1997) clearly summarises the differences between 'inclusive' and 'special' education. He explains:

> Inclusive education is part of a human rights approach to social relations and conditions… It is thus important to be clear in our understanding that inclusive education is not about 'special' teachers meeting the needs of 'special' children in ordinary schools… It is not about 'dumping' pupils into an unchanged system of provision and practice. Rather it is about how, where and why, and with what consequences, we educate *all* pupils. (p. 234)

Therefore, the aforementioned conflation of such terms within New Zealand educational policy is highly problematic. On one hand, the educational experiences are purported as inclusive and valuing of students. Yet neo-liberal, economic perspectives could endanger the presence of students with hearing impairments in education (Slee, 2013). Kelly and Cody's voices shed light on this problem and demonstrate the depth to which discourses of ability, competitiveness, and educative value permeate New Zealand Education (Ballard, 2013).

METHODOLOGY

Kelly and Cody's stories are taken from a broader PhD study examining students with disabilities' perceptions of their education experiences. Kelly attended a large urban low decile girls' secondary school and had a love for all things sporting. Despite her sporting abilities, she felt that she struggled academically and socially. As well as having a hearing impairment that caused her to rely largely on lip reading and sign language, Kelly was identified as having learning difficulties and often reported being bullied by her classmates. Despite this, Kelly was a positive young woman, and saw this research as an opportunity to share her experiences, in the hope that it may improve the educational opportunities of future students.

Cody was in his first year of secondary school during the research project. He attended an urban, low decile coeducational school close to his home. His teacher aide largely supported him due to his other physical impairments that caused limited mobility and the need for a wheelchair. Despite this, Cody had a fierce independent streak, and took his opportunity to share his voice seriously.

This qualitative, participatory research sought to listen and celebrate the voices of Kelly and Cody. Focusing on student voice involves 'listening to and valuing the

views that students express regarding their learning experiences; communicating students' views to people who are in a position to influence change; and treating students as equal partners in the evaluation of teaching and learning' (Seale, 2010, p. 995). Student voice research encourages researchers to move away from assumptions about what students think and instead embrace their knowledge and wisdom (Campbell, 2007; King & Evans, 2007). O'Neill and Wyness (2005) argue that research focusing on 'voice' allows individuals who have previously been silenced/overlooked to be listened to and empowered.

While the concept of student voice encourages empowerment and inclusion of marginalised groups, criticisms have been made as to the extent of the transformative effect of student voice and whether student voice is simply heard or actively listened to (Porter, 2008; Seale, 2010). As Seale (2010) explains, 'giving what children say 'due weight' involves listening rather than hearing. This conceptualising of student voice is not reflected, however, across the whole of student voice activity' (p. 998). In relation to this research, working within a participatory research framework assisted Kelly and Cody to actively engage in research production.

The concept of student voice links nicely to the tenets of participatory research. As Clavering and McLaughlin (2010) explain, participatory research requires a shift in research production from 'on' or 'with' participants, to research 'by' participants in an attempt to 'enable young people with disabilities to become actively included within the research process' (Fitzgerald & Stride, 2012, p. 286). Participatory research endeavours to realise the rights of all students to be heard, irrespective of their desired communication methods, as stated in the UNCRC (United Nations, 1989). Yet, as demonstrated via Kelly and Cody's stories, this right is seldom enacted for them in their respective education settings.

Kelly and Cody were encouraged to discuss whatever they wanted people to hear about their educational experiences, in whatever manner they wished to share their voice. They both chose to communicate through a range of mediums, including books, photographs, storytelling, and sign language (Robinson & Taylor, 2012; Stalker & Connor, 2003). However, as discussed above, celebrating students' voices is not only about identifying gaps in education on a structural scale. Working with Kelly and Cody permitted them, as individuals, to be active members of the research project. It also realised the socially critical goal of making a difference on a personal level (Hill, 2006; MacDonald, Kirk, Metzler, Nigles, Schempp, & Wright, 2002).

While often being the focus *of* research, Kelly and Cody (as with most students) had never had the opportunity to engage in research topics, production, or dissemination. This was particular evident with Cody, who had often been the topic of research, but had never felt included. Finding a means by which Cody and I could communicate with each other was not easy. However, once we established a 'language' in which we could communicate, Cody truly embraced sharing his voice. In particular, he demonstrated that despite what educators think is best for his education, he does not agree. Not only do their stories garner insights into ways educational practices could be altered to improve the experiences of students with disabilities, but their

insights are applicable for all students who may face similar issues (van Amsterdam et al., 2012).

KELLY AND CODY'S EDUCATIONAL EXPERIENCES

Classroom Experiences

Kelly's experiences within the classroom were exceptionally varied and contingent largely upon the teachers she had. She recounts both positive and negative experiences of teachers, giving rise to a range of feelings about herself and her academic ability. For example, her arts teacher 'would draw pictures of what he meant, and he would do it in steps… He is very good at making everybody understand and um, he talks loud and clearly.' As she cannot hear as well as other students in the class, talking 'loud and clearly' is something Kelly finds helps her fit in with her peers. This is a common desire for students with hearing impairments who wish to emphasise their similarity, rather than their difference to others (Macarthur, Sharp, Gaffney, & Kelly, 2007a).

While her art teacher's practices reflect the inclusive pedagogy prescribed in the New Zealand Curriculum (Alton-Lee, 2013), Kelly describes how other teachers cause her to feel different from her peers. For example, despite having a keen interest in Social Studies, she finds it 'frustrating because the teacher doesn't… doesn't teach me, and I don't really understand what she is saying and I find it hard because I don't understand what she is saying. So I don't really understand'. In other classes, Kelly explains that teachers supply her with 'different work from the other kids because I haven't quite caught up yet' causing her to feel frustrated as she is aware of how easy it would be for teachers to help her to catch up:

> I prefer, well, she doesn't talk very clearly. Well, she does talk loud but she doesn't talk clearly so I don't understand her words. Yeah. I would make sure she talks clearly and mainly writes down something, she goes too fast instead.

The difference between Kelly's art teacher who takes the time to help her learn, and the others who cause her to feel left behind exemplifies the difference between educational thinking. Her art teacher clearly prescribes to the inclusive pedagogy, where every student deserves the chance to learn (Ministry of Education, 2007). However, for other teachers, it seems that time and resources are views as valuable commodities within the classroom. The extra time and alternative teaching practices required to ensure Kelly can comprehend appears to be sacrificed for the learning of the rest of the class, indicating a more neo-liberal, cut-throat approach to teaching.

Her experiences also question the assumptions teachers make regarding how students learn – particularly as Deaf and hearing impaired children face a number of issues regarding expectations and assumptions that differ between the child and the teacher (Davis, Watson, Corker, & Shakespeare, 2003; McArthur, Sharp, Gaffney, & Kelly, 2007b). Despite a paradigm shift which moves away from expecting students

to 'fit' the classroom, to one where learning is moulded to 'fit' students (Alton-Lee, 2003) it seems the 'one size fits all model' still persists in some of Kelly's classes.

Cody's classroom experiences greatly contrast Kelly's. Cody attends 'the special needs unit (which he refers to as 'the unit') at his school to cover the 15 hours not funded by a teacher aide. Cody says he is 'happy' with his schooling set up and enjoys his time spent in the unit, where he can watch movies and relax. However, it seems his 'inclusion' in mainstream schooling is something that still relies on the presence of 'the unit'. When it is not suitable for the mainstream class to accommodate Cody, 'the unit' provides a place for him to go to pass the time. Thus demonstrating the prevalence of 'special needs' discourses and practices, where students are removed from the mainstream, despite a theoretically inclusive education environment.

As Cody's experiences attest, school units serve not just as barriers to doing (such as taking part alongside peers), but they also construct a major barrier to being (Thomas, 2013), as they cast students with disabilities as different to the rest of their peers. This is something Cody is aware of, explaining that he often feels frustrated with his separation from his mainstreamed peers, despite his wishes. This separation reinforces special education discourse, which, as Slee (2005) argues, is incredibly dangerous due to the 'potential [it yields] for teachers to feel more confident in their hunches that some kids don't belong in *our* schools' (p. 149).

Overall, Kelly and Cody's experiences point to 'normalised' ways of being and achieving in New Zealand classrooms. Kelly's art teacher was the exception to Kelly and Cody's experiences with teachers. Predominantly, Kelly and Cody say they felt left behind or excluded from their peers due to their hearing impairments. As Gore (1995) explains, 'Indeed, exclusion, as the flip-side of normalisation, is properly seen as integral to pedagogy' (p. 174). In other words, the exclusion of Cody from his classroom, and separation of Kelly, which impacts upon both of their abilities to learn, maintains the status quo of the neo-liberal classroom. Where those who can learn and communicate in the prescribed manner do so together, while those who learn differently, such as Kelly and Cody are separated from their peers. This dichotomy is occurring within light of policy rhetoric, which loudly claims these experiences unacceptable and unjust (Ballard, 2013).

Teacher Aides

Both Kelly and Cody felt that their teacher aides greatly shaped their education experiences. Without them, both agree that their educational opportunities would be severely limited. Kelly is separated from her peers in many of her classes and instead sits beside her part-time teacher aide Suzy (pseudonym). She says that this is due to her own issues with keeping up with the work, rather than anything to do with her hearing impairment. For example, in some classes she explains she must do:

Different work from the other kids because I haven't quite caught up yet. I sit at the back because the things the teacher puts on the board I don't do. Cos I

> do different stuff from the whole class so I am not quite caught up yet. It's so frustrating… Frustrating!!!

Suzy is 'always' beside Kelly during lessons to assist her learning: 'She would help me with what I need a lot of help with, I pretty much get a lot of help.' However, on the days that Suzy is not present, Kelly must sit beside the other students with disabilities, away from her friends and work independently. This separation raises questions about how the structures impact on her learning. For a student who needs 'a lot of help', and has trouble hearing, how is removing her from her peers, and only having support two days a week enhancing her learning? It seems Kelly's experiences are a form of 'educational disablement' (Slee, 2001b, p. 167), in which the fiscal nature of education, where money and time are invested carefully and scarcely, have significantly inhibited Kelly's ability to learn.

Kelly's experiences resonate with those of Cody. His teacher aide, Liz (pseudonym) is often left to teach Cody what she feels is fit for him to learn. Cody does not attend all of his mainstream classes. According to Liz, science 'is just not safe, and maths is just too difficult for him'. Furthermore, the class sizes at his school means that sometimes Cody does not have a desk space. Liz explains, 'Well in some classes there is just no room, because there is up to 21 kids in the class. And that has an impact.' When he is 'unable' to attend classes, he works with his teacher aide in a separate room, which he enjoys and finds 'good'.

Teacher aides being required to take on the primary responsibility for students' learning is something Giangreco, Edelman, Luiselli, and MacFarland (1997) call 'inappropriate and inadvisable' (p. 15), and also contradict their rights enshrined in educational legislation. Yet, as in Kelly and Cody's case, remains common practice (Giangreco, 2013; Giangreco & Doyle, 2007; Slee, 2007). Rutherford (2012) also mentions that there is little consensus and definition of the actual role of teacher aides, in particular, where being an 'aide' ends and teaching begins. Yet their presence in the classroom is often viewed as the solution to inclusion and a worthwhile investment of time and money. Giangreco (2013) explains this further:

> Too often teacher assistants are not used wisely in inclusive classrooms, but rather metaphorically as a bandaid for an injury that at the very least requires stiches and possibly major surgery; no bandaid, regardless of size or type, will meet the need. (p. 2)

In this sense, as reflected in Kelly and Cody's situation, the reality of teacher aide work greatly differs from their rhetorical position. Rather than 'working under the direction of the classroom teacher' (Ministry of Education, 2012, p. 1), Liz appears to have to *become* Cody's classroom teacher, responsible for his learning in place of his teachers – something she is not employed nor trained to do.

Furthermore, Kelly and Cody's separation from their peers contradicts the Human Rights Act (1993) and the Education Act (1989)'s statements that all students are entitled to an equal and fair education and are not to be unlawfully removed from their

peers. For Cody, who receives a large amount of his education separate from his peers due to a perceived 'lack of space' in the classroom, this raises serious concerns about whether or not these rights are recognised, let alone enacted in mainstream education.

Social Experiences

The third theme which Kelly and Cody talked about in-depth was their social experiences of school, and how this made them feel about themselves. Kelly's accounts of schooling focused largely around experiences of bullying, which she felt was compounded due to her hearing impairment and lack of support to remain in the mainstream. She struggled initially to make friends at secondary school, explaining: last year I hardly had any friends… I used to go to the learning support where all the people with disabilities go. That was very quiet… they didn't talk much. This made her feel 'a bit lonely really' and in order to make friends, she:

> Found a girl that is a nice girl that I like, so um, I followed her and I met some of her friends. And I started hanging around each day, just having lunch with them and I began to make friends.

Despite being happy to now have friends, Kelly misses out on a lot of the conversation, explaining, 'Really, I don't understand much. They talk quite quickly.'

It was in Kelly's first year at secondary school, when she did not have many friends that she faced the most bullying:

> Well when I was in year nine it was a pretty bad year because I didn't have any friends, so I felt quite lonely, and most of the girls in my class were mean so it was a pretty bad year. While I was in PE, one of the girls stole my phone… I don't know why they are horrible to me. I don't know why.

These experiences cause her to feel 'really scared' of attending school. She demonstrates this both visually and verbally:

Figure 1. Kelly's drawing of her feelings

To explain this drawing, Kelly says:

> Most of the time I cried, and I said to Mum I don't want to go to this school anymore, so Mum didn't like me being bullied so much like that. So she was thinking of changing schools but then my parents said no, I don't think so, this is a good school for you and you should stay there and I just had to put up with that. And so the teacher said next year they would put me in with the nicer girls, so I had no bullies in my class. And I kind of cheered up at that.

Despite initially stating that she did not know why she was bullied, Kelly believes this is because of her hearing impairment: 'Why are they doing this to me? I have a disability, but I am not going to explain that to them!' She goes on to explain that her friend, who also has a disability, is also the target of bullying: 'even my friend Sarah, she has a disability, the one that thinks very slowly and that kind of problem, she is always, always, always crying and I have to comfort her. She doesn't understand either.'

Cody explains that he did not get to spend a lot of time with his friends at school, as he was often separated and learning in a different area of the school. Cody feels that he does not have as many friends or as much social interaction as he would like, and often feels 'lonely.' His friends Bert, Tommy, and John (pseudonyms) are all educated solely in 'the unit' at his school, and when Cody attends mainstream classes he sits with his teacher aide, separate from his able-bodied peers.

Being the target of bullying and exclusion based on difference is reported to be a common issue for students with disabilities, including those with hearing impairments such as Kelly and Cody (Bourke & Burgman, 2010; Carter & Spencer, 2006). The consequences of such 'discriminatory social processes that shape children's identities through a rejection of the different body' (MacArthur et al., 2007b, p. 29) lie in how the students draw on these experiences to understand themselves as valuable, deserving individuals (Connors & Stalkers, 2007). Furthermore, events such as bullying and exclusion can reinforce and highlight their difference from the 'mainstream' student (MacArthur et al., 2007a). Kelly and Cody simply wished to fit in, and be seen for their similarities, rather than have their differences objectified in cruel acts of surveillance and separation based on perceived differences to the norm (Paechter, 2013).

CONCLUSION

Overall, Kelly and Cody raise questions about who counts within education. It seems that notwithstanding their wishes, they are subjected to discourses that privilege the learning of those who 'fit' the mould of a 'normal' student. Despite their rights being comprehensively stated, it seems they have *conditional* acceptance into the 'mainstream' (Rutherford, 2012), where they are only allowed in when funding, space, lessons, and social structures permit.

What is particularly alarming is how these experiences do not gel with the legislation and policy set out to protect children (Clarke & MacArthur, 2008; IHC, 2014; MacArthur, 2013; Rutherford, 2012). For example, Article 28 of the United Nations Convention of the Rights of the Child (1989) states, 'Young people should be encouraged to reach the highest level of education of which they are capable'. Furthermore, the New Zealand Curriculum (Ministry of Education, 2007) is said to be 'non-sexist, non-racist, and non-discriminatory; it ensures that students' identities, languages, abilities, and talents are recognised and affirmed and that their learning needs are addressed' (p. 9). Yet it is greatly questionable whether the experiences Kelly and Cody's chose to share reflect these statements. Kelly and Cody's experiences raise questions as to whether these experiences would be acceptable for the majority of students, or whether their exclusion is justifiable based on metaphorically sacrificing their education for the sake of the majority (Slee, 2001a).

By listening to the voices of students with hearing impairments, deep-seated practices of differentiation and segregation are identifiable. The practices Kelly and Cody discuss shows that 'disabled students either find themselves excluded or co-opted into shallow exercises of assimilation' (Slee, 2001a, p. 389). However, Slee (2001a) would argue that 'blame' cannot be laid on particular people or structures that exclude Kelly and Cody and prevent them from learning alongside their peers. A lack of clarity about the role of teacher aides within schools, changeable and unclear expectations about the type and level of educational assistance, and funding limitations (which perhaps received greater attention than discussions of rights) have all been acknowledged as affecting students' learning opportunities (Giangreco, 2013; Giangreco & Broer, 2003.) As a result, Kelly and Cody's voices demonstrate that the gap between what is a sufficient education for a 'normal' child and a child with a hearing impairment or other disability may be exceptionally wide and seemingly unjust.

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4. INCLUSIVE EDUCATION IN BANGLADESH

Stumbling Blocks on the Path from Policy to Practice

INTRODUCTION

Like many other developing countries in South Asia, Bangladesh, has taken the principles of inclusive education on board in its education policies, acts, and programmes with the expectation of including *all* school-aged, out of school children, including those with disabilities, within the country's mainstream education system to achieve the milestone of Universal Primary Education by 2015, under the Millennium declaration popularly known as MDG 2 (UNDP, 2010). Bangladesh recognised the importance of universal primary education for all school-aged children in its national constitution (The National Constitution of Bangladesh) as early as 1972. Efforts to achieve this goal commenced in 1981 (MDG Bangladesh progress report, 2011) and gained impetus with the advent of global declarations dedicated to education for all and inclusive education (IE) such as the *World Declaration on Education for All* (UNESCO, 1990), the *Salamanca Declaration on Special Needs Education* (UNESCO, 1994), and the *Dakar Declaration* (UNESCO, 2000). Recent policy and programme initiatives in Bangladesh have increased the number of primary students enrolled, including girls and students with disabilities (DPE, 2011a). Consequently, 'teachers routinely encounter a wide range of students' in regular classrooms (Florian, Young, & Rouse, 2010). The heterogeneity of the classrooms in South Asian countries, including Bangladesh, has been reflected in recent UNESCO statistics demonstrating that South and West Asian countries have made significant progress in improving student enrolment rates, successfully reducing the number of out-of-school children by two-thirds from 39 million in 1990 to 13 million in 2010 (UNESCO Institute of Statistics, 2012). Global studies (e.g., Miles, 2009) reveal that teachers in developing countries are concurrently feeling the pressure of teaching increasing numbers of children with diverse needs, as 'inclusion inevitably challenges schools to provide appropriate support for all children' (Forlin & Rose, 2010, p. 13).

Bangladesh has recently introduced The National Education Policy 2010 to address the contemporary educational agenda, including IE. This policy tackles inclusion of diverse groups of children, including those with special needs/disabilities and those from ethnic communities and socio-economically disadvantaged sectors, in

the existing mainstream education (MOE, 2010). To achieve the goals of providing quality primary education and equal opportunities for all children, the Third Primary Education Development Programme (PEDP3)[1] has been introduced (with an estimated budget of US$8.3 billion) to operationalize the National Education Policy 2010 by 'identifying and minimizing barriers to children's participation in school' and 'creating an inclusive culture based on the principle that all learners have a right to education irrespective of their gender, individual characteristics, or differences' (DPE, 2011b, p. 12).

Despite considerable improvement in student enrolments (e.g., now more girls attend school than previously), there remain a number of issues in enacting IE in classroom practices (Mullick, Deppeler, & Sharma, 2012). A recent newspaper article reported that traditional schools, especially in rural areas outside Dhaka, were not keen to enrol students with disabilities because they lack suitably-trained teachers, appropriate teaching resources, disability friendly school environments and infrastructure (*Quota for Disabled Students*, 2013). This is consistent with recent studies in Bangladesh (e.g., Ahmmed et al., 2012, 2013) that found in-service teachers' attitudes towards the inclusion of students with a disability and teaching efficacy are influenced by teachers' perceived school support. Another study reported that pre-service teachers in Bangladesh have moderately high perceived teaching efficacy and positive attitudes towards implementing IE, even though they were concerned about the success of IE (Ahsan et al., 2012).

The current situation in primary education in Bangladesh, therefore, compels close examination of teachers' attitudes regarding instructing students with disabilities within their usual classes and what are the influential dynamics of these attitudes. As it is recognized that 'teachers are crucial characters in the schooling script' of enacting inclusive practices (Kozleski & Waitoller, 2010, p. 659), such understandings of teachers' views and influences can only benefit inclusion programs in Bangladesh by better informing stakeholders. The few identified studies of IE in Bangladesh examined pre-service and in-service teacher attitudes and teaching efficacy, and reported these variables were, in turn, influenced by a number of demographic variables (e.g., contact with students with a disability, school support). However, those studies were based on self-reported survey questionnaires and lacked any in-depth understanding about either their views or underpinning factors (e.g., Ahmmed, Sharma, & Deppeler, 2013; Ahsan, Sharma, & Deppeler, 2012). Pertinently, a study conducted in neighbouring India reported that pre-service teachers held negative attitudes toward and a moderate degree of concern about, including students with disabilities in their regular classes (Sharma, Moore, & Sonawane, 2009). Given the above conditions, this study aims to address the following key research objectives:

1. To understand teachers' views towards the inclusion of students with disabilities in mainstream classrooms in government primary education in Bangladesh, and
2. To identify background factors teachers believe influence their views to include students with disabilities in their classrooms.

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METHODOLOGY

This study was guided by the conceptual framework[2] of a broader study and the research objectives. As stated, the research objectives were to understand what teachers think and feel about their role in IE and why. To achieve these aims, data were gathered from the schoolteachers in Bangladesh using group interviews (GIs). GIs were considered appropriate since this method allows the researcher to 'engage, understand and interpret the key feature of the life-worlds of the participants' and to uncover the 'descriptions of specific situations and actions, rather than generalities' (Cohen, Manion, & Morrison, 2007, p. 355). Moreover, GI is a well-recognised and frequently utilised method of data collection in academia and research.

Participants

Twenty-two teachers working in government primary schools within the Dhaka division in Bangladesh participated in GIs. In Bangladesh, there are seven regional administrative divisions. To select participants for GIs, the Dhaka division in Bangladesh was purposefully chosen. The main reason for this selection was that Dhaka is the central and most populous division of the country and would, therefore, best afford representation of schools located in urban city, semi-urban city and rural countryside locations. Four sub-districts were randomly selected: one from urban, one from semi-urban and two from rural locations in the Dhaka division. The quotient of sub-districts selected approximately corresponds to the ratio of the total number of sub-districts in these three locations. All government primary schools (293) located in these four sub-districts were included and all teachers serving in the schools received consent forms and explanatory statements about the study. A total of 169 teachers consented to participate in a GI and sent their contact details to the author of this chapter. Additional communications rendered 132 in-service teachers eligible for GI participation (37 of those who initially consented either changed their mind or with whom further communication proved difficult at the time). Taking into account the participants' demographics, such as gender, location of the schools, age of the participants, and availability, a final total of 22 participants was deliberately selected: five from the urban sub-district, five from the semi-urban sub-district and six from each of the rural sub-districts (see Table 1). The aim of this calculated sampling was to *maximise* the diversity of the participants, not to achieve representation of the diversity of the country (Barbour, 2007). Therefore, this sample may not represent the full range of the population in Bangladesh.

Among these twenty-two participants, fourteen (n=14) were female and eight (n=8) were male teachers. The age of the participants was between 24 and 53 years. A total of eight (*n*=8) participants had below Bachelor qualifications while eight (n=8) and six (n=6) participants had Bachelor and Master degree educational qualifications respectively. Teaching experience of the participants was between

Table 1. Details of participants selection procedures for GIs

Information about the selected sub-districts		Total no. of schools	No. of teachers who consented for GI	No. of teachers who changed their mind/ could not be reached	No. of teachers who finally agreed	No. of teachers finally selected for GI
Location	Number					
Urban	1	17	52	12	40	5
Semi-urban	1	116	61	8	53	5
Rural	2	160	56	17	39	12 (6+6)
Total	4	293	169	37	132	22

1 and 26 years. The majority of the participants (n=12) had previous experience in teaching a student with a disability and a majority (n=16) also had participated in short training in IE.

Data Collection Procedure

Prior to data collection, ethical approval was obtained from the university Ethics Committee in Australia where the study was undertaken and permission for data collection was given by the Directorate of Primary Education in Bangladesh. The researcher (author of this chapter), with the cooperation of respective sub-districts' Education Offices, arranged a venue for the GIs at the premises of the Education Office at each sub-district, after giving due consideration to its convenience for participants. The dates and times of the GIs were fixed according to their suitability for participations.

Setting the Scene for GIs

To establish rapport between the researcher and the participants, and among the participants themselves, and to facilitate a lively and comfortable discussion, there was an informal icebreaker at the commencement of the four GIs (Barbour, 2007). The researcher provided refreshments, as a way of showing gratitude to the participants and creating a relaxed atmosphere for the GI. The discussion was guided by a semi-structured interview protocol. However, the participants were freely allowed to change the order of the questions and offer added additional information to suit the discussion (Johnson & Christensen, 2012). Each of the

participants in a GI was asked the same questions but it was open for them to agree, disagree or add their opinion at any stage of the conversation. All the GIs were conducted and moderated by the researcher, in Bangla language, the first language of both the participants and the researcher. The author conducted GIs in four different sub-districts on separate dates. The duration of each of GI session was approximately 45–60 minutes. With the permission of the participants, each of the GIs was audio-recorded.

GI Protocol

A set of guiding questions for the GIs were developed over a piloting process including initial review by three educators acquainted with primary education and IE in Bangladesh and content validation in Bangladesh before employed for data collection. The GI guided questions are as follows:

1. What are your views about the inclusion of students with diverse needs/disabilities in the regular classroom?
2. How confident do you feel in teaching students with special needs/disabilities in regular classrooms?
3. What kind of support (e.g., material/human) do you feel you are receiving (or not receiving) for implementing IE in your regular classrooms?
4. What are the factors you think influence whether you include/do not include students with special needs/disabilities in regular classrooms?
5. What are the barriers to including children with special needs/disabilities in regular classrooms?
6. If you have any additional information/suggestions, please specify.

Data Transcription and Translation

The researcher transcribed the audio data. To enhance internal validity (Creswell & Plano-Clark, 2007), the transcribed data was shared with the participants of each GI group by mail and necessary changes were made, if required, according to their suggestions. Two independent translators who were almost equally expert in both languages were asked to translate the data from Bangla to English. The researcher then reviewed and compared these two sets of translated data and, if any discrepancies were found between these two sets, discussed them with the translator before reaching a final version of the translation (McGorry, 2000).

Data Analysis

The analysis of GI data involved the following steps in identifying the final themes, as recommended by a number of authors (e.g., Braun & Clarke, 2006, p. 87; Creswell, 2002, p. 266; Liamputtong, 2011; Thomas, 2006):

- The researcher thoroughly read and reread the transcribed data several times.
- Sections relevant to the research objectives were selected and assigned codes.[3]
- The codes were revised to reduce overlap and repetition.
- The codes were organised into themes by grouping those with similar topics (across the GIs).

In the discussion, these themes are clustered to correspond with the aims of the study. To achieve internal validity of the generated themes (Creswell, 2002), two researchers were asked to review the process of data analysis (i.e., initial coding to the final themes). After discussions with the reviewers for clarification of the feedback, the author further, and finally, refined the themes. So, the data analysis involved reading the transcribed data a number of times for complete understanding, selecting the important text for coding, checking the codes for overlap, merging the codes and developing the themes.

FINDINGS

The findings of the data analysis are discussed under the headings of the two key research aims of understanding teachers' views and the background factors underpinning their views on including children with disabilities in regular government primary school classes in Bangladesh.

Teachers' Views towards Inclusion

Some of the themes associated with the views of teachers towards inclusion of children with disabilities are consistent with the idea of IE as being unrealistic and with their intentions being tied to notions of responsibility. They are discussed individually, under the latter-mentioned categorisations.

IE as Responsibility

Teachers are willing to include students with disability. Most of the participating teachers indicate they support the principle of IE personally, feeling social responsibility as a conscious citizen of society: they felt the inclusion of children with a disability in local schools was needed to provide, at least, some educational opportunity for them, since there was no other special educational arrangement for those children. One teacher felt:

> While I see in my village that children with disabilities do not go to school and have no opportunity to get the 'light of education', I question myself: Where will they go if we do not allow them to come to the nearby school? (TS3)

One teacher's optimism about IE expands the idea of social responsibility beyond simply providing quality education for children with disabilities:

> One student who couldn't speak well, I saw that, when he started coming to this [regular] school and mixed with 'normal' students, his speaking ability improved a lot. That experience inspired me. I think that if a student with a difficulty [impairment] comes to the regular school, the association with other normal students helps to overcome the problem [difficulties/disabilities]. (TSK 5)

Teachers also support the principle of IE professionally, under the national education policy drive: teachers specifically mentioned that they were instructed by the Education Department to execute IE:

> Thana [sub-district] Education Office always says: 'You have to bring all children including those with disabilities from the nearby locality to achieve 100% enrolment' but they do not tell us how to teach them… We try our best to respond to this government order. (TT1)

IE as Unrealistic

Teachers are sceptical about full inclusion. The majority of the participating teachers expressed pessimistic views about the success of IE in the regular classroom, given the inadequacy of existing facilities such as support services, resources and training. Consequently, many thought that, currently, special schools might provide better educational opportunities for students with a disability than ordinary schools. As one teacher says:

> I believe that if these children [with special needs] are given education at special schools, they will get 'proper' and better education. If we teach them here, there are many problems [such as] lack of instructional resources and specialist teachers. (TS4)

However, they acknowledged that segregated education might trigger isolation and deprive students of the benefits of social inclusion.

Not Fully Confident to Implement IE

Almost all of the participating teachers were found to lack full confidence in implementing IE. This low confidence was associated with a lack of teacher training, limited resources, and limited infrastructural facilities. The following extracts reveal the depth of their feelings about their teaching effectiveness in the circumstances:

> Sometimes I feel very helpless and wish I were trained enough so I could do something for those children ['s learning]. (TSK2)

> It's really difficult for me to manage everything single-handed. There are 38 children in my class, right now. [In this situation] for a single teacher, it's impossible to meet individual [learning] needs of every student. (TM2)

I have a mentally challenged student. He is 'fine', but if I leave him and go to another student, he starts disturbing other children. This [experience] made me concerned how I will face this issue. (TSK2)

Background Factors

The study identified background factors playing a role in teachers' views of inclusive education. They are discussed as follows:

Cooperation from Major Stakeholders

School community. Almost half the participating teachers mentioned the currently available assistance from the school principal and fellow colleagues was insufficient to enable them to successfully implement IE. All of the participants commented that they did not receive cooperation from their school management committee in introducing IE in the school, if it involved allocation of funds, such as for purchasing instructional materials. However, the discussion paved the way to a possible solution to this challenge. In the semi-urban and one of the rural sub-district GIs, a number of participants mentioned how important conversations amongst the school community are. For example, one participant said:

I think it is necessary to have a dialogue with parents, local community, and the school management committee. We do not discuss this issue with our colleagues, principals and parents. (TS6)

Family of the students. During the interviews, almost half of the teachers emphasised the need for collaboration with local parents of students, not only those whose children have a disability but also those whose children do not.

A majority of the participants of two sub-districts (urban and one rural) felt most of the parents of children with disabilities who were from poor economic backgrounds did not show support for education for their children. They believed some parents used their (disabled) children to earn money through begging on the street. As one said:

Many parents believe that if a child with a disability begged on the street he/she could earn 300 to 400 Taka per day. So, the parents with poor economic conditions do not want to send their kids with disabilities to the school; rather, they use them for earning money [through begging]. (TM5)

Some teachers further reported that many parents of children with disabilities did not know that their children could get their education at neighbourhood regular schools. The majority of teachers (across the locations) also commented that most parents of students without a disability expressed support for administering IE and did not oppose inclusion. However, participants of one rural sub-district informed

that some parents did show concern about their children sitting next to a student with a disability in a classroom:

> Many parents do not allow their kids to sit next to a student with a disability, or children from the Bede community [nomadic population] and sex workers. (TSK1)

Resources. The results showed that all of the participating teachers were facing problems in implementing IE due to a lack of available instructional and human resources.

Instructional resources. Majority of the teachers across the locations mentioned that they did not have adequate teaching resources, or an inclusive, education-friendly teaching curriculum, to help them achieve IE. They felt that the major cause of their struggle to implement IE practices in regular classroom was this lack of instructional resources (e.g. flexible teaching curriculum, appropriate writing board, braille). Helplessness of the teachers was reflected in the following statement by a GI participant teacher:

> I am struggling to handle [students with a disability] with my present limited teaching resources. (TSK3)

Teachers' frustration due to teaching resource constraint has been echoed in the words of another participant:

> In my classroom we have a fixed black board. There are two students with low vision problems. I can't help them reading while I write on the blackboard. If we had an 'automatic board' [digital], I think they would not face the problem (TSK5)

Teachers do not have any technology-supported instructional resources to accomplish IE in the classroom, making the fulfilment of IE very challenging. They also suggested that the current teaching curriculum needed to be made more flexible for all students as they felt it was difficult for some students with disabilities and special needs to cope with.

Human resources. Teachers indicated that they needed to receive greater cooperation from both outside (e.g., principal, SMC, colleagues, specialist teachers, parents) and inside the classroom (e.g., teaching aide). Teachers' perception of the importance of human resources for implementing inclusive practices can be seen in the following remark of a participant:

> We need specialist and trained teachers who can support us. In this school we don't have a special needs teacher. (TS6)

The teachers found IE particularly demanding without such support. They also suggested some possible strategies to surmount this situation, such as there be an official requirement to have one special needs teacher (e.g., Special Need Coordinator) assigned to clusters of schools to train/advise classroom teachers.

Training in IE

In-service training in inclusive education was found to be one of the most significant issues for the teachers. The findings revealed that almost all of the teachers regarded such training as instrumental in accomplishing IE successfully in their classrooms. However, existing training was thought to be quite inadequate, notably the absence of hands-on training. Teachers' concerns about the need for training are revealed in the following extracts:

> I am not trained. I do not know how to [teach] these kids with special needs or disabilities, especially children with a speech impairment. I don't understand what that student [with speech impairment] wants to say. I can't teach him well as he can't hear me well. (TS2)

Another teacher added:

> I do not know how to teach [students with disabilities] properly. In the training I leant about basics of IE. [The training] was very short. For perfect teaching I'm not really ready. I am teaching because I have to teach them as a part of my job. … I have been given the responsibility to teach all kids, I do teach… (TT3)

IE friendly school environment. To the majority of these teachers, a disability-unfriendly school environment is one of the important causes affecting the implementation of IE in the classroom. They revealed that buildings did not have disability-friendly access. Crowded classrooms and inadequate resources created a challenging situation. The following words of the teachers bear testimony to this complaint:

> We do not have ramps; if a student comes with a wheelchair he/she can't enter the school [premises]. It's not wheelchair access friendly. (TSK4)

> Our school [infrastructure] needs to be modified for disabled people. At present, it is not at all suitable for [students with disabilities]…[The reason is that] all the construction of the school buildings was done a long time ago. It will take time to bring a change. (TT4)

Class duration. The study found that almost half of the teachers considered their current class duration to be too brief to implement IE:[4] teaching students with a disability was more time consuming than teaching students without a disability. With

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large student numbers and short class duration, the teachers could not spend time equitably or adequately with every student in an inclusive classroom. They asserted that:

> Sometimes we can't spend extra time for these students because of our short 'class time.' (TS3)

> Our class time is only 35 minutes. How can I handle those children [having special needs] with extra care alongside 60 to 70 other [students without disability] within this [short] time? (TSK3)

DISCUSSION

Thematic analysis of the interview data found teachers' views put them in a dilemma – they were simultaneously sceptical about the success of full inclusion, yet supportive of inclusion from social and professional perspectives. The participants candidly admitted a sense of professional inability to implement inclusive practices successfully with the currently available facilities in the school. At the same time, they supported inclusion on the basis of social responsibility and empathy towards children with disability and professional obligation to implement IE. Underpinning factors inseparable from teachers' views towards inclusion were: the lack of support from the school community, extremely limited resources, inadequate teacher training, insufficient class time, parental non-cooperation, and disability-unfriendly school environments.

The data related to teachers' views towards inclusion signify that teachers were cognizant of their system-related inability to address the needs of an IE classroom. Yet they were, simultaneously, emotionally motivated to support the inclusion process, to contribute to the local community and society and they held a highly professional sense of the need to carry out the order of the Education Department to ensure the agenda of enrolling all school-aged children, including those with disabilities. This finding is supported by international studies (e.g. Koutrouba, Vamvakari, & Theodoropoulos, 2008; Nilholm, 2006) which indicate that, in spite of having low levels of teaching confidence and expertise in special education needs, the majority of teachers are keen to support the principles of IE and demonstrate favourable attitudes towards inclusion of students with disabilities, from inherently humanitarian ideals. The views of the teachers in Bangladesh towards inclusion of students with disabilities in their classrooms might be interpreted from the philosophical viewpoint of Barton (1997) that '[inclusive] educational issues are complex and contentious often involving passionately held beliefs and values' (p. 231).

However, findings related to the factors behind teachers' views imply that a number of issues (i.e., lack of support from the school community, extremely

limited resources, inadequate teacher training, insufficient class time, parental non-cooperation, and disability-unfriendly school infrastructure) impede teachers' intentions towards inclusion. This finding is consistent with a study by Koutrouba, Vamvakari, and Steliou (2006), which suggests that successful implementation of IE in schools, depends mainly on the willingness of teachers and factors such as infrastructural adequacy, prejudice and skills in addressing special needs. Similar views were evident in another study (i.e., Rakap & Kaczmarek, 2010), which suggests that 'more conducive classroom environments and more personnel and material support' might make teachers' approaches more favourable toward inclusion (p. 72).

The findings that have been discussed in terms of the stated aims of this study are consistent with, and complementary to, two recent studies in Bangladesh which revealed teachers' positive attitudes towards inclusion and greater teaching efficacy were associated with their perception of having human and material resources and support from the school community (Ahmmed et al., 2012, 2013). These findings are also endorsed by a recent global study which found that, while the majority of teachers supported the 'philosophy of inclusion', only a small percentage had 'adequate conditions (skills, time, and resources)' to implement IE in their classrooms (Chiner & Cardona, 2012, p. 14). This study reported teachers' willingness to undertake IE was inevitably associated with skills, resources, and supports (ibid).

In light of the findings of the current study, stakeholders of IE in Bangladesh (including PEDP3) would be well advised to ensure teachers perceive they are (adequately) supported by their school community, including colleagues, school principal, parents of all students and school management committee, as such perception improves their teaching efficacy and positive attitudes towards inclusion (Ahmmed et al., 2012, 2013). Therefore, teacher-training programs for IE under PEDP3 should consider creating a culture of collaboration among members of the broader school community to secure teachers' successful implementation of IE. International research (e.g., Deppeler, 2012; Loreman, 2007) supports such collaboration as an effective means of improving teachers' professional skills. Teacher educators should develop '*evidence-based* inclusive pedagogies for preparing teachers to become effective inclusive educators' (Forlin, 2010, p. 649, emphasis added). For this, further study is warranted to determine a suitable model and to assess the effectiveness of such intervention in the Bangladesh context. From these findings, it can be argued that PEDP3 needs to provide resources, both human (e.g. teacher aides, special need teachers) and material (e.g., teaching curriculum, special needs equipment, infrastructural) within Bangladesh's logistic, cultural and economic limitations. Experience from two studies in the Asian context (i.e., Alur, 2007; Kalyanpur, 2011) provide encouragement in this regard. Alur, referring to India, argued that inclusion can be achieved with limited resources, provided that 'there is a commitment to do so and a continuum of support given in the right spirit' (2007, p. 104). Kalyanpur (2011, p. 1067) also emphasised the 'effort to identify

or utilise local, low-cost resources' to implement IE in developing countries such as Cambodia. These studies provide an optimistic response to earlier studies (e.g., Evans & Lunt, 2002), which focused on teachers' scepticism about the success of full inclusion, given their lack of resources and negative attitudes of major stakeholders.

This study's findings showed that one of the significant issues that concerned the participants was that the school management committee (SMC) did not stand behind teachers when a request for support involved local funding. In order to ensure support from the school community, PEDP3 should empower schools' leadership by delegation of authority. Ainscow and Sandill (2010) advise sanctioning school level leadership to ensure effective community involvement for IE enactment. However, to fully understand the (non-supportive) attitudes of SMCs and consequences of jurisdictions of school leadership, further in-depth study is required.

Findings about the uncooperative attitude of some parents from poor backgrounds who have children with disabilities need attention from educational policy makers and development partners (e.g., World Bank, ADP, and UNESCO). Poverty and education of children with disabilities in developing countries is a chronic issue discussed in many studies (e.g., Elwan, 1999; Miles, Fefoame, Mulligan, & Haque, 2012; Rousso, 2003). However, the recent success story of a 'food for education' program in Bangladesh that increased student's enrolment in primary schools (Sukontamarn, 2013) indicates that a reasonable incentive, both for the family and the school, might encourage attendance by children with disabilities. This issue needs further investigation to understand the actual causes of the lack of cooperation from parents with a child/children with disabilities.

The results show that noticeable variations among issues raised at the differently located GIs were mainly the *cooperation of the parents with child/children with a disability* and *class duration*. Specifically, participants from the urban and one rural sub-district perceived that the majority of the parents of children with disabilities with disadvantaged economic backgrounds did not support the education for their children. Participants of one rural sub-district expressed that some parents of a child/children without a disability showed concern about their children sitting next to a student with a disability in a classroom. The study also found that almost half of the participants across the GIs, except the urban sub-district, considered their current class duration of insufficient length for adequate employment of IE practices.

Given the findings of this study and the other studies discussed above, the stakeholders of PEDP3 are recommended to undertake effective measures to:

• ensure adequate support from the school community for classroom teachers,
• provide needs-based instructional and human resources,
• provide appropriate and needs-based teacher training,
• revise the teaching curriculum,
• extend class time, and
• make the school and classroom environment IE friendly.

In doing the above, it is essential 'to contextualise models of support', considering the children's and teachers' needs and the availability of resources (Forlin & Rose, 2010, p. 13), and to follow a well-informed plan (Rose & Coles, 2002).

Since Bangladesh is a developing country with limited resources, it must maximise the utility of available resources. For example, it might be economically viable, sustainable and useful if parents of students with a disability undertake the role of teacher aide and schools recruit at least one special needs specialist/coordinator in each sub-district to 'provide professional guidance and support for the regular class teacher' (Forlin, 2001, p. 83). Despite the effectiveness of this kind of professional support in many countries, it requires considerable investigation for contextual applicability (Rose & Forlin, 2010). Therefore, a longitudinal study is warranted to determine the ingredients, events and causes that might positively impact on teachers' attitudes towards inclusion, involving both teachers and students as participants.

There are a number of limitations to this study. The findings were drawn only from group interviews which might not give a complete or factual reflection of the situation. Moreover, the participants were selected only from four sub-districts in Dhaka Division which did not cover the full diversity of the country, such as the tribal population, hill districts, or coastal and islands regions. Readers are, therefore, advised to consider these limitations when drawing on the findings of this study. To understand the differences of the views towards inclusion and the underpinning factors, further study with larger samples across more divisions of Bangladesh is required.

To conclude, certainly IE can be an effective approach if implemented efficiently. Harvesting benefit from this approach needs a steady vision, a pragmatic mission, a context based approach and remedial measures, otherwise it is easy to 'lose' and 'give up in the face of adversity and opposition' (Oliver & Barnes, 1998, p. 102). It is a great advantage that Bangladeshi teachers are emotionally motivated and professionally committed to support inclusive education, despite adversity in the form of scarcity of support and unfavourable circumstances.

NOTES

[1] The PEDP3 covers matters such as school infrastructure, teacher training, curriculum development, textbooks and teaching materials, school based responsibility, and classroom learning.

[2] This report is part of a larger study which explored the predictors of teachers' intentions to include students with disabilities in regular classrooms in government primary schools in Bangladesh and conceptualised key variables (e.g., teachers' attitudes towards inclusion, teaching efficacy, perceived school support, and teachers' behavioural intentions to include students with disabilities in regular classrooms) within the theory of planned behaviour (Ajzen, 1991). While the findings from the survey data have been reported in a number of publications (e.g., Ahmmed., 2012; Ahmmed et al., 2013), this paper is specifically designed to provide an in-depth understanding of the teachers' views towards inclusion and the factors underpinning their views.

[3] Initially, codes were developed individually in different GIs but, as themes presented, coding occurred across the GIs.

[4] Interestingly, teachers from the urban sub-district did not express this concern.

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5. THE PRIVILEGING OF 'PLACE' WITHIN SOUTH AUSTRALIA'S EDUCATION WORKS

A Spatial Study

INTRODUCTION

Educational space manifests itself in myriad ways; one of the most obvious is school architecture, comprising spaces specifically designed with the process of teaching and learning in mind. Nonetheless, there has been a tendency to treat school architecture as a background phenomenon that was not integrated into the power of pedagogy, or, if it was, then it was seen as an innocuous force, generally for the educational good. (Gulson & Symes, 2007a, p. 8)

The causes of exclusion run deep in the architecture of schooling. A priority for researchers in the field of inclusive education is the identification, interrogation and interruption of these patterns of schooling. (Slee, 2010, p. 102)

This study seeks to, in the words of Slee, *identify*, and *interrogate* spatial patterns within one school. It would be disingenuous to claim Slee's 'architecture of schooling' was directed towards the spatial turn alone, though space is considered to be long overdue for attention within educational research (Gulson & Symes, 2007a).

Foucault (1986), Lefebvre (1991), and Soja (1996) have each advanced the profile of spatial theorising within transdisciplinary studies. This spatial turn in the late twentieth century positioned space as no longer a benign background (Gulson & Symes, 2007b). Along with 'place' (a shared name, such as 'special school') and 'spatiality' (socially produced space), 'space' became identified as a fertile source to be critically analysed. Spatial theories are connected to and interwoven with social theories (Gulson & Symes, 2007a). Due to these multiple connections, spatial theory is highly suitable for examining phenomena, such as inclusion, which are socially constructed.

Foucault identified space as locations where surveillance and regulation occurs; a non-neutral arena which is both socially created and which serves to socially create. He conceived space as 'curious sites', both utopias (unreal, perfect places) and heterotopias (real counter-sites which are both represented and contested). A completely inclusive school might be considered an example of the former, and a special school the latter. Foucault considered heterotopias as sites 'in which

individuals whose behaviour is deviant in relation to the required mean or norm are placed' (Foucault, 1986, p. 5). This coupling of deviance and space was similarly identified by Armstrong who saw the special school as 'the confirmation of abnormality, an aspiration for mutual protection for those on the inside and those on the outside; it is a place for 'special' people, with exotic behaviours, appearances and requirements' (Armstrong, 2007, p. 101).

Foucault was interested in what was hidden within 'sanctified oppositions', such as public/private spaces. Both Lefebvre and Soja built on this, arguing that the use of two terms was reductive and therefore never sufficient to characterise the diversity of spaces. There had always to be a third, an 'other'. This thinking led to their development of conceptual trialectics, used to disrupt established meaning and understandings resulting from traditional binaries. Lefebvre's spatial trialectic (Figure 1) considered space as 'lived' (by various inhabitants), 'perceived' (through the senses) and 'conceived' (through discourse). Soja identified three spaces to examine – the physical, the imagined and, following a 'both, and also' logic, a Thirdspace which posits alternative ways to consider space, including elements of both the real and the imagined (Figure 2). This third is an 'other' position. Soja interprets this as 'othering' (Soja, 1996, p. 60), the creation of an alternative to the privileging of the historical and social binary.
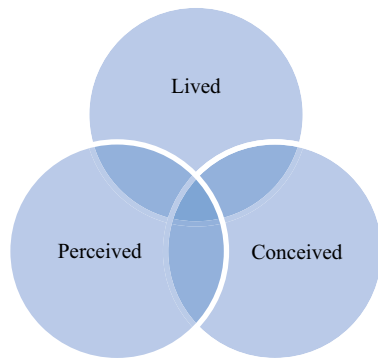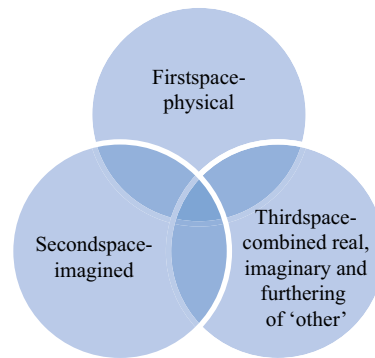

Figure 1. Lefebvre's trialectic   Figure 2. Soja's trialectic

Firstspace focuses on knowledge that is mappable, a concrete geography which can be perceived through the senses. One possible schema entails analysing movements, networks, growth of nodes, developing hierarchies and uneven patterns of each (Soja, 1996, p. 75). Secondspace is discursively created. In inclusive terminology the architectural concept of 'Universal Design' would be an example of Secondspace voice, designing and creating space to meet the needs of all people. Secondspace considers what has been planned for, designed for, and ultimately experienced.

Soja's Thirdspace then critically deconstructs the duality of 'Firstspace' and 'Secondspace' and examines the problematic interplay between the two. It invites 'a challenge to the privileging of either framing of space as entirely material, or as purely subjectively constituted' (Armstrong, 2007, p. 103), or in Soja's own words, Thirdspace constitutes:

> A knowable and unknowable, real and imagined lifeworld of experiences, emotional events, and political choices that is existentially shaped by the generative and problematic interplay between centers and peripheries, the abstract and concrete, the impassioned spaces of the conceptual and the lived, marked out materially and metaphorically in spatial praxis, the transformation of (spatial) knowledge into (spatial) action in the field of unevenly developed (spatial) power. (1996, p. 31)

Soja deliberately and perhaps provocatively revisits and reconceptualises 'Thirdspace' in order to achieve a theoretical approach which is both fluid and open to re-interpretation. In an emancipatory manner, Thirdspace seeks to turn new knowledge into action by 'refolding' back to 'disturb and disrupt established conventions' (Halsey, 2013). Soja elaborates on these emancipatory practices through his inclusion of marginalised voices, including bell hooks (Soja, 1996) and the Bus Rider's Union of Los Angeles (Soja, 2010).

Thirdspace is used as the conceptual framework for this spatial analysis of Eyre Centre, a relocated South Australian special school, as it seeks to find solutions to real world problems, such as human inequality. Many researchers, such as Armstrong (2007), have effectively used Soja's trialectic to analyse new spaces. Armstrong's examination of the closure of a special school and its relocation within a large comprehensive school showed how Thirdspace methodology creates new understandings and highlights areas of contestation within the field of special education. Many binaries exist within special education discourse: special/regular, include/exclude, independence/dependence, centre/de-centre, and normal/abnormal, to suggest a few. Thirdspace looks at and beyond such binary thinking. It serves to question them, to challenge them, and to open up other possibilities.

Inclusion and Place

Where students with disabilities should be taught remains hotly contested (Bakken, 2010), although mainstream and special schools remain the dominant options for parents today. Fiona Forbes, President of ASEPA, argues against the dominant perception that place is essential in inclusion:

> This misconception that inclusion refers to a place and not a process is very pervasive. The current Australian view is restricted to the concept of an inclusive school as a place where everyone belongs, is accepted, and where

special education needs students are supported and cared for by their peers and other members of the school community. This is a Utopian view, where there are no references to the processes and learning environments needed to achieve authentic educational outcomes for *all* students. (Forbes, 2007, p. 67, emphasis in original)

Slee challenges the positioning of special school principals as 'inclusive education advocates and experts' (2013, p. 13) and suggests that inclusion is about location (2014).

Australia's Disability Discrimination Act (DDA) serves to prevent the denial of access to school due to a student's disability (Section 22) and/or the prevention of access to facilities (Section 23). The importance of place and access is similarly embedded within the Disability Standards for Education (Australian Government, 2005). The Human Rights and Equal Opportunity Commission (HREOC) promote court cases such as Finney vs Hills Grammar School as landmark events in the furthering of inclusive education (HREOC, n.d.). Universal Design also aims to remove any barriers within spaces that might lead to discrimination. In considering these examples, we can therefore identify an importance of spatial access within schooling. Indeed, access to space 'is a primary factor for social inclusion and the effective exercise of citizenship of all people' (Dischinger & Filho, 2012, p. 1). Spatial access, as an equity issue, is therefore identified within this study as a pre-requisite for inclusion and the prevention of discrimination. Place and space matter within inclusion. Soja calls this 'spatial justice', the practice of contesting 'the production and reproduction of unfair geographies and global structures of spatial advantage and disadvantage' (Soja, 2010, p. 54). It is important to note that access is of critical importance, but it does not alone indicate nor define the presence of inclusion.

Soja identifies space as existing in variegated contexts:

– absolute, abstract, appropriated, architectonic, architectural, behavioral, body, capitalist, conceived, concrete, contradictory, cultural, differentiated, dominated, dramatized, epistemological, familial, fragmented, fresh, geometrical, global, hierarchical, historical, homogenous, ideological, imagined, impossible, institutional, instrumental, leisure, lived, masculine, mental, natural, neutral, new, opaque, organic, original, perceived, physical, plural, political, possible, pure, "real", representational, repressive, sensory, social, socialist, socialized, state, traditional, true, urban, utopian, and women's space. (1996, p. 59)

Gulson additionally posits a case for 'relational space' (2007). Space in newly constructed special schools is conceived, may be contradictory, and is fragmented, hierarchical, historical, ideological, political, repressive, and certainly social. In Thirdspace-speak this would be 'yes – and'. Each space would be considered in different ways, not excluding the others, but agitating, searching for new meaning.

Inclusive nomenclature around educational place and space is evocative of the countering desires to both include and exclude.

Place: *the mainstream school, the special school,* and, historically*, the institution.*

Space: *the unit, the centre.*

An additional title, the oxymoronic 'inclusive unit' illustrates the re-branding of special education as observed by Slee (2013). The naming of a segregated space as inclusive is both a misappropriation of terminology and a misunderstanding of inclusion. There is also a sense of irony in special education facilities being called 'centres' given that special schooling, and disability in general, exists on the fringes, or to borrow from Slee once again, the 'margins of civic life' (2011, p. 36).

South Australia's Education Works Reform

In 2006 the South Australian Government announced Education Works, its bold plan to reshape South Australian public education. It was to address infrastructural issues inherent within ageing buildings by partnering with private industry to create new schools, each sharing space on new sites. Education Works was to provide '…greater school interaction though clusters' (Government of South Australia, 2006).

Interaction between schools can prevent segregation and reflect a movement towards both inclusive policy and practice. This study explores how the design of new spaces within one relocated Education Works special school, Eyre Centre (pseudonym), may serve to facilitate or restrict inclusion. The philosophy and discourse of inclusive education is then considered against a contrasting need for surveillance, safety and security.

Education Works implicates the importance of place through the physical locating of previously isolated special schools alongside mainstream settings. This relocation intrinsically shows, at least on a geographical level, intent to bring special schools in from the margins, to centre them within an inclusive ideal, whether real or imagined. If these reforms, however, do not create a meaningful difference through increased inclusive practices, then it might be argued that Education Works is no more than a new way to recreate old boundaries, as found by Armstrong (2007), reproducing the separation and categorisation of students with special needs.

EYRE CENTRE

Data sources for this spatial study include maps and 62 annotated photographs of each site. Annotations reflected the researcher's initial thoughts about the spaces, and include comments made by a school leader who accompanied the researcher whilst the data was collected.

Firstspace

Firstpace epistemologies are focused on the materiality of space: what is perceivable through the senses, what's observable, mappable and concrete. Its existence is critical in informing not just the appearance of space, but also both Secondspace and Thirdspace thinking.

Replacing a previous, separate special education site, Eyre Centre was built as a Public Private Partnership on vacant land on the flank of an existing Birth-Year 12 college. It is separated by a tall fence, with two clear points of access between Eyre Centre and the B-12 site. These entrances, both walkways, are usually locked by both drop rods and padlocks, positioned at Eyre Centre's side of the gates.

Eyre Centre's play areas are positioned alongside the dividing fence. Visibility from one site to the other occurs from Eyre Centre's play areas and from the nearby sports courts, car park, and oval within the B-12 site.

Although not represented on the map, Eyre Centre's external play space is sub-divided into a variety of fenced areas. These include a bike track, a play space with trampolines, a Liberty Swing for students in wheelchairs, and a soft fall space which includes equipment such as a ramped play structure and a netted trampoline. Internal spaces are linked through a comprehensive network of ceiling tracks which facilitate the hoisting of students who cannot weight bear. Corridors are spacious. Classrooms incorporate kitchen and washroom elements, and have adjunct spaces planned for either teacher or class use.

Although Eyre Centre has two spaces to be used for sensory and/or physiotherapy activity, additional to a large gymnasium, neither of these spaces is attached to a classroom. Like the library, they are separately defined areas to be utilised by all classes.

The staff room, offices and spaces for administrative purposes are positioned in a separate wing to the learning spaces, far away from the play spaces which abut the B-12 school.

Secondspace

Secondspace epistemologies are immediately distinguishable by their explanatory concentrations on conceived rather than perceived space and their implicit assumption that spatial knowledge is primarily produced through discursively devised representations of space, through the spatial workings of the mind. (Soja, 1996, p. 79)

Secondspace moves from perceived space to conceived space; what's been intended and what's experienced. It informs an understanding about spatial intent. Secondspace is essentially ideational, considering the ideas around, alongside and within space.

Many of Eyre Centre's students use wheelchairs for mobility or require support to weight bear. The intentional design of wide corridors replete with ceiling hoist

systems affords ease of access to multiple spaces. For teachers and paraprofessionals this enables them to work in a manner that is not constrained or restricted by space. The provision of ceiling tracks prevents the need for portable hoist systems which can intrude on the floor level, occupying space, and presenting a possible trip hazard. There is a sense of the vertical in how students with complex disabilities are supported at Eyre Centre. Ground space is at a premium, occupied not only by the traditional equipment of classrooms (desks/chairs), but also the equipment of physical disablement: e.g., wheelchairs, change-tables, standing frames, water/air comfort chairs, toilet chairs, mini-trampolines, sensory wedges, foam steps, walkers, tilt-tables, modified cycles, sensory tents, and leaf chairs. Previous experiences with the cluttering of such equipment had resulted in the new site now having wide enough corridors to allow storage opportunities whilst still affording opportunities for students to transition along their length, not only to fulfil a function (getting from A to B), but to allow for the practicing of necessary mobility skills. Despite planned and constructed affordances for storage, photographs revealed additional spaces were now also being utilised to store equipment. Such spaces included classrooms where outdoor equipment was placed. The school's student population has decreased since its opening so spaces normally required for teaching and learning were now being re-territorialised for storage purposes. Although spaces existed for storage (outside, in sheds) it was more efficient to relocate equipment into classrooms to enable easier transitions. Other locations to receive 'clutter creep' were rooms for students to engage in independent life skills, such as a laundry and a meal preparation room. It was explained that the students the spaces had originally been designed for had already graduated, leaving the spaces no longer pedagogically relevant for the current cohort. These rooms had now become storage receptacles for equipment.

Bentham's Panopticon

Each large classroom connects to two smaller adjunct rooms, one for teacher preparation and the other for teaching and learning. In one of the classrooms, cupboards had been placed as a physical barrier to the adjunct learning space, preventing both visibility and access.

Visibility within space is a rich area of discourse and integral to Bentham's 'panopticon' in the late 19th century, an architectural design for the perfect prison (Symes & Preston, 1992). The panopticon enabled disciplinary power to be exercised through the illusion of continuous surveillance. The imprisoned population would then self-regulate their behaviour as well as each other's through the continual apprehension of being observed misbehaving and punished. Although Bentham's design was ultimately not created in his lifetime, the panopticon concept was influential on spatial designs and analysed by those such as Foucault (1977), who considered visibility to be the panopticon's trap, with directed lighting serving to illuminate the observed, but not the observer. This observer, hidden by darkness, no

longer needed to be in place as the architecture of the panopticon was effective in 'sustaining a power relation independent of the person who exercises it' (Foucault, 1977, p. 201). The subjects, in effect, subjected themselves within the panopticon's 'ingenious cage' (Foucault, 1977, p. 205).

Bentham suggested his panopticon design could also easily become 'the basis of school construction' (Symes & Preston, 1992, p. 207), with the surveilled consisting of both student and teacher populations. Foucault considered this panopticon of schooling: 'there is no copying, no noise, no chatter, no waste of time; if they are workers, there are no disorders, no theft, no coalitions' (Foucault, 1977, p. 201). Symes and Preston suggested that inspection is indeed hierarchical, 'with students being surveyed by monitors, monitors being surveyed by teachers, teachers by head teachers' (Symes & Preston, 1992, p. 207).

Difference and Disability

A common litmus test for inclusion is sometimes considered to be the inability to visibly pick 'the special kid' when walking into an unfamiliar classroom. Students with some disabilities can always be more readily identified, however, such as wheelchair users. Although the advantage of blending in, in a visual sense, may be reduced labelling, a disadvantage could be considered as the homogenisation of the student cohort, a dissipation of difference.

Eyre Centre is undoubtedly physically and visibly different from most schools. The difference is marked, with its ceiling tracks and wide corridors. A visual evaluation of Eyre Centre by another special school leader was that 'It just looked like a hospital' (Cook Centre Leader, personal communication, November 12, 2014). The price of looking like typical schools, however, might be constraints to access, movement, transition, storage capacity and an increased risk to both student and staff safety. These constraints may effectively 'disable' the school from fulfilling its obligation, to teach in a safe and respectful manner. Allegorically, a wheelchair presents its user to being clearly disabled, but to not have a wheelchair would be counter-productive and even more disabling. There is a tension here in the spaces both schools and individuals occupy, between two types of disablement. From a Universal Design perspective, *all schools* would benefit from tracking and wider corridors for the storage of equipment. Such an adoption is unlikely, however, given the expense and opportunity for schools to claim unjustifiable hardship beyond areas of defined and immediate need. Until the 1960s and 70s, wheelchair ramps were rare and served to highlight 'disablement' more than 'access'. That has now changed through Universal Design and the DDA. Ramps are today seen as creating access to not just those with disabilities, but the elderly, people with young children in prams, and those with shopping trolleys. Lefebvre (1991, p. 52) argued that time could not be separated from space, and that *new* space could not be born 'unless it accentuates difference'. Considering this, in accentuating its difference from typical school

space, Eyre Centre may indeed be doing what those first ramped environments did last century, creating new space in recognition of diverse mobility needs.

Surveillance and the Surveilled

Visibility is important in special schools given that their student population is considered to be vulnerable (Government of South Australia, 2013). Visibility, within supervision, is critical in safeguarding duty of care (Government of South Australia, 2007), particularly for students who have health conditions such as epilepsy. Symes and Preston (1992) note that health and hygiene considerations have long been present when designing schools.

During the tour of Eyre Centre it was noted that many staff members were eating their lunches in their classrooms instead of the staffroom which had amenities, ample space, comfort and presented an opportunity for collegial mingling. The school leader from Eyre Centre reflected that this had become somewhat habitual, and may be due to the staffroom being located away from where the students were. Certainly the individual classrooms afforded views onto the playground and student population, whereas the staffroom did not. Eating in classrooms may result in a more efficient break (not needing to go to the distant staffroom). It also could serve to place teachers in a more desirable location, enabling them to then easily facilitate student transitions once lunch had concluded. The staffroom is centrally located within the administration wing. It is used as a thoroughfare to gain access to offices, and is directly observable from the offices of school leaders should they choose to open their doors. As such, those within are exposed to frequent surveillance. The staffroom is an open area, identified by Symes and Preston as 'the place where executants are to be found, another instance of panopticism' (1992, p. 214). The low usage of this space may illustrate a reluctance to be subjected to surveillance and/or the teachers' privileging themselves as observers, seated within their own classrooms (enclosed spaces), surveilling student activity on the playground (open spaces).

One of Eyre Centre's classrooms had recently received an additional lock, placed onto the sliding door that afforded the transition between its space and the playground space. The school leader mentioned that this did not satisfy safety specifications, but its use had become necessary in preventing a particular student from absconding. Such activity may not be classified as segregation or isolation given that the student was being retained, along with his or her class, in the location where teaching and learning occurred. The identified need to add locks does point to the existence of unexpected and unplanned for challenging behaviours, however, and a desire to maintain the student's presence in the learning space without resorting to restraint measures.

Segregation is visible though in the playground where an internally fenced grass area serves to keep the more vulnerable students safe from the mobile ones who

might 'bowl them over' (Eyre Centre Leader, Personal Communication, October 4th, 2013). This mirrored the fencing around the Liberty Swing which protected both the student swinging and students from being hit by the passing swing. In both cases where space had been demarcated for safety, the territorialisation of the space had also changed. Ownership shifted from *all* students to *some* students. Dischinger and Jackson Filho (2012) suggest territorial strategies are ways to mediate control of a population. They caution that the division of space may not always produce increased safety, but it does always produce segregation.

One final feature of Eyre Centre's playground is a memorial garden that serves to identify students who have died. Its existence not only shows a way to remember past students, but also creates a visual marker of the increased vulnerability of Eyre Centre's current students.

Thirdspace

Sibley (cited in Thomson, 2007, p. 117) indicates that those students who create disorder may be rendered as such through geographies of exclusion, the creation of bordered spaces. Safety concerns at Eyre Centre clearly create spatial divisions that contribute to segregating practices. Risk reduction in schools may be considered a priority, particularly by highly safety conscious educators, experienced in working with vulnerable students. The development of risk avoidance skills, however, are learning opportunities to be embraced (Gairín & Castro, 2011) despite 'duty of care' requirements perhaps persuading educators to privilege safety over education (Government of South Australia, 2007). The prioritisation of 'care' over 'education' is an outdated approach, and may serve to resist inclusive education.

Certainly, there are pedagogical implications when using space to reduce risk, as opposed to teaching students how to reduce or manage risks. Risks may well be reduced, but the student is not productively learning in the process. This missed teaching and learning opportunity may be critical in developing independence and the capacity to recognise and manage risks in the broader community. Participation in society involves a degree of risk identification and management – whether buckling seatbelts, applying sunscreen, or checking before crossing the road. Inclusive education aspires towards societal inclusion beyond the schoolyard. To achieve this though, experiencing measured risk must be advocated. The spatial elimination of risks may serve to limit the development of the very skills required for inclusive participation in one's community, rendering students as passive. In protecting and sheltering its more vulnerable students, educators at Eyre Centre segregate space, effectively constructing the restrictive environments that inclusive education eschews. These spaces may in effect enforce the dependency of students, requiring them to have such safely fenced spaces duplicated and maintained throughout and beyond their schooling. Educators, as spatial planners and constructors within their own sites, should therefore consider deeply the implications of spatially protecting

students and how this might ultimately serve to compromise a student's participation and citizenship.

The Margins

This importance of 'place' is central within *Education Works*, as shown by its decision to relocate special schools alongside mainstream settings. The chance to mix with their new neighbours may reduce Eyre Centre's marginality and that of its staff. Special educators can feel neglected and isolated by the education system in which they work (McQuat, 2007), but through Education Works Eyre Centre is, at least physically, being brought in from the periphery.

This adoption of marginalisation may, however, prove to be a strategic positioning by special educators, wary of inclusion as a homogenising practice. Slee (2013, p. 11) posits that 'inclusive education presents challenges to schools that have long sought to homogenise the student body'. Building on this, consider that student bodies may be perceived either homogenously (we are all alike) or heterogeneously (we are all different). In the first instance, inclusion is the instrument to 'make normal'. In the second, there is 'no normal': difference between students is the norm. Such a perspective, a celebration and an expectation of diversity, can be successfully adopted as an inclusive position as it recognises individuality without measuring students against what might typically be expected. Special educators may be more likely to consider inclusion in its heterogenic form given that their work requires regularly attending to the individuality of learners through the use of Individual Education Plans. If inclusion is considered by special educators as homogenising or normalising, however, then it may appear undesirable, resulting in lost expertise and a diminished advocacy for both the special education profession and their students. Marginality can therefore be interpreted as a heterotopia of resistance. Eyre Centre may use it to create what hooks terms 'oppositional practices' (cited in Soja, 1996, p. 129) to challenge the pedagogy of the mainstream.

Within the school, efforts to centre Eyre Centre's own staff may be considered problematic if educators feel the centre is a space of increased surveillance. The positioning of the new staffroom, and a reluctance to use it, may indicate how centred space is less appealing than spaces on the periphery. Teachers may feel more empowered when self-excluding to the periphery/margins, into spaces where they are the observers, not 'the observed'. When marginalisation is occurring it is important to consider who is selecting marginalisation and who has marginalisation forced upon them. Students, unlike schools and teachers, are more likely to be having marginalisation 'done to them', especially if directed towards fenced spaces which are specifically created for the purpose of segregation. It is worth noting at all times the extent to which those who are marginalised, can independently position themselves 'in' or others 'out'.

In considering the centre/decentre binary, both as it applies to schools and teachers, we should also look to 'other' possibilities. In her examination of school exclusion Thomson (2007) proposed the construction of counter-public spaces as an alternative, enabling agency, an escape, and 'a tangible shift in identity' (Thomson, 2007, p. 125). Building on this suggestion, a blurring of lines between environments might occur through the creation of spaces within each other's school. This is already evident elsewhere in South Australian whereby a mainstream school's secondary classrooms are used by its neighbouring special school to teach *their* students, with *their* teachers. This territorialising of space by 'the other' may serve to break down rigid perceptions of 'yours' and 'ours'.

OPENINGS AND CONCLUSIONS

Special schools are inherently more restrictive than mainstream schools (Rozalski, Stewart, & Miller, 2010). This is represented spatially at the new Eyre Centre through real and imagined spaces, both the planned environment and what has been re-considered and recreated since. Relocating a special school beside a mainstream one is not a panacea for exclusion. The importance of 'place' over 'space' within Education Works could serve to show the very misunderstanding highlighted by Forbes (2007). Spatial injustice occurs as easily in mainstream classrooms as it does within isolated, specialised settings. Its prevalence is so historically significant as to suggest schools may be unjust societies, constructed through categorisation and the demarcation of space.

Closing the inclusion gap, between utopia and heterotopia, between centre and margin, between the special school and the 'idealised landscape' of the mainstream (Armstrong, 2007, p. 100) may be more quickly realised if policy makers, school planners, and educators newly privileged 'space' over 'place'. Space is, after all, 'active in shaping the experience of school and the understanding of education' (Burke, 2006, p. 490). By better understanding, then shaping, the spaces in which teachers teach and students learn, we may then create more just and inclusive schools.

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6. CHOOSING TIME

Supporting the Play of Students with a Dis/ability

INTRODUCTION

Play is an important part of childhood that is essential to a child's development. It is the aim of this chapter to explore the way play is approached and viewed for children with dis/ability. Frequently play is used either to measure and compare play skill and ability or play is used for the basis of an assessment for diagnosis. This chapter explores some of the research that has a focus on skill acquisition and deconstructs this research from a disability studies perspective. It also discusses an alternative approach to supporting play, where children access play and interact according to their own abilities. A small case study is used to examine approaches in the classroom that provide opportunities within extended access to play. The shift in theoretical perspective analyses not only how children with dis/ability are viewed but also their ability to communicate their skills and knowledge.

Whilst there is a large body of work that focuses on play, there is little literature that discusses children with dis/abilities as being independent, cognisant players that play for fun. Burke (2013), Davis, Watson, and Cunningham-Burley (2000), and Goodley and Runswick-Cole (2010) are some of the few that acknowledge play for all should be fun. All children can, and do, benefit greatly from accessing play on a regular basis. The notion that play is important is generally agreed upon – though questions need to be asked about the use and accessibility of play. Play, when spoken about in reference to children with dis/ability, often conjures the image of therapy. Play is used as therapy, in therapy and for assessment related to therapy. In the few instances where it is used in school settings it is often on advice from specialist or therapists either for therapy or to explicitly teach play skills (Goodley & Runswick-Cole, 2010; O'Connor & Stagnitti, 2011; Stagnitti, O'Connor, & Sheppard, 2012; Wood, 2007).

What follows is a brief literature of play in special settings for children with dis/ability. The review of some of the influencing factors for current play approaches used in special settings in Victoria is analysed through a disability studies lens and some alternative attitudes towards access and support of play are considered. The focus here is on children who are deemed, within the educational setting, to have a dis/ability. Most of the research discussed was conducted in special settings and in the aim of inclusivity; participants will be referred to simply as children throughout

this article. When further distinction is applicable, students will be referred to as children with dis/ability. This phrasing has been deliberately chosen to signify the change in perspective and understanding, and highlight the abilities of children.

There are several aspects of play that are generally agreed on to be the most important: that is being child lead, spontaneous, intrinsically motivated and without rules (O'Connor & Stagnitti, 2011; Pramling Samuelsson & Johansson, 2007; Walker, 2007). It is commonly accepted that play effectively scaffolds learning, and learning through play builds skills that help participate in everyday life and interact with the community. The privileging of skill acquisition in our schools means that particular types of play are privileged over others. An example of this is found in O'Connor and Stagnitti (2011) where it is asserted that imaginary play is linked to oral language development. This assertion then favours not only imaginary play above other types of play as being the 'highest' or 'most desirable' form of play, but also typical communication. This could be construed to be the beginnings of leading the child away from spontaneous play toward adult directed play through the simple form of praise – the child wanting to please the adult and 'performing' more of the same. Questions are raised about the representation of play in these instances and whether teaching specific play skills represents true playing and learning (Luckett, Brady & Roberts, 2007). Play that is not seen as conventional by adult players does not mean it is seen from the players' perspective as anything other than engaging play (Jordan, 2007).

An alternative perspective, the one being offered here, is that if we follow a different yet commonly accepted definition of play, we find that in play is 'behavior that appears to have no apparent function or where the means of a behavior are more important than the end' (Bjorklund & Pellegrini, 2000, p. 1693). That is, play is spontaneous and pleasurable and is acted out by children for no greater reason than they find it pleasurable (Waite, Rogers, & Evans, 2013)

This definition of play is grounded in the idea that the base of play is social and lays the bigger foundation blocks of becoming a 'functioning' member of society. If it is conceded that 'as children develop they learn and as they learn they develop' then it is conceivable that every time children play, they build their identity. They find out more about themselves and their world. Learning is an inexplicable part of growing up, and children engaged in play cannot help but learn. It is argued here that this is the case, regardless of what the play looks like. ALL children engage in play. It is generally accepted that 'play is a cultural universal.' Children are observed playing in 'every society studied by anthropologists' (Lancy, 2007, p. 274). Bjorklund and Pellegrini (2000) discuss play's ubiquitous nature and its integral role in childhood. Children access play in many places and in many different ways, yet currently play in schools tends to be viewed in a particular way, usually linked to skill development.

If it is the case that 'each child's lived experiences influence his/her way of understanding and acting' (Pramling Samuelsson & Johansson, 2007, p. 50), then it

can be considered that as children play they are extending their current knowledge and creating their own identities. Through play of all kinds, children explore, engage and understand more about themselves, where they fit in the outside world and how the world interacts with them. What then becomes of children who miss out on early access to play and continue to miss out on opportunities to learn through play (Jordan, 2003)? It could be seen that children are deprived of developing as themselves – of building identity and agency – as they are shepherded towards adult directed activities that build their adaptive skills and encourage them to engage in 'age appropriate' activities (Wood, 2007).

Further to this, when play is led by the child, they are able to practice their decision making skills, move and learn in their own way and at their own pace. They are offered a chance to discover their own interests and immerse themselves in activities and engage in the world around them to follow a passion of their own interest(s) (Ginsburg, 2007; Goodley & Runswick-Cole, 2010). The very definition of play is all encompassing and needs to be re-visioned or re-imagined (Goodley & Runswick-Cole, 2010) to demonstrate this in educational settings.

Another commonly accepted definition focuses on why play is important. The most conventional understandings are that play is healthy for brain development. The imaginative and creative approach that is used in play assists children to develop their imagination and dexterity. Play builds physical strength, cognitive capacity and emotional resilience (Ginsburg, 2007). In addressing play as a whole, rather than breaking it in to specific types, it builds a picture that play supports the development of a child as a whole. The United Nations Convention on the Rights of the Child recognises that children have the right to 'engage in play and recreational activities' (p. 9) and further to that declares that children with a dis/ability 'should enjoy a full and decent life' and 'active participation in the community' (p. 9). This acknowledgement of importance suggests careful reflection and questioning is needed not only about what happens to children who miss out on play, but also the range of ways in which play skills can be demonstrated.

When supporting access to play it is important that we acknowledge children as cognisant partners in play (Bishop, Swain, & Bines, 2010) capable of making play choices, demonstrating their engagement and interests in a way that suits them. As adult play partners, we need to be aware and open to understanding and acknowledge the play styles and abilities children communicate with (Rinaldi, 2005; Clark, 2005; Tisdall, 2012). If we accept that play builds cognitive capacity and emotional strength, we cannot assume that because we are not seeing typical play that play is not happening and these strengths being developed. It is documented that children with dis/ability play 'beneath' their peers, which devalues their understandings and representations in play (Bray & Cooper, 2007; DiCarlo & Reid, 2004). Children demonstrate their understandings in ways that may not be easily interpreted and have hitherto been marginalised by adult players looking for expectations rather than expressions.

ACQUIRING PLAY SKILLS

This section reviews two studies that underpin teaching attitudes towards play in Victorian special settings. These studies focus on skill acquisition (both play and 'adaptive') of children with dis/ability. It also introduces research that addresses play in special settings. The approaches in this last study view play from a perspective that focuses on individual abilities.

There are two recent studies that have influenced what is happening regarding play in special settings. The first of these studies was conducted by Sigafoos (1999), who researched the link between play and adaptive behaviour improvements in children with dis/abilities. The study examined the development of 13 children with 'severe disabilities' over a 3-year period, where they were given time to participate in 'unstructured' free play for approximately half an hour a day. He also tracked their gains in adaptive behaviours – their development in the areas of self-help, motor skills, communication and social skills. Their play was assessed by being video-taped and analysed for the percentage of 'appropriate' play. Adaptive skill gains were measured through standardised metric tests. Whilst it was noted that children made some gains in play, it was also noted that they 'appeared to stagnate at a functional level' (Sigafoos, 1999, p. 159).

Sigafoos (1999) concludes that 'play needs to be used as the opportunity to teach a variety of functional adaptive skills' and play opportunities should be structured so that 'children are deliberately and explicitly taught a range of play skills' (p. 158–169).

Staginitti's ideas build on the notion of explicit play instruction suggested by Sigafoos. She has developed a program called '*Learn to Play*' (1998). The program provides a range of opportunities for parents, therapists and teachers to foster a child's development, focussing on pretend play. Throughout the study, there were 19 children in a special setting taught specific play skills. Providers were trained before helping to implement the program. In this study there were the two classroom teachers, three Occupational Therapists and two Speech pathologists. Stagnitti (2012) reviewed the impact of this program by studying the play, social competence and language of a group of 5–8 year old children in a specialist setting, focusing on pretend play and modelling skills for students. After following this program children associated with the 'Learn to Play' demonstrated increases in their social and language skills.

Other background studies on play (in relation to children with dis/ability) are often based on either assessing students' play or teaching them to play. Bray and Cooper (2007) note that play in children with 'special needs' does not change significantly when they were observed in mainstream and special settings. The authors do note that whilst there is a slight rise in a mainstream setting of imaginary play – overall play is 'well below' that of typical peers. O'Connor and Stagnitti (2011) compared the play skills of two groups of children in a special setting. Each group accessed different teaching and learning programs throughout the duration of the research. One group

participated in a play intervention program, the second group in a classroom using traditional methods. Thirty-five children in total participated in the research – 19 in the play intervention group and 16 in the comparison group. The study found that those in the intervention group showed 'significant decrease in play deficits'. The report also acknowledged that children not participating in the program also made progress in each of the assessed areas.

Research conducted by Claughton (2009) observed the play of children in a special setting through a critical social science lens. The focus of the research was to support access to a play-based curriculum based on the Australian Developmental Curriculum, developed by Walker (2007). The aim of Walker's work is to provide extended periods of play for children. Teachers need to be very involved with this approach to play, and as often as possible use the play to help build engagement in explicit teaching. She advocates the use of real life play items (real plates and cutlery, access to outside play, and a wide, extensive range of activities) for children to experience.

A sample size of one class (5 students which was 13% of the school population) participated in the study over a 10-week period. The research was conducted in a Special Developmental School. In Victoria, this means a school that has a restricted enrolment for those deemed through assessment approved by the Department of Education and Early Childhood Development (DEECD) to have an IQ of 70 points or below. Participating children had a range of abilities, skills, interests and communication levels. Assessment included pre and post testing using a modified version of the Observation Survey and raw scores from an early years test called the Action Picture Test (Renfrew, 1997).

Participants engaged in ongoing and extended play opportunities. The aim of the research was not to provide play as a reward, or build on the opportunities to interact playfully at times throughout the day, but to provide children with prolonged access to play. An hour and a half every morning 5 days a week for 10 weeks was devoted to play as part of the learning program. Children were supported to access their play, rather than teach them play skills. The research showed significant improvements in social skills, language and personal motivation through children's actions, interactions and communicative skills. This is discussed in further detail later. Children's language skills were also reported to have increased during the research period.

Disability Studies

With the emergence of disability studies the framework for research is slowly changing. Previous research needs to be reflected on and contemplated from this perspective. It moves the theoretical aspects away from what is referred to as the 'medical model' – which pathologies dis/ability – to the 'social model' which analyses and breaks down social barriers that are disabling to those with impairments

(Thomas, 1999). To frame research in this way is essential for changes to happen in education.

A consistent thread in the above-mentioned studies is the comparative nature of them. It is interesting to note that all of these studies collect and analyse quantitative data. They are often comparative studies where there are control groups. If there are not control groups, children are measured against each other or typical norms (Goodley & Runswick-Cole, 2010). There are some instances where quantitative data is supported with qualitative data, however results were usually deficit based, constructed from data that included comparison of skills (Goodley & Runswick-Cole, 2010). The individual needs, abilities and nuanced responses of each child were not taken into consideration. Aspects of assessment that include analysis of an individual's ability, engagement and intrinsic motivation could be a way to measure individual progress where the only comparison is to the children's abilities before and after.

The disability studies perspective is enabling, suggesting through its very nature that it is time to stop comparing children when assessing. It is time to stop comparing children with dis/ability, defining their ability in relations to another's ability and acknowledge their independence and agency. Rosenbaum and Gorter (2011) refer to the expectations inherent in the ideology of pathology that parents are given to expect an 'appropriate diagnosis will lead to the right interventions and that the underlying biomedical impairments will be ameliorated to the patient's advantage' (p. 457). Further underlining this concept of a deficit approach, Davis (2004) states that 'the perception exists that disabled children are unable to put forward their own views and that they lack competency and agency' (p. 144). Disability studies instead 'challenges… [list of workers] to find ways in which people with severe and profound intellectual impairments can be listened to, using behavioural and subtle communicative cues, in addition to, or instead of, conventional verbal or gestural forms of communication' (Globe, 2004, p. 45). Critical Disability Studies offers a challenging perspective that challenges perceptions of children's rights. It challenges deep-seated notions of what it means to play and interact. It challenges ingrained attitudes and pedagogies which frame the way we approach children's learning and listen to their voices.

An alternative way to evaluate achievement and research programs could be to reconsider the interaction and exploration of the world and move away from what could be described 'able bodied' norms to embrace and explore the world using a new dialogue (Goodley & Runswick-Cole, 2010). It is being asserted that children in special settings do not play. More accurately, children with dis/ability play 'inappropriately'. This raises a simple, yet important question: do not play according to whom? With atypical development comes atypical play, an example of independence and agency in which these students demonstrate building their identity.

In using a disability studies lens, we need to question the notion of 'appropriate' play. What exactly does it mean? It seems that by the above mentioned use of

assessment, play is an 'able bodied' concept – something understood and observed only in relation to typical development. Those who do not follow these normative comparisons of play are immediately 'othered' and their play considered to be inferior (Goodley & Runswick-Cole, 2010). By applying this distinction of 'appropriate' there is an inherent value judgement attached to play. Exploring Sigafoos (1999), Stagnitti (2012), and Claughton (2009) shows how research can demonstrate judgements on ability, play skills and children's abilities.

According to Sigafoos's (1999) analysis 'inappropriate' play is defined as aggression, property destruction, self-injury, tantrums or stereotyped toy play (any use of a toy in a repetitive manner – spinning a toy, mouthing a toy or spinning the wheels on a truck).There is an obvious expectation on what play looks like and that children have to perform to this standard. Assessing play in this way sets up a culture of surveillance on students, striving to meet unspecified, poorly communicated goals that meet the needs of other children's play (Davis et al., 2000; Goodley & Runswick-Cole, 2010). It could be that these are examples of children regulating behaviour, frustration caused by communication challenges or inability to achieve personal goals.

Stagnitti (2012), as discussed, places high expectations on imaginative play. Why are these specific play skills (that Stagnitti has chosen to privilege in her study) considered to be more important than other play skills, the ones she has opted to disregard? Stagnitti argues that imaginative play is closely linked to oral language development, and this communication skill is what puts imaginative play as the most desirable outcome for her work. This focus on verbal communication conflicts with Globe (2004) who advocates that using multiple and subtle forms of communication should be considered a right rather than an option for those who use alternative means of communication. Multiple ways of listening (Clark, 2005) and a multi-modal approach to data collection (Tisdall, 2012) can provide a way for children to communicate that does not privilege verbal language.

The assessments used by Claughton (2009) demonstrated a deficit model focus by tracking progress through means-tested comparison models. Children's abilities to perform to these standards meant that the only way to track progress was in the form of raw scores. This calls in to question the validity of the testing as it cannot be analysed and used in its original capacity. Davis and Watson (2004) in discussing teachers working in schools and setting goals point out that in such instances 'the requirements of their structural role within the education process' (p. 64) is implicated 'to govern their perceptions of the children' (p. 64). Claughton (2007) was governed by the need to assess and provide outcomes to show and define the progress of children (Waite et al., 2013). The process of selecting the methods of data collection was decisively based in and justified by the education process rather than student needs and abilities. The growth of participants was best demonstrated through the photo book shared each day and the observational notes that were taken.

Expectations of play and assessment are set up through perceived or privileged outcomes as highlighted by respected academics and contemporary research. In turn,

these expectations are filtered through the education system to form a basis of top down push that influences policy to reflect measurement, success and benchmarking through standardised tests (Walker, 2005). Disability studies highlights the way social agendas create an atmosphere that produces labels such as 'inappropriate play' and compare skills to imply play is 'inferior'. The disability studies research perspective allows for critical reflection on pedagogical and assessment approaches. It is imperative that disability studies academics challenge the notions put forward by other academics that children with impairments don't play. Burke (2013), Goodley & Runswick-Cole (2010), Luckett et al. (2007) and Wood (2007) all challenge the notions of play, what it is for and how it is used.

FACILITATING AND SUPPORTING ACCESS TO PLAY IN THE CLASSROOM

Having explored play and dis/ability, this chapter turns to auto-ethnography by analysing the research done by Claughton (2009). The critical reflection on the findings from the original research by Claughton (2009) has allowed for 'the shifting of aspect of self' (Hamilton, Smith, & Worthington, 2008, p. 9) to be seen 'in a broader social context' (p. 22). That is, the recommendations suggested here are the outcome of analysis of original results, as reflected on and viewed through a disability studies lens. The auto-ethnographic approach is important as it provides a base for critiquing culture and a way to 'loosen disciplinary constraint' (Hamilton et al., 2008, p. 22) which allows us to reconsider how play in education can be accessed, how play is approached and ways of communicating and interacting. The place for play in education and how to support children to access play can be broadened from the experiences into recommendations that challenge the current culture in classrooms.

Through this process of critical reflection and analysis it became apparent that specific aspects to teaching and learning were imperative to the success of both teachers and participants. Planning (Baglieri & Knopf, 2004), listening (Rinaldi, 2005) and teaching approaches (Avaramidis & Norwich, 2002) in the classroom were essential to achieving positive results. The inclusive attitudes and the relationships built by them were pivotal in opening up the classroom to discussions. It acknowledged and recognised children as motivated and trusted learners. As suggested by Luckett et al. (2001) by breaking down the barriers around play, and accepting children as playful, interactive and explorative learners, it opens an avenue of engagement and motivation that would otherwise be impeded by difficulties and stumbling blocks in the shape of communication, behavioural issues and engagement. By seeing individual actions as purposeful and meaningful it builds on skills and interests they already have and acknowledges a dialogue specific to the children and begins a conversation in a language they understand (Luckett et al., 2001).

It is acknowledged that the power and privileged position of the teacher, especially the way they can interpret interactions (Alderson, 2000), could have had an effect on

the results. However, as the research progressed, the relationship between teacher and student changed. As play became more engrained, students became more engaged. The power of communication, as explored later, changed. Essential to being able to do this is 'understanding the question and answer process and for highlighting the ways in which children may differ from adult respondents' (Scott, 2000, p. 101). As expectations changed it became evident that children were responding to the way the curriculum was being run. The reflective journey in reviewing results shifted the focus from a 'traditional model' to one that aligned with disability studies. Children demonstrated ability and agency to show which parts of the curriculum and communication approaches resonated with them and their engaged responses illustrated this.

What follows is part of the analysis of the results framed around the teaching approaches that seemed to have the biggest impact. The results discussed here draw from observational notes and a pictorial scrapbook that was created with participants and links to the areas of planning, listening and teaching approaches. This scrapbook was added to and reflected on daily. Adults supported the children to create and record a sentence about the photo added to the scrapbook. Whilst it was only a small study and may not be generalised beyond this group, it is interesting to note that supporting access to play saw what could be described as intrinsic improvements. Children gained skills in a range of ways, all of which were an unexpected result of the research.

Planning

Essential to a successful play based curriculum is planning. Teachers need to plan to play and commit to themselves and students to ensure time is dedicated each day. It is important that planning considers not only the types of play available each day (active play, imaginary play, messy play etc.) but that consideration is given to how children access it. Above all, teachers need to trust that children want to play and learn (Goodley & Runswick-Cole, 2010).

Children were reluctant at first to participate in some play. A possible reason for this was sensory defensiveness – messy play can be quite confronting for some. Some children find working in close proximity an issue, which happens a lot during messy play. Another reason for the reluctance is the expectation of independence on children – few had prior opportunities to play in an independent fashion. To help children through this, routine became an important part of accessing play. Children were supported to build routines around accessing play – how to find an activity, where to find an activity and how to set/pack up an activity. They were deliberately taught 'around' play, left to independently interact with their activity in any way they found engaging. As in any play situation, the teacher would scaffold learning around this interaction. This attitude of expectation links to Baglieri and Knopf (2004) that recommend 'the needs and interests of each student to drive the choices made about

instructional practices' (p. 527). That is to say, working with children in such a way provides an equal platform for children to access play, but also allows for individual needs and personal goals to be met.

Increased motivation was demonstrated through concentration. At the start of the play program the children seemed to make such a mess! As the weeks went on there was a noticeable change in transition between activities. As children engaged more in the play, they would draw to natural conclusions in their play. They would independently pack up the activity they were using and move on to a new one. It got to the point where they would play with one or two activities each session and really get engaged in what they were doing rather than paying fleeting attention to an activity before moving on like they had at the start. Interestingly, this was with 'non structured' toys such as blocks or trains.

As with any child engaged in play, repetition and practice form a part of the play cycle. Throughout the study, children often participated in the same activity. Rather than show concern about the possibility of 'inappropriate play' (Sigafoos, 1999) of this repetition, adults engaged with and encouraged children to continue with their exploration. Despite the misconception that obsessive behaviours will keep students with autism from engaging in meaningful play (Luckett et al., 2010), every child engaged in a wide variety of activities in a variety of ways. Children found being assisted to access play on their terms and demonstrating their agency – their ability to understand and their enthusiasm for learning – was liberating. Within five weeks, they were choosing activities that were not kept in the classroom but in other classrooms, the library and therapist room. The therapy room has small boxes of oral language, visual, tactile and other sensory activities available to borrow. An example of this follows:

> During this Choosing Time, a student brought over a picture of a person. This was decision time: two potential reactions 'not what we're doing now' or 'follow their lead' and trust they want to play and learn. Following the student's lead, they went to visit the person in the picture. The student wanted access to an activity that was in that room. The communication was not one that we'd set up, but she obviously was trying to tell us something and we were open to find out what that was.

Listening

To be able to be meaningfully engaged it is important that the communication partner listens carefully. As noted above, communication comes in many and varied ways and being open to hearing, interpreting and reflecting on communicative interactions is essential (Davis et al., 2000; Rinaldi, 2005). Working with children to reflect on and revisit the play they engaged in each day was one way adults were able to demonstrate their listening skills throughout the research.

Linking back to the play that children engaged in can be important. It acknowledges the different ways they have been independent, reminds them of their autonomy and demonstrates their choices matter. Importantly, it shows that those in a position of power are listening to the children – how they interact with the world, what their interests are and that they care enough to remember and discuss it the next day. A range of individual learning goals can be linked back to the things that interest each child and build on concepts they've used in the play. Children also enjoy a visual and verbal reminder of the success they have had in play.

This approach to teaching built on the relationships already in the room, and changes in communication styles steadily grew throughout the study. An example of how communication changed for one student:

> Student K continually goes to the outside toilet and finds it locked. Each day for the first 6 months of the year, she would come back and pantomime the issue, drag someone out to unlock the toilet or show someone the key and say help. After several weeks [of participating in the research], she came inside and simply stated 'help, toilet locked!' This continued for the rest of the research.

Acknowledging each child as an individual with important things to say, do and remember had an effect on their communication. Over time, children took ownership of the pictures used in communication and slowly their use morphed from adults using them to communicate expectations to students using them to communicate their needs and wants (Davis et al., 2000). The ways in which we started listening changed to embrace a range of styles (Rinaldi, 2005). Children started to dictate their learning – modifying the timetables, especially in relation to the amount of time or access to the block of play, which became known as Choosing Time. By listening carefully to how (Rinaldi, 2005) and what (Clark, 2005) they had to say gave them the confidence to continue to practice and experiment with their communication abilities.

Teaching Approaches

Teacher attitudes are a significant aspect of inclusive teaching, with research showing this is especially true for teachers involved with children with impairments (Avaramidis & Norwich, 2002). By redirecting children away from certain types of play, those in power are making value-laden judgements on how they should be engaging in play and dismissing the individual agency at achieving their personal goals.

Recognition needs to be given that children are very aware of how they learn best and activities that engage them and assist them to reach a state in which they are in an optimal learning zone. Teachers often try and stop behaviours that children access when they are feeling anxious, which are usually individual techniques used to help relax and calm the individual. By acknowledging children's need to interact in their world in their own way, and providing ways of doing so, this research demonstrated

children often turned these activities into play instances. Crashing and banging on mats often turned into acting out rhymes like 'Row, row, row your boat'. When children try to involve the teacher in some of these ways it can turn in to some interesting games as you can engage in the play and help build their skills – provide those obstacles that build play, like not moving when they ask, telling them you are sick, thirsty etc. Building on the strengths of individual abilities (Luckett et al., 2007) increased the interactions children had on a daily basis. An anecdotal story from the resident Occupational Therapist (OT) shows the change of interaction for one child.

> Every morning when I walk past Student S I always say 'good morning Student S!' and he always continues on without speaking. Sometimes he may look at me, but usually he walks right past. This morning when I said hello he looked at me, waved and said 'Good Morning Cara!'. This behaviour continued for the rest of the research period.

These approaches and attitudes were essential to the increased engagement of students. Breaking down routines, building up choices from several to many and listening to the range of communication styles used by children recognised and accepted them as capable and responsible learners. This accepted understanding between staff and children allowed for everyone to engage and interact on a different level.

Amazingly, changes in behaviour were detected very quickly. Children were motivated and engaged in the play sessions from the beginning. The independence, trust and freedom liberated them from the usual confines of surveillance and outside expectations to engage in learning in a new way. This was demonstrated through taking ownership of the learning and making it their own. The following vignette is one of the most poignant moments of the research:

> Two weeks in, a student with echolalia, who rarely spoke in anything other than movie and TV quotes, came in one morning. He put his hand on my shoulder and, in his 'speaking' voice, asked "Amy. Choosing time?" – Students hovered near him to hear the answer (perhaps he had been practising on the bus?). All students were relieved to hear the simple answer of 'yes' pass my lips. Collectively, students were happy with the phrase 'choosing time' and the block of play became known as 'choosing time'. It was officially acknowledged with a new PCS made especially for it.

CONCLUSION

It is vital that children be given support to access play. All children are seen to play and exceptions should not be made about what effective and engaging play looks like. Play should not be limited to outside measurements of what is considered appropriate.

In supporting access to play that supports individual needs and abilities, intrinsic improvements were made in areas they decided were important and were able to share (Claughton, 2009; Goodley & Runswick-Cole, 2010). It is possible that the motivation and engagement came not only from engaging in play, but also being acknowledged as independent, choice making and trusted learners.

It needs to be recognised that children are autonomous and capable in their play and making decisions that impact their lives (Watson et al., 2000). The structure of the program offered in the research by Claughton (2009) and the way it was conducted in classroom offered an avenue for children to demonstrate their autonomy and agency. Children's rights to access curriculum and engage in respectful interactions (Priestly, 1998) was acknowledged and acted upon. By continuing to research through the disability studies perspective and support access to play it challenges the perceptions around children, their abilities, play and dis/ability.

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PART 2

EDUCATION – HIGHER EDUCATION

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7. INCLUSIVE EDUCATION FOR THE DISABLED

A Study of Blind Students in Nnami Azikiwe University, Awka, Nigeria

INTRODUCTION

Inclusive education is about the child's right to participate and the school's duty to accept the child. Inclusion rejects the use of special schools or classrooms to separate students with disabilities from students without disabilities. It ensures that all learners have access to quality education that meets basic learning needs of the child. Still, today, millions of children, youth and adults continue to experience exclusion within and from education around the world. This study examined inclusive education in Nnamdi Azikiwe University, Awka, in Nigeria with interest on blind students.

The practice of special education in Nigeria began from an inclusive education premise. The National Policy on Education makes inclusive education the norm rather than the exemption (National Policy on Education, 2013). There were no structure in place for early detection and identification of children with disabilities and special needs at the government levels. Thus, the phenomenon of exclusion continues to grow as some of the mechanisms for inclusive education are contributing directly to exclusion. The responsibility of bringing up children with special needs rest squarely on the parents of such children. As such, some parents who have children with disabilities, send them to special schools while others who see them as a burden prefer to leave them at home rather than taking them to school. In this way, the fact of exclusion has come to be seen as natural; it is a part of the order of things (Slee, 2013). Special education compromised democracy by excluding students from the right to be enrolled in their neighbourhood school, and educational administration provided the organizational rationale and infrastructure to do so. In order words, special education provided the means for exclusion of those increasing numbers of children considered to be disabled (Slee, 2011). However, the Federal Government of Nigeria also recognizes the importance and relevance of people with disabilities when in the Third National Development Plan, decreed that 'Educational services for the disabled people shall be the joint efforts of all tiers of government.' To this end, the Federal Government directed that two percent of positions in their establishments be allocated to Training Centers for the disabled people as a matter of priority.

Another effort of the Federal Government on the disabled people is the establishment of National Council for Special Education in 1976, with the aim of looking into the issues of the disabled people and advice the government from time to time. Furthermore, the Federal Government established a College of Education called Federal Government Advanced Teacher Training (Special) Education, Oyo in 1977 (now Federal College of Education [Special]) and saddled it with the responsibility of producing teachers for the handicapped students as well as the gifted and the talented students. A Special Unit was also created at the Federal Ministry of Education while Special Education Section was also created in all the State Ministries of Education in response to a directive from the Federal Government. Finally, some Universities namely the Universities of Ibadan, Calabar and Jos offer courses in special education to both the undergraduates and post-graduate levels (Oladeji & Oladeji, 2011).

Inclusion in education is an approach to educating students with special educational needs. Under the inclusion model, students with special needs spend most or all of their time with non-disabled students. Implementation of these practices varies. Schools most frequently use them for selected students with mild to severe special needs (Allen & Schwartz, 2000). According to Slee (2013) inclusive education has firmly planted itself in education and public discourse. Libraries and bookshops have dedicated shelves to this genre. Education jurisdictions around the world have adopted the vocabulary of inclusive education (it is a flawed vocabulary, but it is distinctive and recognisable) and invested significant resources into the production of policy texts, the development and renewal of capital and human infrastructure, and modified curriculum programmes to make schools and higher education more inclusive. In many countries around the world, universities and training colleges are setting enrolment targets to demonstrate their inclusiveness. School inspection schedules and cyclical reviews now carry inclusive education items to which schools must comply. Special education departments in Faculties of Education have undergone rebranding exercises so that they are now Departments or Schools of Special and Inclusive Education, offering special education courses to teachers so that they will become more inclusive in their classrooms.

Inclusive education differs from previously held notions of integration and mainstreaming, which tended to be concerned principally with disability and 'special educational needs' and implied learners changing or becoming 'ready for' or deserving of accommodation by the mainstream. By contrast, inclusion is about the student's right to participate and the school's duty to accept the student. Inclusion rejects the use of special schools or classrooms to separate students with disabilities from students without disabilities. A premium is placed upon full participation by students with disabilities and upon respect for their social, civil, and educational rights. Inclusion gives students with disabilities skills they can use in and out of the classroom (Tapasak, Renee, & Walther-Thomas, 1999).

Fully inclusive schools, which are rare, do not distinguish between general education and special education programmes; instead, the school is restructured so that all students learn together. This is because the right to education, as a universal right, should extend to all children and youth in all parts of the world, including those with disabilities. According to a flagship project report by UNESCO under the Education for All programme, "The goal of education for all will only be achievable when all nations recognize that the universal right to education extends to all and when all nations act to establish or reform public education systems that are accessible to meet the needs of individuals with disabilities" (UNESCO, 2010).

The Society recognizes this and tries to accommodate the disabled persons in the educational systems. According to Ekpenyong (2003) and Achebe (2005) the traditional African society was a homogenous society. The family is fluid. There are no boundaries distinguishing one family from another or one community from another. There was communal living and brotherhood. This popularly referred to as *madu nile bu ofu* or *madu nile bu nwanne* (everybody belongs to one big family). Onwuejeogwu (1992) further stressed that members of the society identifies with the society to the extent that the society's interest is put above theirs. People put their life at risk in order to protect their neighbours and their properties. Everybody is regarded as a brother to his neighbour-what is known as *nwanne malu nwanne ya* (know your brother) or *onye aghala nwanneya* (do not leave your brother).

Scholars like Mba (1995), has criticized Nigerian education for its failure to take account of individual differences among learners into consideration. According to him, the need to consider individual differences is not unconnected with the fact that human beings do not develop the same way. For instance, while some may be tall and thin, others may be short and fat. These and many others are just examples of differences in human's physical development. There are also some differences in intelligence, emotional, maturity and social development among human beings. Thus, we have the visual impaired persons, the hearing impaired persons, people with learning disabilities, the gifted persons, the talented persons, the mentally retarded persons and host of others. These persons with variations in their total development are those which special education is meant to take care of. According to Osakwe (2010), the school systems now face increasing pressure to raise standards, develop social and personal skills, broaden curricula, pay greater attention to equal educational opportunities and prepare young people for rapidly the changing world. Invariably, the modern trend all over the world is shifting towards addressing the educational plights of students with one form of disabilities or the other so as to better their life. The rationale behind this is contingent upon the fact that people with disabilities also have invaluable roles to play in national development, and to be able to do this effectively and meaningfully, their education needs to be given proper attention.

The Nigeria policy on education captured these special needs. According to section 7 of the policy, special education is a customized educational programme, designed to meet the unique needs of persons with special needs that the general education programme cannot cater for. The categories of special needs persons includes the followings: visual impairment (blind and partially sighted), hearing impairment (deaf and the partially hearing), physical and health impairment, intellectual disabilities (mild, moderate, severe and profound), emotional and behavioural disorders, learning disabilities, speech and language impairment, multiple disabilities, the gifted and talented and albinos. The policy further stated that these persons shall be provided with inclusive education services in schools which normal persons attend; in age appropriate general education classes directly supervised by general teachers (National Policy on Education, 2013). The major aims of special education are to provide access to education for all persons in an inclusive setting and to equalize educational opportunities for all persons, irrespective of their genetic composition, social, physical sensory, mental, psychological or emotional disabilities. The questions then are; do the visual impaired students receive equal educational services with their sighted counterpart? What provisions have been made in different institutions to make sure that these students receive equal education services? This study therefore seeks to examine inclusive education in Nnamdi Azikiwe University, Awka using the blind students as the subject of analysis.

Objectives of the Study

- To examine the people's acceptance of inclusive education in Nnamdi Azikiwe University, Awka.
- To examine the blind students' perception of inclusive education in Nnamdi Azikiwe University, Awka.
- To identify the things put in place to by the university to make the environment suitable for students with disabilities.
- To examine the challenges faced by blind student in Nnamdi Azikiwe University, Awka.
- To suggest ways of reducing the problems faced by blind students in Nnamdi Azikiwe University, Awka.

Theoretical Orientation

The study adopts the equity theory as its theoretical framework. The equity theory is one of the middle range theories bequeathed to sociology by Robert Merton, who was driven into this novel idea by the need to pragmatize sociology. The theory, which is particularly useful in the study of industrial sociology, can be applied in various other sociological studies (Anugwom, 1999). The equity theory is build on

the assumption that social beings have an inherent tendency towards comparing their situations with those of significant others, that is other people who they see as similar in most respect to themselves. Such comparison invariably produces a feeling of satisfaction or dissatisfaction as the case may be. In fact, people usually use such evaluations to measure their benefits from social groups or organization vis-à-vis their contributions and rewards of other people with equal or approximate contributions (Okeibunor & Anugwom, 2005). In this case people generally believe that equality should underline social group and to that extent people with equal contributions or stakes should benefit equally. In fact a perception of inequality invariably breeds dissatisfaction and may engender action towards achieving equity (Dittrich & Carrel, 1979). The blind students should be given equal opportunities as the sighted students. In other words, they should be treated alike with the sighted students. Not giving them equal attention as their sighted counterpart will breed the feeling of inequality and dissatisfaction.

Methodology

The study was carried out at Nnamdi Azikiwe University, Awka, Anambra State in Nigeria. Nnamdi Azikiwe University, Awka has a population of twenty-four thousand seven hundred and six (24,706) students in the full-time programme and twelve thousand four hundred and seventy-six (12,476) students in the part-time programme, distributed into divers range of causes during the 2012/2013 academic year (http://en.wikipedia.or/w/index.php?title= Nnamdi Azikiwe University, Awka). The study employed qualitative and quantitative methods of data collection. The instruments for data collection are the questionnaire and in-depth interview guide. The questionnaire is divided into two sections; section A is for the social demographic characteristics of the respondents while section B is for the thematic issues of the study. The questionnaire has more open-ended questions than close ended questions. This is to allow the respondent the opportunity to express his opinion (Anikpo, 2009). Two hundred (200) respondents were purposively selected from four (4) faculties in the University. The faculties include; Arts, Education, Law and Social Sciences. The rationale for selecting these faculties is because they are the home faculties of the blind students. Fifty survey questionnaires were distributed in each of the faculties. Two trained research assistants were employed to explain the study rational to the respondents. Analysis was by frequency tabulation, simple percentage and description.

For the qualitative data, eight (8) sections of indepth interview was conducted on eight (8) visual impaired students in the four selected Faculties also two (2) other sections was conducted on two (2) principal officers of the University. In all, ten (10) interview sections were held.

FINDINGS

People's Perception of Inclusive Education

Table 1 shows the social demographic characteristics of the visual impaired students.

Table 1. Personal data of un-depth interview participants

Demographic Variables	Options	Frequency	Percentage
Sex	Male	6	60
	Female	4	40
Age	18–27	8	80
	28–37	–	–
	38–47	2	20
Year of study	100	2	20
	200	2	20
	300	5	50
	400	1	10
Faculty	Arts	3	30
	Education	2	20
	Law	3	30
	Social Sciences	2	20
Religion	Christianity	10	100
	Islam		
	African Traditional		
	Religion		
Period they lost their sight	From birth		
	Childhood	8	80
	Adulthood (after age 18)		

Table 2 shows the demographic characteristics of the respondents.

People's Attitude towards Blind Students

Majority of the respondents accept that sighted students and their visual impaired counterpart should be taught in the same classroom condition. This will help the blind students to overcome stigma. The response from the blind students also supports the quantitative data. According to them, it helps them to interact with

Table 2. Personal data of respondents

Demographic Variables	Options	Frequency	Percentage
Sex	Male	120	60
	Female	80	40
Age	18–27	193	96.5
	28–37	7	3.5
	38–47	–	–
Year of study	100	80	40
	200	20	10
	300	60	30
	400	40	20
Faculty	Arts	50	25
	Education	50	25
	Law	50	25
	Social Sciences	50	25
Religion	Christianity	200	100
	Islam		
	African Traditional Religion		

the public and this gives them a sense of belonging to the society. A female blind student noted:

It gives me a sense of belonging and motivates me to work hard in order to meet up with the challenges before me.

However, 11% of the respondents do not accept that blind students should be taught in the same classroom with sighted students. Their argument is that they distract the class by asking too many questions thereby making the lecturer to be slow in teaching to enable them benefit from the teaching.

Table 3. Peoples attitude towards staying in the same class with blind students

Questionnaire Item	Responses	Frequency	Percentage
Do you accept blind students staying in the same class with you	Yes	178	89
	No	22	11
Total		200	100

Blind Students' Perception of Inclusive Education

All the blind students interviewed said that they prefer inclusive education to the exclusive method of education where visual impaired students are kept in a special school and though by specially trained teachers. According to them it helps then to prove to the society that blindness is not a limitation that they can compete favorably with their sighted counterpart. However, one of the participants has a yes and no response to the question on their perception of the inclusive education. According to her, in the special schools they are treated specially. It was at the special schools they learnt how to type, how to use the braille and even how to use their walking stick. The teachers in special schools are also trained to meet their special needs.
A female blind student indicated:

> I like to be taught in the same classroom with sighted students because they help me to overcome some of the challenges I face in the classroom. They get a good sitting position in the class for me.

A male blind student indicated:

> It is better to be in the same class with sighted students, in my class everybody puts me into consideration when taking a decision.

A female blind student said:

> Being taught in the same class with sighted student is good. It helps us to prove to the world that blindness is not a curse. We can compete favourably with our sighted counterpart. Also special schools are very necessary because there are so many things a blind person cannot learn in an inclusive setting. Things like how to type, how to use the braille and how to use the walking stick are all learnt at the special school.

Thus, it is recommended that parents who have disabled children should endeavour to send them to school early. This will assist the children to develop self confidence and be able to compete favourably with their peers.

Study Rationale

The questions this study tries to answer are: do the visual impaired students receive equal educational services with their sighted counterpart? What provisions have been made in different institutions to make sure that these students receive equal education services?

Provisions by the School to Meet the Needs of Blind Students

The school does not have any special provision for the needs of blind students. This is so that they do not feel stigmatized. However, the school made sure that the

environment is made comfortable for disabled persons. The University built a walk-way in all parts of the University. At the department level teachers pay attention to the blind students who are allowed to sit near the lecturer in order to have the lecturers clearly recorded. During examinations a lecturer is attached to each blind student to help him/her read out the questions. Not only that, they are also given extra time during as to examination. The departments fix lectures at venues that are accessible to them. The school also access special scholarship funds for them. One of the principal officers interviewed said:

> We don't want them to feel stigmatized. All the school does is to make the environment friendly for everybody, especially the disabled students.

Figure 1. A blind student sitting very close to the lecturer

The Challenges Faced by Blind Students in Nnamdi Azikiwe University, Awka

The blind students noted that their major challenge is stigmatization. They don't like to be stigmatized. There are times they don't get help when they need help. A male blind student said:

> I don't like my friends to treat me like a handicapped person.

He further said:

> When people see you as a blind person, they avoid you, they don't help you when you need help. So in order to make good friends, I pay for most of the services I receive.

Mobility is also very expensive as they may need to pay the transport fare of the person helping them to access the lecture halls. According to them, education under the inclusive method is very expensive as they have to pay for most of the services

they receive and also pay for all their reading materials – the tapes, recorders braille and typewriters. A female blind student said:

> Education for blind students is quite expensive. Our reading materials: the tapes, recorders, braille, braille machines and typewriters are all very expensive. Most of us cannot afford them.

Thus, it is recommended that the school should source for scholarships for the blind. They should also assist the students to get some of their reading material like the tape recorder empty tapes, braille etc.

The Challenges Faced of in Teaching Blind Students in Nnamdi Azikiwe University, Awka

One of the principal officers interviewed said that there is no recorded challenge faced by the departments that have blind students. However, the departments recognize that they are there and take them into consideration when taking important decisions. The timetable officers of such departments make sure that lectures for classes that have blind students held on the ground floor of their buildings.

The Blind Students' Coping Strategies

In order to succeed in their academic endeavour, blind students make friends with sighted students who serve as eyes to them. They maintain these friends by paying their fares and by providing a timely lunch. These friends help them to read and record the textbooks. They help them locate the lecture halls and any other helps they need.

In response to the question on how he is coping in the school, a male blind student said:

> I make friends with sighted students and all my friends are wonderful especially the female ones. They help me to locate the lecture hall; they also help me to record my textbooks. In return I give them gifts.

In African traditional society as earlier stated, there is this concept of 'be your brother's keeper' – *Nwanne malu nwanne* and *Onye a ghala nwanne ya.* Thus, it is usually very easy to get someone who is ready to help the blind. They have their typewriter and tape recorder with them always. All these help them to cope with their studies. However it is recommended that sighted students in these departments should be advised to love and give assistance to their visual impaired counterparts**.**

Ways of Reducing the Problems of Blind Students in Nnamdi Azikiwe University, Awka

The respondents noted that the school can help the blind students overcome their challenges by making the environment friendlier. This would be achieved by

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Figure 2. A blind student waking on the walkway with a friend

organizing two weeks orientation training for every first year blind student in the university. The training will involve walking round their departments and introducing them to all the facilities in the department at least seven times. Build hostels with toilets and bathrooms that are suitable for blind students with rails on the walk-ways where two or three blind students can stay in a room with one or two sighted students to help them. The school should source scholarships for them from international organizations, non-governmental organizations within and outside the country and also help in providing all or some of their reading materials.

CONCLUSION

Inclusive education helps to remove the feeling of stigma from disabled persons. Its implementation creates a sense of belonging for the disabled person. This is because the focus on production and exportation for the world market (founded on the extraction of labour through slavery or serfdom) also implied that those who were seen as unfit (among them disabled people) or schismatic to the European presence and order had to be normalised (to function and produce), or else subjugated and isolated (Grech, 2012). Not only do most disabled persons usually dislike being treated as the handicapped – it will also bridge the gap of inequality. With the advent of globalization, all the world is made to look the same, simplified, reduced and homogenised, which in turn permits the sale of one's own epistemologies to everyone, everywhere. What does not fit is removed, rejected or resisted. Thus, inclusive education will give every member of the society equal opportunity to be educated, thereby giving the blind people opportunity to contribute to the development of the society.

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8. MANAGING THE BARRIERS IN DIVERSITY EDUCATION THAT WE CREATE

An Examination of the Production of University Courses about Diversity

INTRODUCTION

It is important to provide beginning teachers with the skills they need to support students with diverse needs in the classroom. These skills are especially needed to support students with autism. Without the tools needed, beginning teachers go into schools where the teachers may or may not have the requisite skills needed either. University preparation is therefore crucially important, but we would argue that the importance of this task is dogged by university and auditing authority compliance audits and controls and by a limited view of what catering for diversity actually means. This chapter investigates the tensions that four university academics face in their day-to-day work as they teach a course on diversity and disability studies within a context of audit and control by outside parties.

The chapter has four participant authors. Each of these authors has taught in the first year diversity course offered to all students in all education degree programs at our university. Each author was keen to also provide a statement of what they thought the third year diversity course should look like given the constraints of auditing and control previously mentioned. One of the participant authors is a PhD candidate from Bangladesh who is also a tutor. This person has a psychology degree and therefore sees disability as the DSM-5 would see disability. But to stop there would be to deny the multiple lives within which this person lives. Mahbuba believes that catering for a disability is about power and activism and in her home country of Bangladesh she is engaged in daily activism in order for the clients in her care to gain a quality education.

Barbara, another participant, has spent 43 years in the classroom where she has learned about the power of systems and individuals and brings this lens to her study of diversity and disability. She has been a special needs head of department in schools and is a policy sociologist. She is also the academic in charge of delivering one of the diversity courses in question. The third participant, Satine, is a PhD student in the field of autism, who is also a parent of a child with autism and has experience with policy and governance of universities. Her concept of the subject matter of this

chapter derives from a desire for the human rights of her child and all children to be respected and maintained. The fourth participant, Lynn, is also a parent of a child with autism, a special educator and a prospective PhD student. Her years as a Head of Special Education have reinforced her desire to see diversity and disability studies break the bounds of the field of special education and faculties of special education to become mainstream and part of teacher training courses "everywhere, every day and for everyone" (Australian Human Rights Commission, 21/08/2014).

The data provided in the chapter are taken from statements that we each wrote about our observations of this course design process. One participant, Satine, speaks of her understanding of the university's vision for undergraduate courses such as those for diversity and speaks back to that vision. Barbara speaks about the vision provided to her through the credentialing authority and the constraints that are placed on her through audits. Mahbuba and Lynn speak about what they would like teachers in schools to be able to do with children who have diverse needs from the points of view of parents and teachers. The particular form of diversity that we had in mind when writing the chapter was that of autism. It is worth mentioning here that we are interested in the provision of *mainstream* courses concerning diversity and autism, rather than those courses that are autism specific and provided as part of a special education higher degree program or within and through an autism centre of excellence.

When we combined our written statements and looked for themes or clusters of ideas (Harding, 2013) within these statements we were also compelled to consider the context within which our statements were created. The context and tensions of the contemporary university have been described in the literature as being broadly based on three themes. Luke, Green and Kelly (2010), for example, have argued that tensions arise as education systems attempt to provide a *quality* education system that caters for *equality* in a manner that is *controlled* and *controllable*. The quality agenda involves the university in the recruitment of students in order to receive income and to gain world status (Luke et al., 2010). The equality agenda derives from the widening of participation to include students who increasingly travel to gain a better education or are the first in their families to seek higher education. Many students with a disability now attend university and universities are engaged in the removal of barriers to participation in order for this to occur.

We would argue, though, that the control agenda is the stronger and more legitimate, performative education culture that binds these parameters together. Previously Garrick (2013, 2014) has argued that this agenda is influenced by policy actors from the OECD, the United States of America and the World Bank (Wiseman, 2010) who valorise empirical evidence that measures how much is learnt, how many learn and how much is taught. In this sense, quality defined as "how much" can be assessed summatively in order to gauge "how close" to excellence the student, lecturer, university, state and nation has come (Wiseman, 2010). University administrators then tie tenure, funding and promotion to these measures (Wiseman, 2010). These actions have both a controlled and controlling

element to them. These are evaluative measures written in performance indicators expressed as numbers.

We took these contextual tensions as a starting point to our research and acknowledged that today, more and more; universities are drawn towards the global market place through the strategic provision of world class, internationally focused degree programs. The problem we feel with this triad of aims, namely *quality*, *equality* and *control,* lies in the power that each separate voice has within the overall education system. Indeed, we do not have the personal first person voice of the university or the auditing authority at this stage as we only know what that voice is through policies that we receive. We do know from the first person voices of parents and a practitioner in schools that there are differences between the stated aims of policies of diversity and their implementation. We wonder at this point about the child with autism in such a system. How can we ensure that this child is provided with a quality education that is equivalent to their peers, but is also measured in bite size chunks so that policy actors located elsewhere can recognise and evaluate them in terms of perfect quality? We therefore argue that the barriers that we found that exist between each stakeholder need to be further explicated and addressed.

This chapter is the first move in this regard. What follows now is a review of the manner in which we addressed the literature relating to diversity education and education systems at one university. Here we place a poststructural lens over the issue and make a number of decisions about how each voice can be read. We then turn to the data and identify a number of themes that appear. These themes are language and expectations, power imbalances and the issue of rights as a means to move beyond restrictions. The chapter then concludes with the outcomes of our deliberations. We now turn to a discussion of the philosophical lenses that guided our work.

Possible Educators, Possible Stories: Poststructural Theory and Diversity

The chapter's theoretical and philosophical framework is that of poststructural theory. Poststructuralism is a theory that encapsulates ideas of the contradictory subject created through contradictory discourse or the action orientation of individuals as they position themselves either within or against the prevailing and legitimate discursive practices available. As Davies (1997) argued,

> The subject of poststructuralism, unlike the humanist subject, then, is constantly in process; it only exists as process; it is revised and (re)presented through images, metaphors, storylines, and other features of language such as pronoun grammar; it is spoken and re-spoken, each speaking existing in a palimpsest with the others... Poststructuralist discourse entails a move from the self as a noun (and thus stable and relatively fixed) to the self as a verb, always in process, taking its shape in and through the discursive possibilities through which selves are made. (pp. 274–275)

Both our theory and our method also derived in part from our reading of a poststructural paper entitled *Producing Possible Hannahs: Theory and the Subject of Research* (Honan, Knobel, Baker, & Davies, 2000). These authors argued that

> …a number of theoretical readings of ... data produce different possible subjects located in differently constituted possible worlds. By putting theory at the centre of analysis, [they showed] how theoretical approaches radically influence what can be found in the data and how it can be found there. (p. 9)

What we found relevant here is the idea that individuals can often only become what is available for them to become. Said another way, language helps create the possibilities for becoming and also the possibilities for un/becoming (Butler, 1990). We perform language and are affected by it. We examined our data from this point of view to see the discourses that have been made available to us as we design university courses on diversity and to find sites of transformation and creativity for future course design. The data were examined through the use of d/Discourse Theory with the ideas of poststructuralism in mind. We then drew on Bernstein's (1999) ideas and those of Freebody, Maton, and Martin (2008) to place names to the ideas that emerged. Each of these theories are evident in the discourse that sits around the topic of diversity and disability. These theories are now described.

There are many discursive ways to view the topic of diversity and disability. For this one topic alone we could take a medical position where students are imagined as being in need of special and therefore different services in order for them to achieve in schooling. We could take a human rights perspective where all students have the right to an education and to be included. Here governments are responsible for legislating and enacting policies and procedures that support the rights of people with disabilities (Piotrowicz & Kaye, 2000; Campbell, 2006). Or we could take the premise that we have, namely beginning with the human rights model, but adding a disability studies perspective where students with diverse needs are imagined as a construct within the social, political and cultural contexts of our times.

This construct forms the context of our poststructural reading of the data. We see that language has created the courses that we offer and so therefore language can help deconstruct them and recreate them. This is a project of fluidity, contingency and change. Within this definition we suppose that it may be that the autism community is fine, but the rest of us need assistance. Here we see that the terms diversity and disability are complex, dynamic, value laden, open to interpretation and debate (Barnes & Mercer, 2010; Clapton, 2009; Edwards, 2005; Shakespeare, 2006). When applied to autism, we recognise that the literature can be based on the DSM-5 or the sociological disability studies movement. Here we agree with Straus (2010) that by creating the new classification of autism.

> Kanner and Asperger participate[d] in the endless reshaping of the map of psychological disorders, which rise and fall historically, as much in response to cultural and social pressures as to any neutral, scientific observation.

Today, autism may appear a secure, natural category, but it is as historically and culturally contingent as neurasthenia, hysteria, and fugue-science based and neutral medical categories of a previous era-and may someday share their fate. (p. 536)

We make the point therefore that such a slippery term is hard to encapsulate within a 13-week semester of university course work.

The choice as to the definitions we use in this chapter eventually was predicated on our personal ideas and experiences about and with diversity and disability. Here none of us feel that students who are diverse are "categories" of individuals to be dealt with by someone else, somewhere else. However, this is where trouble starts within the faculty. The ideas that lie around our views of disability and diversity are open to contestation by powerful forces that control the agenda. These forces are now discussed through the data provided from our statements.

The Discourse That Is Available for Take-up: Legitimation Codes

Poststructural theorists tend to ask *what* and *how* questions rather than *why*. For this research we asked the poststructural question as to what is out there to know in relation to diversity and disability studies, autism and the discourse that is available for take-up. We first used the lens of d/Discourse analysis to examine the language that currently exists in our faculty about diversity and disability. We then examined language and experience from the perspective of poststructural theory. In this task we are buoyed by the work of Honan et al. (2000) who observed that

> [W]e aim to speak across and through our differences by showing how diverse frameworks can produce quite different "clicks of recognition" (Lather, 1991, p. 69). Each framework generates a different way of reading the data, a sense of what can be found in it. (p. 10)

Method: Discourse Theory

The data in this chapter are taken from 4 statements written for the purpose of course design, but analysed for the purpose of research scholarship. The method of data collection and analysis was Discourse theory. For the researcher, Discourse theory fundamentally is about finding patterns and groupings of discourse in what Gee (1992) calls *Discourse memberships*. Gee argues that there are particular patterns in the way talk or discourse occurs and how such talk is acted upon, valued and believed. d/Discourse theory and poststructuralism relate at the level of language.

As an opening move for our data gathering, we first met together and considered the multiple discursive memberships we inhabit when designing a university course about diversity. These memberships include our diversity specialist discipline, our membership as staff members of a university, our membership of the broader community of teachers and human beings, student/supervisor memberships and

finally our experienced membership as parent and teacher practitioners. We then agreed on the rules. Power relationships were evident at this stage as Barbara was both an employer, supervisor and friend to all 3 participants. In terms of the first two memberships Barbara stated clearly that she could not give away her responsibility as the academic in charge of writing the course, but she did work collegially and we felt that everything else was up for discussion. She did aim to make us all feel valued and did take on suggestions and ideas so that we worked as colleagues in collaboration. We drew on ideas of the negotiated curriculum, where some aspects of a curriculum are able to be changed and others are not. But herein is the dilemma, some of the audits and controls have to be met and we all worried about this.

Next, our membership of different discourse categories were named and discussed in detail so that we could each write our statements with our needs in mind. The course we had to design was to build on the first year course that relied heavily on the ideas of *Universal Design for Learning* (https://www.cast.org, 21/08/2014) and concepts of everyone, everywhere and every day (Australian Human Rights Commission). In this course a child with autism was considered to be a fully-fledged member of the classroom where their needs were met using an *all, most* and *some* design (Foreman, 2014).

We each then wrote our statements about what we thought should occur in a third year university course on diversity and disability studies as a follow on from the previous first year course. Two of us searched the literature and devised our statement from the perspectives of the strategic plan of the host university and the credentialing needs of the auditing authority. These formed a kind of document scan for us. This we had to do, as every year, every day and for everyone increasingly we are tied to system priorities of what courses at university should look like. One of us wrote her statement on behalf of parents of children with autism. Her data derived from a study she is undertaking in this area. Another participant wrote about her experiences and feelings as a teacher in a secondary school special education facility. We were saddened to realise at the end of our data gathering that we had not thought to audiotape our discussions. This was because we met as colleagues discussing ideas that we later saw would have provided a much richer background to our written statements.

The data were then analysed for themes and memberships. There were several stages in data analysis. We began our data analysis within the context of our university staff membership. Here the language we investigated was that which is available for us to take up about "widening participation", "quality and standards" and "human capital". These data are provided from statements where Satine and Barbara comment on the university discourse available to them. Lynn mentions data in her statement, but Mahbuba did not. In this analysis we did not miss the point that courses on diversity in universities now have both an economic and social function and that this may well be the reason for the provision of courses on diversity. We then considered our membership as developers of courses on diversity where, at least for the moment, we have some say in how the courses can be designed. Here

we respond to the university discourse. We then examined the statements of the two parents and the head of department as stakeholders in the work we do. The different membership categories were very obvious when our two participants who are parents of a child with autism wrote and talked about their statements. Lynn and Satine tended to agree with each other about their child's behaviours and about their desires for their child. This voice was different to the other two participants who do not have a child with autism. But this is not to then suggest that each of the parents then *always* spoke with one voice. Often there would be heated arguments between the two about the *type* of schooling that is best for their child. Here we are reminded of a fundamental tenet in the diversity/disability literature, namely that individuals are persons first (Foreman, 2014) who may then have points of difference. The d/Discourse that unites us therefore is that of our humanity and our desire to protect the human rights of those we encounter. Here we agree with Honan et al. (2000) that we are

> … constructing opportunities for people to "be," and to display being, particular types of persons. For everyone, these displays of social identity and Discourse membership are multiple and always under negotiation in the contexts, practices, and politics of everyday life. (p. 11)

Last we spent time looking at the four statements for themes in common and these we report below. These themes are language and expectations, the ideal implementation and the reality, power imbalances and the issue of rights.

What the Data Revealed: The Discourse That Is Out There to be Taken up

Here we describe the four statements as data. Again, the statements were first written individually and provided the raw data. Each participant then re-coded each statement for common and/or contrasting themes. We then coded together as a group and once more separately in our membership categories. Consequently there are two statements written by Satine and Barbara that derive from a study of the University's *Strategic Plan 2013–2017* (2013) and statements from the *Queensland College of Teachers* auditing authority. These two participant authors are responsible for meeting the requirements set out by the University and by the College. Their statements are examples of institutional membership. There are also the first person accounts of five parents told through Mahbuba's statement and Lynn's statement from the point of view of a practicing head of department of a special education facility. These statements are about membership of parent and teacher groups.

Institutional Membership

Statement one: Satine.   The first statement describes the university's concept of an ideal course of action in relation to the provision of university courses both at the undergraduate and postgraduate levels. Satine has access to the university's

governance mechanisms and used this insider knowledge to write her statement. She observed in her statement that the host university's Strategic Plan 2013–2017 (2013) sets out the university's mission as a desire to be

> … one of the most influential universities in Australia and the Asia Pacific Region by…*engaging in outstanding scholarship*. (p. 2)

She noted that the strategy further states that students

> … will be provided with an excellent education and the capacity to use knowledge gained to exercise influence and make meaningful lifelong contributions to their communities. (p. 2)

In the pursuit of excellence in teaching and research, she added that the University is committed to:

- Innovation
- *Bringing disciplines* (our emphasis) together
- Internationalisation
- *Equity and social justice* (our emphasis), and
- Lifelong learning.

> for the enrichment of Queensland, Australia and the international community. (p. 1)

Satine observed that these accountabilities pass down to faculties and schools and then on to Program Conveners who are responsible for the *Annual Program Review and Improvement Report* for each program and they also monitor the course profiles for each course in the program. Individual academics are then held accountable through the *Student Evaluation of Course* and the *Student Evaluation of Teacher* mechanisms in place to determine the effectiveness of teaching in all courses in degree programs.

The *Student Evaluation of Course* (SEC) and the *Student Evaluation of Teacher* (SET) questionnaires check that the strategic goals are met. Once a semester students are required to evaluate the courses that they undertake. Indeed, Satine noted that Goal 5 of the strategic plan aims

> … to reduce the proportion of courses with SEC mean satisfaction scores below 3.5 to less than 10% in all academic groups by 2017.

The first year course in diversity, examined in this chapter as part of the preparation for the third year course, forms part of this strategic goal. Satine concluded that

> … the university would be happy with this particular diversity course offered in the first year of the Primary and Secondary Degree programs as the *SEC* and *SET* ratings are above 4 on a 5 point scale. So the strategic goals of the university have been met through this course based on the evaluation mechanisms provided.

Satine felt though that the SET and SEC scores told only *a small part of the story*. Her statement showed that the processes and products of this course were not *illuminated at all by statistical analysis and that the work undertaken in the course should not be reduced to numbers*. Satine called for other ways to *show excellence in diversity courses that did not reduce the value of widening participation to a set of mean scores*. From her membership as a parent of a child with autism she also noted that the scores *told her nothing about what the first year course achieved for the preparation of pre-service teachers and her child*. She also noted that the course profile did not address her concerns as well, but did not elaborate further.

Statement two: Barbara. At this point Barbara's statement becomes important. As a member of faculty Barbara is bound by the practices and procedures of that faculty. She observed in her statement that these practices and procedures are becoming *increasingly uniform and controlled*. Barbara noted that this is best evidenced in the organization of the course profile. Barbara described the process of course profile preparation in her statement. She observed that *from the university's aims, course profiles are then written and this process is heavily influenced by the university's strategic plan and the auditing authority which in this case is the Queensland College of Teachers*. The strategic plan asks course conveners to include the university's Graduate Attributes in the course profiles and the relevant attributes here are:

XXXX University aims to prepare its graduates to be leaders in their fields by being:

- Knowledgeable and Skilled in their Disciplines
- Effective Communicators and Team Members
- Innovative and Creative with Critical Judgement
- Socially Responsible and Engaged in their Communities
- Competent in Culturally Diverse and International Environments (2014).

Barbara observed in her statement that the course profile process is also *heavily influenced by the Queensland College of Teachers (hereafter QCT)*. She described the *QCT* as a statutory body established under an act of parliament entitled the *Education (Queensland College of Teachers) Act 2005* that is charged with the regulation, enhancement and promotion of the teaching profession in Queensland. She went on to note that the *QCT* was one of the first accrediting authorities of its kind in Australia that functions to approve and monitor pre-service teacher education programs for provisional registration, to position the professional standards at the core of university education programs and to ensure that the current Primary and Secondary degree programs meet compliance standards of the profession as outlined nationally and described through the *Accreditation of Initial Teacher Education programs in Australia: Standards and Procedures (AITSL)*. The national accreditation documents are intended to assist higher education institutions to develop programs that will enable graduates to be registered as teachers in Australia. Barbara observed that this accreditation process is *most notable in the aims and objectives of diversity*

courses currently provided in universities. These aims and objectives are written in course profiles and include:

After successfully completing this course students should be able to:

- Evaluate the historical, philosophical, legislative, policy and practice frameworks underpinning inclusive education,
- Understand learner diversity and functioning unique to and common across such dimensions as Indigenous, socio-cultural and linguistic diversity, gender differences, and impairments
- Use strategies to engage in effective relationships with students by harnessing learner competence and applying the characteristics of quality teaching,
- Explain frameworks for designing and implementing effective inclusive curriculum, learning, teaching, and assessment practices,
- Demonstrate the value of skills needed to work collaboratively with students, parents/carers, fellow teachers and teacher aides, support staff and professionals external to the educational setting, and
- Develop greater awareness and appreciation of the social, political and economic position of international issues and perspectives in inclusive education.

Barbara observed that the particular diversity courses examined in this chapter *comply with the requests of the auditing authority and the courses are organised around the relevant AITSL standards*. However, Barbara also expressed frustration with this process. She observed that

I feel that all I do at work now is edit. I edit others and others edit me. I absolutely hate the SET/SEC process and although I get great results, none of it talks about the student with a hearing impairment that I helped incidentally or the student with an acquired brain injury who gave our lecture series a new life. At the end of the day I could be doing anything in my lectures and no one would care! As long as the SET and SECs are good, I could be teaching about cabbages! I get so frustrated by the tick and flick mentality that is coming into our profession.

From Satine and Barbara's statements, we became concerned as a group with the idea that diversity as a subject can be neatly packaged according to the employing authority's ideas of what constitutes diversity and disability. The statements show that the university and college use terms such as "evaluate", "framework", "skills" and "strategies" and it is clear that ideas of skills and tools are pre-eminent with the *QCT*. Whilst we agree that tools and skills are relevant, we would also argue that questioning the categories of diversity and disability are of equal importance and this questioning is not present within the objectives as they are written. Barbara noted this concern in relation to a diagnosis of autism. She argued that we can *trouble the diagnosis through arguments that the disorder exists primarily discursively and has been talked into being each and every time regulatory norms are used to shape and define the diagnosis*. Here a diagnosis of autism is social and discursive. Yet,

there are also medical and psychological understandings of the same term. Autism is not a straightforward construct. The question for us then became an issue of what the words of these standards and the strategic goals ask of academics and how compliance with these words plays out in relation to our other key stakeholders such as parents and teachers. This is especially in relation to children with autism.

Further analysis of the first two statements shows a distinct type of language. This is of course understandable given the role and function of both the university and a statutory body such as the *QCT*. First and overwhelmingly the language used by these two groups is formal and that of influence and power where students and the university are meant to influence and be influenced by their communities. Second there is a discourse of scholarship and excellence in scholarship and one would be dismayed if this discourse were not present in a university's documents. Third though, the documents reviewed showed a heavy reliance on the discourse of compliance, regulation, standards, review, improvement, evaluation, targets and ranking. Again this is understandable, but we would argue is often at complete odds with the targeted stakeholders that the institution is meant to serve. We suspect that the sub-text of this compliance is that the auditing authority wants pre-service teachers to be able to cater for diverse children in their classroom and that the sub-sub text is that they want pre-service teachers to be able to handle perceived difficult children such as those with ADD or autism. We sense here that the control and quality agendas override the equality agenda. Without the space to question whether certain categories of individuals exist then only normalisation and standardisation can occur.

Parent Membership

Statement three: Mahbuba. The discourse that Satine and Barbara found that is available for academics to take up at the university level is in stark contrast with that of parents, teachers and often themselves. One of our colleagues wrote her statement from the data that she had gleaned in her PhD research. For the purposes of her study Australian and Bangladeshi parents living in Australia and a teacher were asked about their experiences of the inclusion of children with autism in schools and were asked to talk about an ideal set of circumstances for them. She observes in her statement that parents firstly spoke in terms of their experiences about the school, home school communication and satisfaction with the school services and facilities. In addition, the parents also discussed their rights and finally their perceptions regarding the concept of inclusive education. Based on the study, the parents interviewed wanted two-way communication with their school so that the needs of their child with autism could be addressed. All (n=7) suggested that one way communication was not helpful at all. All of these parents were in receipt of a communication book where teachers regularly told them about their child at school. Parents though also wanted to tell teachers about their child at home and of any problems that might affect their child at school. Also, and in common, parents

did not use the terms inclusion at all, but instead spoke of allowing their children just to "be". All 7 parents suggested that they want their children to be children first, to be free to be children, to play and not be pressured at home in the same way that pressure is placed on their child at school.

Here the membership discourse is about "helping", "communication", "play" and "collaboration" and these words are in stark contrast to Satine's and Barbara's.

But this is where the similarities in the parents' stories stop. Mahbuba also noted in her statement that there were stark differences between well-educated parents and those less so and parents who are native to this country. Parents from both countries who are well educated tended to talk about their child's rights and justice more than those without a similar education. The parents from Bangladesh however spoke about wanting to help their schools more. They said that they wanted to be in the classroom to help their child and did not understand why this is not allowed. Mahbuba quoted one parent, who observed that,

> Though we are not Australian, we found most of the time the communication is going one way not in both ways. I wrote several times in the communication book for the permission to sit in the classroom, but I did not receive any reply from the school. If they call us we go, but we know that whatever decision they will take for our child they will just inform us, they will not take our opinion. We don't have any opinion because we are not citizens here. So whatever service we are getting it is ok so far.

Our analysis of Mahbuba's statement shows that parents themselves are not a homogeneous, pre-packaged set of individuals. We took from this that any mention of parents in the third year course must be cognizant of this heterogeneity. What was also clear from this statement was the idea that parents speak in completely different terms to the formal discourse of the university. We are aware that parent representatives sit on the various committees within the *QCT*, but we are reminded that these parents may not be representative and may know nothing of the lived experience of schooling. We are worried that trying to do these parents justice, trying to trouble diversity, trying to meet the needs of everyone is a tough ask in a 13-week course about diversity. What often happens at this point is content is watered down and shortcuts are taken. We are not arguing for more time here, but time better spent.

Equally, these parents have been "packaged" as customers in receipt of a service only. The parents in Mahbuba's statement are having education done "to" them, rather than "with" them. The fact that these parents feel that they have no rights in this country is alarming.

Practicing Teacher Membership

Statement four: Lynn. The previous three statements were reports about what others see as important. Each author then added their own comments regarding

these concerns. Lynn's statement, on the other hand, was the most direct of all of the statements. It was clear that Lynn had something to say. She spoke about her frustrations in trying to cater for the needs of her students with autism within a mainstream setting. She observed,

> I work as a Head of Special Education Services (HoSES) in a mainstream school. It is my job to advocate for students with disabilities to ensure that they have the same access and opportunities for learning as every other mainstream student. Indeed in our teaching standards it dictates that every student has equal opportunities. More and more my daily frustration is talking to mainstream teachers who cannot, will not, or do not differentiate for their classes. They still adopt a "one size fits all" approach, which, in this society does NOT [*participant's emphasis*] cater for the majority of our students.

Here Lynn expresses the goals that diversity educators and diversity courses aspire to, namely catering for diversity, but she expresses them in an increasing context of frustration and annoyance. She alludes to the language of standards and regulations that drive our courses at university, but she feels that the message of the standards is not getting through to the practicing classroom teacher no matter how recent their graduation from university. This concern is worrying given the emphasis that is placed on these standards in universities. She continues,

> Gone is the idea of a classroom populated by white middle class students and in its place we have a richness of races, abilities, religions, socio economic groups. Loretta Giorcelli tells us that our classrooms in mainstream may now only hold a minority of the students for whom the curriculum appears to be written.

Lynn acknowledges her awareness of theory in this statement and her desire to acknowledge the diversity of our student population, but below she argues that this is somehow spoiled by the fact that

> We are asked to collect data on a regular basis and you would hope that is for the improvement of our students' learning. To inform where capacity is lacking in our mainstream schools. But no matter how much data we collect the challenge remains. Teachers in mainstream schools are not differentiating for their students. The advent of a new curriculum appears to have exacerbated the challenge, not lessened it.

In this comment Lynn alludes to the standardisation agenda of modern schooling where because education systems in each nation state now have the ability to compile massive online databases of student performance and curricula for the eyes and ears of OECD representatives to quibble over, they do so. Here Lynn expresses frustration that the compilation of data does little to affect teaching in schools. To this point the language of standards and data gathering, so important to the university and auditing authority, seem irrelevant to this teacher. Indeed the language of standards and

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data appear to have little impact on mainstream teachers in differentiating in their classrooms. Here the themes of language and expectations, the ideal implementation and the reality, and of power imbalances seem clear.

Lynn also tends to essentialise and totalise her ideas in relation to mainstream classroom teaching and this is of concern. She notes that *teachers in mainstream schools are not differentiating for their students*. As a group we would argue that we prefer to know *which teachers* and *under what conditions* is mainstream teaching lacking. Lynn though then corrects her language and argues for a more nuanced reading of teachers by noting

> Do I believe it's because teachers can't? or because teachers won't? A little bit of column A and a little bit of column B. Sometimes there is not much we can do about the won't. But we can change the can't. Universities need to take the diversity and differentiation courses away from being a Special Education domain. We need teachers in mainstream who have as much knowledge of diversity and differentiation as the Special Educators, because, we are all special educators. No student comes without challenges. Some just have more.

Lynn shows us that, like the rest of us, she is a contradictory subject and in her frustration she totalises her experience in order to make her point, whilst forgetting that she too must cater for diversity in her speech and acts. We would argue that the university course in question *is* provided for all students in all degree programs in education at the university. The problem then that is addressed in this chapter becomes the manner in which these programs are packaged using the available discourse to take up, namely stardardised and regulated ideas about what everyone, but the academic in charge may think is necessary. Lynn is frustrated with the data that is gathered currently in schools and observes instead that

> We need to embed the concept, the skills and the knowledge of diversity and differentiation into the DNA [participant's emphasis] of our schools and we must start with the teachers and their learning. An intrinsic part of the teaching courses must be based around diversity and differentiation. Our teachers need a toolkit, a strategy, a mind-set that allows them to embed differentiation into their teaching practices. Only by ensuring that the concepts of diversity are interwoven into mainstream teaching courses can this be achieved.

Here, Lynn is suggesting that a diversity element must be built into every course in every education degree. Again, the discourse available for take-up here can only be effective if all academics in all universities have the requisite "*DNA*" to carry this off effectively. This comment aligns with Bensimon's (2004) ideas of a diversity scorecard where teachers learn to develop and nurture an equity cognitive framework. Without this, the topic of diversity is further diluted and dissolved. We of course cannot and would not want to ensure that everyone is the same and so solutions must lie elsewhere. We cannot make all the same to service one. But what this participant alludes to is more than a set of skills and tools, but a mindset and

this we feel we can do something about. What follows in the next section is a further discussion of the ideas available to take up.

Clicks of Recognition: How Do We Interpret What Is Out There to Know and Do?

We undertook two research moves in this chapter, namely an examination of the d/Discourse that is currently available at our university to take up about diversity and second a poststructural reading of that discourse. The first move was to examine four statements about stakeholder ideas of diversity and disability. Given that diversity as a subject of study is fast becoming important to educators, we wanted to know more about what that topic of study actually is and our roles in perpetuating good and bad practice. We were keen to learn what the third year course may entail and whether or not the first year course met the aims and objectives dear to stakeholders. As the world moves from monocultural and monolingual understandings of talk and text we feel our work is timely. We exist at an important time in this process. As a body of knowledge, diversity and disability studies as disciplines of study are now being talked into being. It is incumbent upon advocates in this area to be aware of the language, tools, and affordances we, and others, talk into existence.

Theme One: Power Imbalances

A review of the d/Discourse that is available to take up about diversity and disability studies at one university shows that the topic has been packaged into discrete 2 X 13 week chunks of instruction with aims and goals specified. These 13-week chunks occur across all degree programs in education and in both the first and third years of study. This chunking and specification of course parameters is of course understandable, as universities do have to control the product they provide. We would argue though, that in this process, we suspect that we have lost some quality and some hope of equality. We must be able to ensure widening participation of heretofore-neglected groups at university and in our schools. We cannot know exactly what the individuals who initially wrote the goals of our diversity courses had in mind when they devised these courses, but we do know that the process of designing the original courses was egalitarian, democratic, group oriented, and inclusion focused.

Since that time though the courses have had several iterations and have been interfered with by powerful stakeholders. Examples of this interference include changes to degree structures to suit auditing authorities, grouping degree programs to ensure economies of scale, changing the courses from an on campus framework to a blended learning framework and so on. The spirit of the course goals as originally written has been lost and is now only resurrected if the academic teaching the courses remembers and agrees with the original process. We see this in the parents and teacher reaction to ideas of inclusion of children with autism. These individuals

show us very clearly that they talk a different language in relation to what is taught in universities and they feel frustrated and powerless that some in-service teachers are still not catering for diversity. At least three cohorts of pre-service teachers at this university have now undertaken courses on diversity, but the goal to *Demonstrate the value of skills needed to work collaboratively with students, parents/carers, fellow teachers and teacher aides, support staff and professionals external to the educational setting* seems not to be met, at least for the parents and teacher interviewed. Listening to these individuals we can now see that parents of children with autism and one of their teachers feel disenfranchised. We must now take this into account in course design.

Theme Two: Language and Expectations

We argue that the discourse of the university and the auditing authority cloak original and foundational ideas of course design within standards and regulations and we have aimed to make this process visible. Here we agree with Freebody, Maton, and Martin (2008) that there is an increasing effort to shift education in universities to the discussion of knowledge as topics such as literacy, numeracy, comprehension, motivation, *diversity,* and the consequent excision of information into parts that can be managed. Freebody, Maton, and Martin (2008) talk about epistemological constraint that is exercised as knowledge is managed into identifiable chunks of material. Accountability markers are used to

> … indicate the knowledge and processes that students will be held accountable for knowing, the salient and portable learning's potentially relevant to future classroom work or assessment, or to applications outside the classroom. These accountability markers tend to appear prior to, during, and after the elaboration/ activity phase/s of lessons and units, and consist of both emphasising moves (e.g., repetitions, pitch variations, multiple illustrations) and explicit connecting moves (e.g., *remember last week we …*). (p. 195)

Legitimation markers or codes then embody the knowledge that is important and provide the procedure by which this knowledge is imparted (Freebody, Maton, & Martin, p. 193). Our interest has been in this area, as we have wanted to know what matters and what counts to each individual stakeholder. What we find important then is how we manage code clashes and code shifts that emanate from this legitimation: this was our second research move.

Theme Three: Issue of Rights as a Means to Redirect Efforts and Create New Possibilities

A poststructural reading of the language and talk of diversity provided our second research move. Using poststructuralism we have begun to make the invisible, visible and this process helps us to determine how we react to the epistemological constraints

that we have been faced with. Here we have several affordances and possibilities. Bernstein (1999) calls these affordances *horizontal knowledge structures* (1999) and Freebody, Maton, and Martin (2008) call them *intellectual agency.* The affordances we have found through the language and talk of diversity and disability studies at our university help us to talk back to power using the very talk with which we are provided. There is room to speak back to, speak with, and to speak against what is established by using the possibilities that data provide, the language that parents and teachers provide, and the learning that the academic/s responsible for each course on diversity have undertaken in consultation with others. Examples of possibilities are replete in the data and range from simply listening to all stakeholders, to using the legitimation codes as a means of activism.

For example, one of the themes in the data is the language and expectations that flow from the discourse. Here the language of the university and the auditing authority expressed as numbers provides an unexpected tool. Meeting those numbers and meeting targets provides the individual with the institutional clout to talk back to them. During the writing of this chapter, Barbara was asked to be on an "expert panel" in relation to the tools and strategies she used in this first year diversity course. She has been asked to mentor other academics in the field and to report on her progress. She has talked back to the institution's statistics in ways that are meaningful for her, but made more significant to the institution through the use of numeric results from the *SET and SEC* data that the institution understands and can recognise. Here Barbara has been subjected to power through her positioning and recognisability as the academic responsible for this first year course. She feels she has been able to surpass the limits of power assigned to her by such things as the auditing authority's idea of what a course on diversity could be. She has read objectives such as *Explain frameworks for designing and implementing effective inclusive curriculum, learning, teaching and assessment practices* to mean that she can question disability categories and question disability groupings and organisations in ways that are current and take into account all forms of diversity education from the medical model to the disability studies model. By providing her students with a space to argue, she feels she has met her task. She also recognises that she may be deluding herself and supporting a statistical calculus of her work that she does not agree with. Here is her postmodern angst and contradiction played out in very real ways.

As a practitioner of and negotiator of d/Discourses Barbara has also had to coordinate her activities and her identities and subjectivities in and out of the university. She began the dialogue that is reported on in this chapter. Her interest was never to determine which of her participants were right or wrong, but rather when and how each one's ideas could be useful and for what purpose.

The parent voice and the teacher's voice were so compelling that the possibilities opened up by the d/Discourse is that their ideas should now form part of the first and third year course. Barbara now recognises that the goal to *Demonstrate the value of skills needed to work collaboratively with students, parents/carers, fellow teachers and teacher aides, support staff and professionals external to the educational setting*

was only partially met. From now on students will hear the perspectives of these parents and the teacher as raw data and add these to a discussion about the data's meaning. We now plan to attend program evaluations and to influence "up" so that the ideas of the parents and teachers are heard. We also intend to grow the research beyond this small account.

Conclusion: Code Shifting

In this chapter we have described some of the competing tensions that existed as we sat down to write a course on diversity. We quickly became aware that these competing tensions caused a clash of codes with the legitimation codes of the university and auditing authority initially seen as the most powerful. Legitimation codes for governments and their associated policy actors derive from their legislative responsibility to enact human rights legislation. These codes currently lock governments in a human rights, quasi-medical model of diversity and disability.

Through the process of the study, however, we have discerned a subtle code shift towards the needs of all stakeholders where we have realised that we can use the themes we found in this research namely power imbalances, language and expectations, and the issue of rights as a means to redirect our efforts and to create new possibilities. We have the ability and responsibility to move thinking toward a disability studies perspective where students with diverse needs are imagined as a construct within the social, political and cultural contexts of our times. We have undertaken to continue this project despite the push of legitimizing audits and control over the nature of our work. By undertaking this study we now each have an understanding of the other that was not really present before this exercise. In conclusion we agree with Honan et al. (2000) who observed that their project was

> … a demonstration of the idea that different analytic approaches radically influence what can be found in the materials. Many more readings could be produced from them. Each analytic approach works with a different vocabulary, and each vocabulary signals the different ways in which individuals and social practice are characterized within that approach. Each of the readings that we have produced calls on different orders of evidence for its claims to adequacy. Each presents a different proposal for how to read the materials and for making sense of them. (p. 30)

We have used d/Discourse theory, poststructuralism and the ideas of Basil Bernstein and Freebody, Maton, and Martin to observe what we do. There is more possibility opened to us now and the process has helped us see where we can further act and interact to increase our positioning as equally legitimate so that students with disabilities, in this case students with autism, have a fair and equal access to and

engagement with our education systems. At the least, and for our next project, we will audiotape the discussion!

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GILL RUTHERFORD, LEIGH HALE AND DENISE POWELL

9. 'WE PUT IN A FEW RAMPS IN HERE AND THERE, THAT'S ABOUT IT'

The Need to Ramp Our Minds in Academia

INTRODUCTION

Concern about the lack of recognition of disability matters, other than putting "a few ramps in here and there," prompted the pilot study outlined in this chapter. As academics working in different university divisions and disciplines, we share a desire to move beyond mere ramping of the physical environment, to investigate means of enhancing the university's responsiveness to disability matters in its teaching, research, policy and administrative roles. While appreciative of the contribution of a growing body of research literature regarding disabled students' experiences of higher education, we wanted to explore disability matters from a different perspective; specifically, to examine the role of lecturers in promoting student and staff awareness and understanding of disability as a natural part of being human, within a context of human rights.

Why does this matter? Consider the following statements made by undergraduate students over the last two years:

> Of course you'd terminate a pregnancy if test results indicated Down syndrome – why wouldn't you? (bioethics student, following a seminar on genetic screening)

> Those kids are not my problem. (student teacher, at the conclusion of an Inclusive Education lecture)

> Yeah, we use the word *retarded* all the time with our mates – I probably wouldn't say it in front of someone who was, though. (student teacher after watching a film clip about the offensive nature of the "R" word)

While anecdotal in nature, these quotes are consistent with the findings of a pilot study conducted by Rutherford (2013), which examined first year student teachers' knowledge of disability. The 22 participants' responses to a survey revealed that the majority interpreted disability in deficit terms, as an individual 'problem' that required various kinds of 'special' 'help.' These students' pathological (mis)interpretations of

disability, which are confined to the "boundaries of treatment, torment, and troubles" (Ware, 2011, p. 249), reflect the hegemony of normalcy (Madriaga, Hanson, Kay, & Walker, 2011) and the construction of disability as a human aberration. Interpreting disability in this way legitimizes eugenic thinking and practice, as claimed by Madriaga et al.: "The eugenicist legacy of the past century is (re)produced, taken for granted, left hidden and unmarked today in notions of meritocracy, inclusion and widening participation" (p. 901). Such thinking exacerbates the likelihood that any deficit interpretations of disability remain undisturbed (or even realized) as students move from their first year through to graduation and beyond (Myers, 2009; Osei-Kofi, Shahjahan, & Patton, 2010). That 'value added' graduates leave university armed with a qualification that gives them power within society, unaware of current thinking about disability as an inherent aspect of being human and as a human rights' issue, is problematic. It is therefore imperative that students are prepared to think critically and thoughtfully, to question and change, rather than reproduce, the inequitable status quo, and to work in ways that respect rather than diminish our shared humanity.

As "the ultimate arbiters of what counts for meaningful knowledge" (Barnes, 2007, p. 139), universities play a critical role as "seedbeds for tomorrow's politicians and policy-makers" (Barnes, 2007, p. 141). This means that current thinking and knowledge regarding disability, which offer a rights-based and dignified view of difference (Barton, 2003), unburdened by the pessimism that shadows the lives of many disabled people, need to be explicitly embedded throughout university degree programmes (Barnes, 2007; Myers, 2009), rather than omitted or considered as "an afterthought" (Myers, 2009, p. 16). Hence the rationale for this pilot study, which explores the disability related experiences and teaching practices of a group of lecturers within a New Zealand university.

As a means of contextualizing the study, the chapter begins with a consideration of the overarching purpose of universities in general. This is followed by an outline of our research questions and methodology, prior to presentation of the four key themes that constitute the study findings. The final part of the chapter provides a discussion of findings in relation to extant literature, and a consideration of the implications of the study for the development of further research, policy and practice.

THE UNIVERSITY CONTEXT: CRITIC AND CONSCIENCE OF SOCIETY AND/OR BASTION OF PRIVILEGE AND POWER?

Education is not … a mirror of social or cultural inequalities. That is all too still an image. Education systems are busy institutions. They are vibrantly involved in the production of social hierarchies. They select and exclude their own clients; they expand credentialed labour markets; they produce and disseminate particular kinds of knowledge to particular users. (Connell, 1993, p. 27)

The purpose of universities has been described by Slee (2010, p. 562) as an "indivisible trilogy" of teaching, scholarship, and activism/service. Situated in a neoliberal economic context in which education is regarded as a private good, the corporatization and marketization of universities is evident in numerous ways, including competitive cultures of performativity (Ball, 2003), in which New Zealand academics' value is determined by the ranking of their research productivity via the Performance Based Research Fund (PBRF) process that measures individuals' 'research outputs.' The kinds of knowledge production and dissemination that are privileged tend to be those that enhance universities' status and global ranking (e.g., 'hard' sciences, including health sciences), as well as that which is aligned to commercial ventures (Barnes, 2007; Osei-Kofi et al., 2010). The focus on economic rationality and viability serves to de-value and marginalize knowledge that is not of economic/commercial benefit, and/or is regarded as a challenge to or irrelevant to hegemonic ways of knowing, and/or is regarded as a drain or burden on university resources (Osei-Kofi et al., 2010). The present dismantling of teacher education in New Zealand is but one example of market forces at work within the academy. Given the critical role that teachers play in 'producing' future university students, the diminishing of this field of scholarship is particularly ironic.

The privileging of neoliberal assumptions within academia also has an impact on the kinds of students who are considered desirable and eligible for higher education. Traditionally those with the right kind of cultural and social capital have been successful in gaining entry to the ivory tower, thus perpetuating the reproduction of privilege, normalcy and inequity (Madriaga et al., 2011). While there is now increasing recognition of under-represented groups, students who have impairments are relative newcomers, whose presence and achievement in universities is questioned by some academic elitists (Madriaga et al., 2011). Comments made by highly educated senior academic staff in a prestigious US university, "Learning disability? Well they're dumb. Why are we letting them in?" (Luna, 2009, p. 170), unambiguously reflect deficit assumptions and the workings of a pathological epistemology, which legitimizes the exclusion of particular students on the basis of their perceived deviance from the 'norm.' In a national context, it is worth noting that in a recent article, *Who is missing from higher education in New Zealand?* (Strathdee & Engler, 2012), disabled students are missing from the study. Obviously, the lack of representation of disabled students has an impact on the likelihood of increasing numbers of disabled academics, and on the possibility of such students and staff incorporating disability issues as an inherent part of degree programmes and postgraduate research ventures (as has been the case with other marginalized groups of people, such as those representing Māori and Pacific cultures).

Within such a context, it can be argued that the role of universities as critic and conscience is compromised. As Paul Gibson, New Zealand's inaugural Disability Rights Commissioner, asked in a University of Otago memorial lecture entitled *Te mana o uenuku: The critic and conscience of an increasingly diverse society*

(29 May, 2014), "can a modern university claim to be a critic and conscience of society if it doesn't reflect that diversity? Who currently is under-represented or not represented?" Given that at an individual level, one in four people are touched by disability at any particular time (Statistics New Zealand, 2014), and that all of us will experience impairment at some point in our lives, understanding disability is central to understanding what it is to be human (Taylor, 2011). Recognizing disability as "a valid human identity" (Davis, 2011, p. 3), and "humanizing disability both in and out of the [university] classroom" (Myers, 2009, p. 19) is necessary for the fair representation of human diversity. At a societal level, in response to the discrimination and oppression experienced by disabled people, there are numerous covenants, laws, and policy documents that safeguard the humanity and rights of all citizens (e.g., Human Rights Act, 1993; Kia Ōrite [Achieve, 2004]; New Zealand Disability Strategy [Minister of Disability Issues, 2001]; United Nations Convention for the Rights of Persons with Disabilities [UNCRPD], 2006). However, the continuing absence and/or invisibility of disabled people and disability matters within academia do not appear to have troubled the conscience nor stirred the critic of many universities. Issues of equity and social justice, although proclaimed in university mission statements and strategic plans, still tend to be empty promises, "untroubled frontiers" that "remain largely at a surface level" (Osei-Kofi et al., 2010, p. 337).

THE STUDY

Concern about the overall lack of disability matters within the university provoked this pilot study, which sought:

1. To understand and describe identified good teaching practice that raises the awareness of disability in general;
2. To provide recommendations of how teaching and learning activities could be improved to enhance awareness of disability issues via both content and accessible delivery.

A mixed methods research design (Creswell & Plano Clark, 2011) was utilised to develop and carry out the study. Described as the "third methodological movement" (Creswell & Plano Clark, 2011, p. 1), following quantitative and qualitative research orientations, definitions of mixed methods research continue to evolve. The essence of such inquiry however is that drawing from both quantitative and qualitative approaches within a study results in a richer understanding of a question or topic than the use of only one approach, as the 'mixing' of different sources of data provides "multiple ways of seeing" (Creswell & Plano Clark, 2011, p. 4, citing Greene, 2007, p. 20). Mixed methods research is effectively used in interdisciplinary studies such as this project, in which we bring our particular philosophical beliefs, from Physiotherapy and Education respectively, to shape the design, implementation and interpretation of our focus of inquiry (Creswell & Plano Clark, 2011).

We chose to use a sequential mixed methods procedure (Creswell & Plano Clark, 2011) in order to understand the complexities of lecturers' perspectives and teaching practices regarding disability matters. Quantitative (questionnaire) and qualitative (semi-structured interviews and focus groups) methods were used to generate a breadth and depth of understanding of participants' experiences, with the emphasis placed on the qualitative component (Morse & Niehaus, 2009). Ethical approval was granted by the university's Human Ethics Committee, and ethical requirements were carefully adhered to throughout the study.

The pilot project consisted of three phases. Phase one involved the establishment of an advisory focus group, consisting of 15 people, representing academic staff, general staff, and students. Members of this group were selected on the basis of their interest and involvement in disability issues within the university. The focus group met once for approximately 90 minutes to discuss what constitutes 'good inclusive teaching practice' at the university, and assisted us to identify people and/or departments that demonstrated commitment to such practice.

In Phase two, individuals recommended by the advisory group were recruited into the study by the university's Higher Education Development Centre administrative staff, who were not involved in the research. The recruitment process resulted in a purposive sample of twelve academic staff members (8 female and 4 male, aged 40–65 years), who were known to be inclusive in their respective teaching practices. Participants had been working as academics (as Teaching Fellows, Senior Lecturers, or Associate Professors) for varying lengths of time (from one year to over forty years), in one of the four university divisions (Health Sciences, Sciences, Humanities and Commerce). Collectively these individuals taught across a range of levels, from first year undergraduate to post-graduate, with class sizes varying from 10–500 students, using a range of teaching modes, from face-to-face lectures, tutorials and practical laboratory-based teaching to clinical supervision and distance teaching. None of them had been involved in any form of professional development regarding inclusive teaching practices and/or disability matters.

Each participant completed a short questionnaire that focused on relevant demographic information, teaching experience, and opinions regarding teaching, prior to taking part in individual semi-structured interviews, which ranged from approximately 30 to 90 minutes in length. Guiding questions focused on participants' teaching philosophy, their experiences and understanding of disability, how they incorporated disability matters into their teaching and course content, and examples of specific strategies/resources that were effective in facilitating students' awareness and understanding of disability issues. Further data were generated through the review of course documents provided by some participants, and, where feasible, through observations of lectures given by participants.

The advisory focus group discussion and individual interviews were audio recorded and then transcribed by a professional transcription service. The quantitative data were summarised and used to provide context to the qualitative findings. Data were analysed using thematic analysis (Braun & Clarke, 2006), which comprised

an iterative cycle in which the research team, after reading all of the transcripts, engaged in discussion and debate to develop coding frameworks. NVivo software was utilised as a tool to refine coding until final consensus was reached on key themes and supporting quotes. The analysis was presented to and discussed in a focus group of three members of the study's advisory group. This served to both verify and more deeply understand the data and the analysis. In Phase 3, findings will be shared with university staff in a half day workshop.

THE STUDY FINDINGS

This paper focuses on the findings from the individual interviews. Initial analysis of the qualitative interviews generated four key themes:

1. The fundamental importance of lecturers' values and beliefs in underpinning 'good' teaching for all students;
2. Specific teaching and learning practices that facilitate student engagement and learning;
3. Barriers to including disability matters as an integral component of university studies;
4. Possible ways of addressing these issues.

1. The fundamental importance of lecturers' values and beliefs in underpinning 'good' teaching for all students

> I can't understand the perspective that you wouldn't teach to everybody – why would you choose certain subsets? (Participant 3, Health Sciences)

In the analysis of interview data, the significance of participants' values and beliefs as determining influences on their teaching practices was particularly evident. The primacy of values, a sense of fairness, respect for people, and willingness to do the right thing were clearly conveyed. For example, when discussing her concern about the extent to which society is disabling, Participant 6 (Sciences) emphasized "not wanting to be part of that disabling – I want to be on the other side." Participant 5 (Humanities) stated that "over the years, my philosophy would be to be as inclusive as it's possible to be in a classroom, with the understanding that everybody has ability of some sort, and that everyone should be valued for what they bring." Another explained:

> They [students] all paid for the same price of admission. They all buy the same ticket, so they're all in; they're all entitled to have, you know, their money's worth for their ticket. You know, I would turn it around and say, why wouldn't you cater for [all students]? And I'm being paid by the taxpayer to deliver something for the benefit of the individuals that are here, which in theory is supposed to benefit society. You can't walk away from that. You can't just choose – I'm going to teach to the 70% and the other 30% can go… That's like

saying I'm only going to take 70% of my salary because I'm only working for 70% of the paying clients. … For me it's a no brainer. I can't understand the perspective that you wouldn't teach to everybody – why would you choose certain subsets? (Participant 3, Health Sciences)

Also of significance were honesty, care and acknowledgement of the complexity and vulnerability of teaching, as noted by Participant 2 (Humanities):

I guess that's probably the thing that is most typical of my teaching – that I'm very aware of vulnerability and expressing it and recognizing it in myself and others… recognizing that we are all capable of wounding and of being wounded – that's about being human.

Having genuine enthusiasm for one's subject and sharing this with students, to foster meaningful long-term learning, was emphasized by Participant 1 (Sciences):

I suppose if there were two things [about teaching] it's trying to sort of be passionate about it, but also trying to show students why it's important for them to know it, beyond just being able to answer the exam question – to actually be something they carry with them, rather than, 'well, I've done that now.'

Openness to learning and new possibilities was evident in the observation by a lecturer who had little experience of disability:

This [participating in this project] in itself was really good, because it's made me think about [disability], and how I should incorporate it into my teaching more, so that's good in itself. I do a little bit, but it made me realize I want to incorporate it more, because I think it's an important part of what we should be teaching. (Participant 9, Commerce)

Another participant echoed these sentiments, in realizing that discussions of diversity could be expanded beyond ethnicity. She noted, "Now that I think about it, this is a real opportunity for opening up questions around ability as well." (Participant 8, Humanities)

That values figured so explicitly in all of the interviews with participants is heartening. As Booth (2011, p. 308) states, "values are fundamental guides and prompts to action. … To act responsibly in education we have to relate what we do to our values." The strong sense of values and beliefs underpinning participants' teaching can be considered in relation to Shulman's (2004) conceptualization of professional learning. He proposes that the education of individuals who are aspiring professionals (e.g., in law, medicine, teaching and so on) involves the interaction of three apprenticeships, relating to the heart, the head and the hand. The apprenticeship of the head focuses on the specific knowledge that forms the theoretical basis of a profession, while the apprenticeship of the hand refers to particular practical and technical skills required

in a given profession. Underpinning both is the apprenticeship of the heart, involving the professional and personal values, beliefs, ethical and moral dimensions that are central to each profession. While knowledge and skills are critical, what we know and do is determined by and reflects what we value.

2. *Specific teaching and learning practices that facilitate student engagement and learning*

> So I suppose it's trying to be everything to everybody – trying to be all things to all people all at once. … teaching everybody one at a time. (Participant 3, Health Sciences)

It is interesting to note that, while the purpose of the study was to understand and describe teaching practices that facilitated awareness of disability matters, few lecturers were incorporating disability issues in explicit ways in their teaching in various disciplines. Instead, the focus of much discussion was on 'good teaching' practices, which were underpinned by a commitment to teaching all students well. The need to utilize a diverse range of inclusive and interactive teaching strategies and resources to 'reach and teach' all students is illustrated in the following account:

> My philosophy in what I do is to try to find a way. … acknowledge that there are a range of motivations and to try to tap into all of those in what I'm doing. … to structure what I'm doing in a variety of different ways to at least partially tap into whatever, however any/everybody approaches that situation. … I still try to teach it like I'm teaching individuals, everybody individually … by delivering a point in multiple different ways – so trying to hit everybody with the same point, but hit in five different ways and hopefully one of them will resonate with [students]. … So I suppose it's trying to be everything to everybody – trying to be all things to all people all at once. … teaching everybody one at a time. (Participant 3, Health Sciences)

Similarly, Participant 6 (Sciences) emphasised the importance of getting to know students (whenever feasible, such as in smaller classes and workshops), and to incorporate a range of activities and resources that were responsive to individuals' unique ways of learning.

Meaningful participation within a safe and positive environment was emphasized, as was incorporating disability related material in a matter of fact way throughout a course, to encourage students to regard this facet of difference as a natural part of the human condition:

> I always try to make it very safe, and to say, 'you know, you may not have thought about this, but I wanted to talk about this… Or you may find this quite strange, I'm talking about this. … I just sneak it [disability related readings] in there you know, like it's just in there and then someone says, 'oh wow!'… I think things are most powerful politically if they're introduced without a

quibble and any sense that this is dramatic, that it is liberatory, it's just got to be everyday ordinary business. … It's also opening people's eyes to this wide variety of what is normal humanness. (Participant 2, Humanities)

Several participants spoke of challenging students to 'think outside the box,' or, in Participant 8's (Humanities) words, "thinking beyond what's habitual and normative. We want them to think, to not assume the normative all the time. … you're always thinking critically about the ordinary assumptions." Similarly, Participant 9 (Commerce) commented, "If I can influence just one or two people to think slightly differently and do something different, then…that's one of the reasons why I like teaching." Providing opportunities for students to engage with disabled people, as experts whose experiences and ways of knowing were privileged over or alongside 'professional' knowledge, was a strategy that Participant 12 (Health Sciences) found powerful in interrupting or troubling deficit assumptions that may underpin students' developing practice as future health professionals. As well, she drew extensively on "real life examples" to inform students' understandings of the diversity of people they would serve in their future careers.

The importance of ako, a Māori term that signifies reciprocity of teaching and learning, was identified as central to Participant 6's (Sciences) teaching philosophy: "I love the idea that as a teacher, I am continuously learning from my students and from the professional practice that I do." While "trying to give some of my knowledge to the students," this participant genuinely valued what students had to teach her, and made a point of listening and being open to their suggestions. Having high expectations in terms of both excellence and equity, and being responsive to and respectful of students were also highlighted. As Participant 1 (Sciences) remarked in reference to teaching in lab contexts, "we would move heaven and earth for people if they tell us [something's] an issue." In a similar vein, Participant 9 (Commerce) explained:

It's finding ways to allow students to learn, in the best environment they can, recognizing the constraints within a university environment. … I'm always trying to look for new ways to incorporate [effective teaching strategies] … If students bring things up because they're having difficulty or whatever, then we'll try and change things around… It's also about making things enjoyable.

Participants' accounts of their teaching practices reflect what Florian and Linklater (2010) describe as 'inclusive pedagogy,' that which "focuses on extending what is ordinarily available as part of the routine of classroom life as a way of responding to differences between learners rather than specifically individualizing for some" (p. 370). Whether or not these lecturers had disabled students in their lectures and classes, they were committed to teaching in ways that were responsive to the natural diversity of students – making a concerted effort to teach "everybody one at a time."

3. *Barriers to including disability matters as an integral component of university studies*

There are huge gaps in our programme in terms of recognizing diversity – human diversity, everything … we don't have those other voices. (Participant 3, Health Sciences)

Despite the dearth of examples of how disability related content was embedded in lecturers' papers, participants recognized the need to do so, and offered insightful consideration of barriers to the inclusion of disability as an integral aspect of university curricula across disciplines and divisions.

Numerous structural constraints were identified, one of the most common being time. Competing demands for time were noted by Participant 8 (Humanities), when discussing her interest in learning more about disability issues. She explained "it [disability related workshop] goes on my list of a hundred workshops I should go to. For me, I've sort of ruled a line under workshops, partly because they're always on in a morning and you think, 'well, that could be my research morning.'" In jest (or not?), it was suggested that including a reference to 'PBRF' could increase attendance at such workshops. The pressures of performativity (Ball, 2003) are also noted by Barnes (2007, p. 141), who observes that "the combination of heightened teaching, research and administrative responsibilities in most universities and colleges means that, all too often, academics and researchers have little time to be actively involved in 'non-academic' activities." These include involvement in 'extra' activities such as learning about disability matters, which are generally perceived as being the purview of the 'Disability Office.'

Comments were also made by numerous participants regarding the crowded curriculum and the lack of time to address subjects in depth; lack of funding for guest lecturers (e.g., disabled guest lecturers); 'one size fits all' mass lecture delivery; and huge classes – concerns that are often problematic in the teaching of many undergraduate university papers. Physical accessibility, besides "a few ramps here and there," was raised as an issue in terms of getting in and out of buildings; once 'in,' poorly designed teaching spaces posed further restrictions. As well, limited web accessibility was identified as a significant concern. The sense of frustration with structural constraints is well summarized by Participant 6 (Sciences) in her observation, "You know there's only so much you can do. But it is frustrating you know, because when it's your passion, you want to [do justice to incorporating disability within the curriculum]."

While perhaps less visible and tangible than structural limitations, attitudinal barriers play a powerful role in limiting both disabled students' educational opportunities and access to knowledge of disability matters, whether by acts of commission or omission. The notion of having to do 'extra' for certain students (e.g., adapting teaching and learning resources) is conveyed in Participant 1's (Sciences) opinion, that "I'm not sure that I would get much support from the rest of the teaching staff to overtly do stuff in lectures for what would be perceived to

be a vanishingly small percentage." Interestingly, another lecturer reframed such responses by describing his experience: "I changed for the one and it improved the three hundred" (Participant 3, Health Sciences), which suggests that his teaching practice was underpinned by quite different values and beliefs.

Several lecturers attributed the absence of disability matters in paper content to a lack of thinking about disability in general. As Participant 3 (Health Sciences) remarked, "A part of it is, you don't know what you don't know." When describing the organization of a class field trip that was accessible for all students, Participant 9 (Commerce) observed, "I don't think people are deliberate in [leaving disabled students out of curricular activities], *they just hadn't thought…*" When discussing the incorporation of disability issues within particular papers, some participants expressed a sense of willingness, mitigated by a fear of not knowing/not getting it 'right.' According to Participant 10 (Health Sciences), "I think, sometimes, people's inability to even start that conversation is the fear of offending."

Issues of language were also raised as significant in perpetuating or challenging deficit and stereotypical thinking. Participant 2 (Humanities) noted, "I try to use language about 'stigmatized' groups that they themselves find appropriate. … I'm particularly mindful when I use the word 'we' in class that I never say that without saying, 'whoever we might be.'" Providing students with opportunities to reflect on their knowledge of disability, as a means of interrupting deficit ways of knowing, was regarded as important for Participant 10 (Health Sciences), who described "Getting people to explore the use of language, and it's not about being PC [politically correct], but it's about trying to tap into their established attitudes and where those messages come from." As Beauchamp-Pryor (2012, p. 291) claims, "The issue of language is important: definitions are powerful and have the power to transmit dominant values held within society."

The role and power of the university in society was raised by Participant 3 (Health Sciences), whose remarks convey his beliefs about the organizational and individual ethical obligations associated with academic life:

Thinking about the place of a university in society … some aspects of the university are training professionals. So you've got a duty of care, responsibility and excellence, because those professionals are going out and serving the population, again, that are paying for us to do this. You know, I don't want students coming from [university] ending up on the front page of [the local newspaper] because they've done harm to society, because we haven't done something properly – that's our contract with society.

What else do you get by coming to university? You get all of that stuff that we talk about in terms of critical thinking, analysis, robustness, and I suppose from my perspective, not everybody needs to be a brain surgeon – but wouldn't it be good if everybody in society had a really well tuned bullshit meter? … If people have got either the good fortune or the luxury of coming here, then we should be sending them out as, I hate to use the word 'better citizens' because

that's a value judgment, but at least better equipped citizens than they were
when they came in – with a set of tools that they didn't have when they arrived.
… So we need to structure our teaching to make sure they have that. To not
spend too much time on content, because that's everywhere. To spend time on
all of those things that allow you to tune your bullshit meter. … We need to be
conscious that there is more to this place than academic. … We're charged with
stewardship and I don't think we should back away from that.

While there are various ways of interpreting these comments, the notion of
the university having a duty of care, a contract with society, and stewardship is
consistent with the argument that students must be equipped with the kinds of current
knowledge, skills and beliefs that will enable them, upon graduation, to serve people
who represent the diversity of humanity, in equitable and ethical ways.

4. Possible ways of addressing these issues

To fail to challenge the ways in which our higher education system is implicated
in social and economic inequity is to hand over higher education to the interests
of the powerful at the expense of the many. (Osei-Kofi et al., 2010, p. 336)

Participants expressed enthusiastic willingness to contribute to the process of
change necessary to center rather than continue to marginalize understandings of
disability within academic studies across the university. Like participants in Myers'
(2009) study, they emphasized the need for "disability education that moves beyond
a limitations mentality and toward humanizing disability both in and out of the
classroom" (p. 19).

Practical strategies for developing academic staff's understanding of current
disability theorizing, research and practice included both mandatory and informal
learning opportunities. Incorporating disability matters as a required component of
the induction of new staff, and of ongoing Professional Learning and Development
initiatives (as is required/expected in respecting Māori tikanga/culture) were
suggested as possible ways of reaching all staff. Including a requirement in
university departmental reviews that every department needs to show that 5% (for
example) of programme/paper content is devoted to 'alternative world perspectives'
would also enhance awareness and (hopefully interest) in disability issues. Including
questions about disability related content and teaching in student course evaluations
was identified as another possible way of drawing attention to the importance of
disability matters within higher education. Informal learning opportunities were
also suggested, such as incorporating a disability/diversity focus within a general
series of university wide seminars, and offering brief, focused visits to departmental
staff meetings (described by one participant as "back of the truck sessions" – short,
focused, and specifically tailored to each department and discipline).

As well as the above initiatives, several participants advocated for the
development of papers and a degree option that focus on Disability Studies, an inter-
and multi-disciplinary field of scholarly inquiry that privileges disabled people's

perspectives, experiences and ways of knowing within a social justice framework. Interpreting disability as a social construction that elicits a range of cultural, social, political, legal and other responses, Disability Studies has widespread relevance for cross-divisional teaching and multi-disciplinary research, and is well established internationally in numerous universities (Taylor, 2011). The ultimate goal, suggested by some participants, would be to establish a Centre for Disability Studies as a multi-disciplinary forum for collaborative teaching and research ventures.

How such change is driven, whether by a mandatory (top down) and/or via a 'hearts and minds' (by interested staff, described by one participant as 'champions') approach, is yet to be determined, yet it is likely that both are necessary to realize the magnitude of such a shift in thinking, values, structures and practices. It is worth noting the experiences of Osei-Kofi et al. (2010, p. 336) in their attempts to create a social justice concentration in a graduate program:

> The process of developing the concentration speaks clearly to the ways in which what should be institutional agendas are in reality more often championed and carried forward by small groups of individuals with deep personal commitments to institutional and social change work, rather than institutional actors with formal responsibilities for creating change.

Whatever and however change is sought, according to Participant 3, "somebody just needs to do the bloody thing."

BEYOND JUST A FEW RAMPS…

> We believe we must continue to strive to center subjugated knowledges in the academy, to honor different ways of knowing, and to work for progressive social change by engaging in projects that create an academy that is truly inclusive. (Osei-Kofi et al., 2010, p. 326)

The experiences of participants in this pilot study suggest that 'higher' education, as in other education sectors, tends to reproduce rather than transform the status quo and hegemony of normalcy (Liasidou, 2014), in which certain kinds of human beings and certain kinds of knowledge are valued, at the expense and exclusion of others (Liasidou, 2014; Patton, Shahjahan, & Osei-Kofi, 2010; Scanlan, 2012). While it is heartening to witness the increasing recognition, representation and presence of 'minority' groups in terms of students, staff and fields of scholarly inquiry within academia (e.g., Indigenous Studies, Māori Studies, Pasifika Studies, Women's Studies, Queer Studies), disability – if even mentioned in diversity discourses (Davis, 2011; Myers, 2009) – still tends to be constructed "mono-dimensionally" (Liasidou, 2014, p. 123) in terms of abnormality and individuals' 'needs' (Beauchamp-Pryor, 2012; Davis, 2011; Liasidou, 2014; Runswick-Cole & Hodge, 2009) rather than rights. Indeed, Davis (2011) suggests, "If diversity celebrates empowerment, disability seems to be the poster student for disempowerment" (p. 2).

In discussion with participants, it was evident that questions about disability matters in the university context typically elicited responses that focused primarily on the 'Disability Office' – that this administrative service was responsible for 'disability.' These reductionist assumptions are consistent with those documented in international literature (e.g., Liasidou, 2014; van Jaarsveldt & Ndeya-Ndereya, 2015), in which, with the exception of universities that have established Disability Studies initiatives (e.g., Taylor, 2011), 'disability' is primarily about the provision of support services in a kind of compensatory response to disabled students' *needs*, rather than recognition of the latter's human and educational *rights* (Beauchamp-Pryor, 2012; Liasidou, 2014). It appears that, to varying degrees, the hegemony of 'special education' ideology and practice remains unquestioned in higher education. Indeed, it could be argued that disability support services act as the university equivalent of 'special ed departments,' with their support personnel carrying out the role of teacher aides, thereby absolving academics of their responsibilities to teach *all* students.

Clearly, the continued marginalization of disabled students and ways of knowing about disability is inequitable and must be addressed if universities are to authentically honour their commitment to act as a critic and conscience of an increasingly diverse society. According to Liasidou (2014, p. 130):

> It is imperative to enhance staff members' as well as non-disabled students' understandings of the complex nature of disability experience and the needs of disabled individuals to create positive attitudes and to enhance disability awareness in terms of disabled people's rights and entitlements as these are stipulated in international laws and conventions. This kind of education should be provided on a compulsory and systematic basis…

Individual staff and the institution as an entity need to be held accountable in terms of recognizing and implementing their international, national and institutional legal and policy obligations (e.g., university values, strategic plans, codes of conduct) (Beauchamp-Pryor, 2012; Bessant, 2012; Liasidou, 2014; van Jaarsveldt & Ndeya-Ndereya, 2015). Working in a proactive manner to inform all university staff and students about these responsibilities – and facilitate their enactment – is not only the right thing to do, but, from a pragmatic perspective, also diminishes the risk of having to react to potential charges of institutional discrimination. The suggestions offered by participants in this study (see *Possible ways of addressing these issues*) are worth considering as a starting place for change. Similar and additional strategies are outlined by van Jaarsveldt and Ndeya-Ndereya, who advocate for staff professional development that focuses on both (a) knowledge and skills to support lecturers' development of confidence and competence in addressing disability matters, and (b) understanding of reflexive practice. They argue that attention to the latter is critical in revealing and constructively processing discriminatory assumptions and attitudes that serve as powerful barriers to respectful understanding of disability issues.

Thoughtful consideration of the kinds of knowledge produced and disseminated via research and teaching activities is also critical, given the tremendous power held by universities in reproducing or disrupting and transforming inequities in society (Osei-Kofi et al., 2010). The concept of "epistemological equity" (Gale & Tranter, 2011, p. 42) is useful in that it challenges the privileging of dominant ways of knowing over others that are marginalized (e.g., interpreting disability in terms of abnormality and deficit rather than natural human diversity and human rights). Similarly, Scanlan (2012, p. 1069) advocates for "epistemological pluralism" (attributed to Capper, 2001), which involves coming to know and learn through critical engagement with multiple perspectives, including narratives as well as formal academic publications. In drawing from a range of disciplines and perspectives, Disability Studies may be considered as an example of epistemological pluralism, and has much to offer in facilitating understanding of disability within higher education. It would also be useful for university leaders to develop "epistemological literacy," to enable them "to critically analyze epistemological underpinnings to personal and institutional practices" (Scanlan, 2012, p. 1083).

The findings of this pilot study provide a New Zealand perspective regarding the role of lecturers in one university in promoting student and staff awareness and understanding of disability matters. We hope that this chapter makes a modest contribution to the growing body of international research that illuminates the need to recognize, rethink, and respond respectfully to disability issues in academia. It is evident that much needs to be done within this university context to move beyond mere physical inclusion of an albeit growing minority of disabled students. A participant's observation, that "we put a few ramps in here and there, that's about it" appears to reflect progress to date in sanctioning the inclusion of disability matters as a natural aspect of university life. While attending to material structural barriers is a start, the ramping of minds, in terms of imagining and thinking otherwise about disability, presents a much greater challenge. This seems particularly ironic in an institution that has as its core work the creation, legitimation and dissemination of knowledge. It is however understandable in an era in which neo-liberal capitalistic values, the corporatization and performativity of higher education, and profit-generating knowledges are privileged.

In an article focusing on initiatives to incorporate disability education within British medical schools, a Health Council cautions, "If we, the present generation, fail to teach the next generation more about disability equality, we will leave a terrible legacy behind us" (Pritchard, 2006, p. 402). Evidence of such a legacy was presented at the start of this chapter. The bioethics' student whose comment was cited had assumed, without hesitation or question, that the presence of Down syndrome legitimated the termination of a pregnancy. Students' lack of exposure to current and different ways of knowing and understanding the lives of individuals who have this particular (or any) syndrome, and apparent lack of knowledge of human rights and ethical considerations, have profoundly troubling implications for individuals, families/whānau, and society. We need to ensure that upcoming generations of

students, whose own futures are lit with the promise of contribution and leadership in society, leave university with the capacity to at least question deficit assumptions about individuals' humanity. Better still, we need to ensure that students leave, in Participant 3's words, "better equipped citizens than they were when they came in," prepared to use their values, beliefs, knowledge and skills wisely, for the good of others, irrespective and respectful of their human differences.

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PART 3

FAMILY & COMMUNITY

RUTH CORNELL

10. A MOTHER CAUGHT IN TWO WORLDS

An Autoethnographic Account of a Mother's Mindset and Perception
When Teaching Her Son with Asperger's Syndrome to Drive

INTRODUCTION

I will never forget the look on my son's face after his driving test. As he walked through the back door, his expression was glazed and unemotional. He was giving nothing away, but my maternal instinct told me that he looked too calm. Heart full of anticipation, I asked him:

How did you go?

Teaching a child to drive is a stressful time for any parent. It requires 'considerable patience, empathy, and the knowledge of what is needed to best prepare [them] to become a skilled, responsible driver' (Carleton, 2014). Many parents approach the task with 'nervous or apprehensive' feelings (Hagon, 2011). My experience, however, was complicated because my son has Asperger's syndrome. The journey that we embarked on together made me question how I fit into this world as a mother, and particularly as a mother assisting her child to transition to adulthood. It made me want to challenge my own and other people's assumptions about Asperger's and most importantly to explore my interpersonal and emotional life to deepen my connection with my son.

> Autoethnography requires that we observe ourselves observing, that we interrogate what we think and believe, and that we challenge our own assumptions, asking over and over if we have penetrated as many layers of our own defences, fears and in securities as our project requires. (Jones, Adams, & Ellis, 2013, p. 10)

In order to achieve these aims, I needed to understand and reflect on myself as a mother, both critically and lovingly. I chose autoethnography because I am interested in the connection between the personal ("auto") and cultural ("ethno"). Jones, Adams, and Ellis (2013, p. 34) have suggested that, 'centering the work inside personal experience, autoethnographers not only have an investment in the experience they study but can also articulate aspects of cultural life traditional research methods leave out or cannot access.' Scientific data does not interpret a

person's thoughts or feelings. As an autoethnographer, I must focus on the lived experience.

Ultimately, I wanted to promote cultural change with respect to Asperger's syndrome and at the same time challenge my own assumptions by peeling back the layers of maternal fear and uncertainty.

Quinn and Rosenthal (2012) suggest that it is perception itself and its changeability that enables new knowledge to be formed. For Gray, Young, and Waytz (2012), perception is flexible: that is, it is possible to change a person's view of the world. Dizen and Berenbaum (2011, p. 115) hold that 'the way people attach meaning and significance to events and situations is via their perceptions of what the events mean for their sense of self'. Once meaning and significance are perceived, an emotion develops. Perception is closely linked to mindset or 'mental attitude', as perception is dependent on whether a person is willing to alter how they respond and interpret situations at any given time to produce a particular outcome.

According to Carol Dweck (2006), a 'growth mindset' is based on a belief that your 'basic qualities are ideas you can cultivate through your effort'. A growth mindset enables one to become open to knowledge and to learn from it. By understanding mindset as potentially fluid, a mother may see opportunities to change her own reactions in specific situations. A 'fixed mindset', Dweck continues, is not open to the views of others and does not take experience into account. Mindset is not as sharply divided as Dweck (2006) would have us believe, but is, rather, a blend of both growth and fixed mindset that varies along a situational spectrum of its own.

In the following pages, I examine myself as a mother teaching her son to drive. It is the story of my struggle with labels and preconceptions and the way in which I began to perceive my son differently and to develop a different mindset.

<div align="center">LABELING</div>

I felt closed in. In the Domain Tunnel there were countless cars, semi-trailers, buses, and trucks on the road. I tried to remain as calm as the sea on a beautiful day, but I could feel my palms becoming sweaty and my heart racing faster as every emotion in me bubbled up. The harder I tried, the more difficult it was to enjoy the drive. I heard myself shouting at my son:

Slow down! That car is stopping. Move into this lane!

My breathing was becoming faster and I felt sick with the thoughts racing through my head. He might not see what he needs to – what if he has an accident or a meltdown? The image of the calm sea began to dissolve as I turned to look at him and noticed that he was still wearing his sunglasses. My immediate reaction was bewilderment. How on earth could he see with his sunglasses on in the dark tunnel? By now my hands were shaking and my need to control the situation intensified. I shouted:

Take your sunglasses off, you don't need them in the tunnel!

He remained focused on the road, as though I had not spoken. I felt angry at being ignored, and terrified that if he made a mistake we had nowhere to go – in the tunnel, one accident could have a domino effect. In a scared, quavering voice, I said:

Please slow down, you are going too fast.

I could see how tense his face was getting and how tight he was holding the steering wheel. A car changed lanes and I heard myself yell again:

Slow down and let him in!

By now my son's face was starting to go a little red. I asked him if he was all right and he said, "Yep," in a gruff voice, but I could see his emotions boiling up inside him like a pressure cooker. The car accelerated. I felt certain that he was going to have a meltdown right then and there in the tunnel.

I started to panic, my mind racing at one hundred miles an hour. Please don't let him have a meltdown now, I kept saying to myself. I just want to make it home in one piece! But seeing the potential for disaster, my feelings were too overwhelming; I felt like I was drowning in fear. This was the last thing I wanted for my son. I didn't want him to fail! I had always helped him to achieve his milestones, but suddenly this milestone seemed beyond reach.

I felt the car accelerate even more. Finally, we left the tunnel, only to merge onto the freeway. My son was driving faster than any other car. This was it: he was out of control and the meltdown was going to happen at any minute.

Stop the car!

He ignored me, and kept on driving and driving. After what seemed like forever, we exited the freeway. My son pulled the car over and threw it into park. Saying nothing, he jumped out of the driver's seat and began to run. I screamed after him, imploring him to come back and talk about it. But he kept running.

Not knowing what to do, I cried uncontrollably. I felt as though I had been hit by a tsunami, caused by my own emotions and expectations. I was so ashamed that I had failed my son as a mother and teacher because I was too caught up in his diagnosis. The Asperger's label had made me over-analyze the situation, and prohibited me from allowing him to show me what he could do. I felt like such a bad mother Gill and Liamputtong (2011). I should not have pushed him to this breaking point, should not have doubted his ability.

When I finally arrived home, defeated after searching for my son, he was already there. The only words he said to me were:

I can drive.

According Russell and Norwich (2012), labels devalue people. The experience in the tunnel made me think about the way that my son was stigmatized because of the

Asperger's label – not only by the wider community, but by me as well. Why was I hindering him so much? I did not want to perceive my son in this way. I wanted to perceive him as an individual apart from his diagnosis, who could achieve anything he set his mind to. I wanted to make a positive difference, to focus on my son's abilities. The label was difficult to escape, but I was determined not to let it define my son.

UNDERSTANDING

Why was the need to control him so intense in me? Why did the Asperger's matter so much? Learning to drive is part of becoming an adult, so why was I denying him this opportunity? What kind of mother was I? With so many questions running through my head, I needed not only to stop and think clearly, but also to rationalise my thoughts. I needed to take stock and look hard at myself as a mother, in order to understand my own reactions.

I could see what my son wanted but I was placing the limitations on him due to my own expectations and knowledge. It was my fears of other cars on the road. All of the external factors were influencing my mindset and perception and I was viewing my own son as an extension of myself. At the time I just could not understand why he needed his glasses on in the tunnel. I would not, so why did he?

Now that the crisis had passed and I was calm again, it seemed so obvious. My son has sensory sensitivity. In order for him to process the world around him, he needs to limit the amount of light to which he is exposed. After our disastrous drive, he reminded me abruptly that the lights in the tunnel had seemed to him as bright as the sun. He needed the sunglasses to filter the strong, unnatural light. In the panic of the moment, I had completely forgotten about my son's sensory issues.

In the car, I had been obsessed with the 'what if?' scenarios. My son often struggles to interpret other people's intentions. What if he failed to understand other drivers' intentions on the road Tyler (2013)? But I was beginning to understand that the struggle on the road had been more about my own inhibitions and personal expectations. I was creating a hostile world of mixed perceptions for my son because I felt that I was not meeting society's expectations of me as a mother. I felt like a failure.

Even though I was terrified of getting back in the car with my son, I forced myself to confront my fear head-on. It was a weekday and the roads were extremely busy; cars, buses and trucks moving in and out of lanes just to get to their destination on time. This time was different, however. I knew now that I had to let my son show me what he could do independently, while I concentrated on being calm and relaxed. Additionally, since our last journey together, we had developed a strategy to help my son interpret and adapt to different situations on the road.

The 'Rule Book' consisted of both pictures and words relating to my son's driving activities, as my son learns best when he can rote learn the rules. Each time an

incident occurred, a new rule was added to the book. The start of the book consisted of concise, illustrated elaborations on the following:

Rule number 1 – Not too close to other cars
Rule number 2 – Stick to speed limit
Rule number 3 – When the car in front of you is going under the speed limit, so will you, until it is safe to pass them.
Rule number 4 – You need to adjust your mirrors and seat before you begin to drive.

With this strategy in place, I was determined to focus less on analysing my son's reactions, and more on my own. I really wanted to understand how I could make my son's transition to independence easier and I wanted him to feel ecstatic that I did not interrupt or try to control the situation. In my mind, I went over all of the things on which I needed to focus. My son was different to me, he was his own person. I needed to watch, give him space, and allow him to learn from his own mistakes.

When a truck merged into our lane, I remained relatively calm. My son slowed down. I praised him on how well he had checked his mirrors. I spoke little and instead focused on breathing and letting him be. My thoughts ran back to how I had been as a learner – but no, stop. My son was not a replica of myself.

I could feel myself relaxing. Trying to understand my son, rather than to control him, was making me feel less out of control. When I did speak, I noticed that my voice was calmer and more direct. We even had a short conversation that was not about driving.

Mum, that's the car that I want to get.

Suddenly, I didn't feel as though I needed to analyse his every move. Instead, I allowed him to plan independently what he was going to do. After all, that is what he would have to do if he was in the car without me.

As I watched my son in the driver's seat, I realised that the time was coming when he would not need me as he had in the past. Like for all eighteen-year-olds, a driver's license would mean greater independence. Even though I wanted this for my son— wanted him to be successful—his diagnosis had made me doubt that this day would ever come. As a result, I had not really prepared myself for the thoughts and feelings that a mother must experience when her child transitions to adulthood.

Before, I had felt that I needed to control my son, because I had always protected him and provided him with a safe space. I had always tried to be his shining light, his rock; someone to look to when no one else understood. But now I realised that my need for control was what had caused the tsunami feeling in the first place. Not only that, but it was stopping me from recognising my son's abilities and instead making me focus on the Asperger's label.

Learning to drive was my son's first step towards independence. Reflecting on the difference that my more flexible, positive mindset had made to this drive, I knew that

I needed to change. In order to support my son in becoming an independent adult, I needed to reject my fixed mindset and develop an open one. Fast.

ACCEPTANCE

This new profound change in the way I perceived myself began to assist me not only to accept my son but to have a better relationship with him. The driving became more like an enjoyable mother and son activity. I was beginning to see how important driving was to my son. Each driving experience was not only calmer, but I felt a greater sense of appreciation for my son and what he could achieve. I could see his natural ability. He was showing me he really wanted this, and it seemed like the first time in his life that he was really motivated to achieve a goal. This experience was of utmost importance to him and as his mother I should respect that.

Each drive improved on the one before. I could understand that my fixed mindset was becoming more open-minded and accepting of my son's differences to me. His meltdowns seemed to reduce – perhaps this was because he felt as though he had control over his life now, or because I was becoming more relaxed and enabling him to make his own decisions.

Instead of making excuses to avoid taking him driving, I would respond eagerly:

Do you want to practice your driving? Let's go!

One particular drive resonates with me as I write this chapter. We were going to the beach on a really sunny Melbourne afternoon and the heat made us feel like sausages sizzling in a pan. It was excruciating.

By now, my meditation techniques and my son's rule book enabled me to relax as the passenger in the car. Each time my son got into the driver's seat, I made sure that he had gone over the rule book to familiarise himself with the different social rules in the car, and he had rote learnt it well. My job was to meditate before I got into the car and take deep breaths if I felt any sort of twinge in my body that would overwhelm me. Whenever my mind started to feel like a wild, roaring ocean, I would use the ritual of meditation to allow me to focus on my son's abilities.

He started the car and off we went. I could feel the positive energy, not only from the sun shining through the glass but throughout my entire body. My son had even mapped his own way there: he had always been like a walking GPS! The way he was going was different to the way I would go but instead of saying something, I told myself there are many ways to reach a destination. This is his way – sit back, relax, and enjoy the drive.

He continued on this journey to Philip Island, just under two hours from Melbourne and the longest drive he had yet completed. Each decision he made on the road complemented the next. His drive was not too fast or slow. He changed lanes with confidence and ease, checking constantly, which had been difficult for him in the past. He didn't even make any abrupt moves on the road; he was so calm

and relaxed that he almost seemed like a different person altogether. Could changing my own mindset be affecting my son this much? Of course, he also had more driving experience now, and it would not be long until he sat his driving test. I could tell from his demeanour that he was trying to tell me:

Mum, see what I can do now.

As usual, my son lacked emotion and I had far too much of it! This thought made me really consider the way in which thoughts and emotions can influence perception. My son was enjoying this snap shot in time, showing me what he could do left to his own devices. How much I had underestimated my son's ability due to the Asperger's label. He never once asked for my advice but instead focused solely on what he had to do on the road.

This entire trip with an open mindset made me reflect on my acceptance of my son. If I gave my son a chance, it did not matter what any paediatrician, doctor, or specialist said he would or would not achieve. If only they could see him now! I began to notice that when I did not focus on the Asperger's, I forgot that it was even there. I saw my son for his true attributes and what he could achieve independently.

Understanding myself as a mother was a blessing in disguise for me. I understood that I needed to work thorough my own inhibitions in order to see my son's true accomplishments. This was the 'Aha!' moment in which I realised that it was not society that was the main problem here but my own thoughts, mindset, and perception in terms of what society would think of me as a mother and what happened if my son could not live independently in society would all be a reflection on how I parented my son (Lauchlan & Boyle, 2007).

Here I was back again at the calm sea seeing my son as an independent person navigating the world of life around him the best he could. I no longer felt the need to prove my son was 'normal' as I understood him to be a different kind of 'normal'. I had just accepted that this was the way it was. What is normal anyway? To be normal is to be the same as everyone else; to conform to society's rules. I had finally accepted him for the person he wanted to be!

LETTING GO

The day arrived, the day that my son would get his license. I had known for a few weeks that this day would come, and I felt much more prepared now. I needed to stand back and allow him to show me what he could really do. I needed to 'let go'. I had all the mixed emotions that any mother would feel when their child was about to take a driving test. I hope he goes well! I hope he passes!

He had worked very hard not only learning to drive but getting me to understand and accept him for who he really is. I pushed my thoughts away, looked at my son and said simply:

Good luck.

He looked back at me and said:

> I don't need luck, I can drive.

I was so proud of my son, he had worked immensely hard to achieve this goal with the limitations of the label and the bad 'mothering'. Really, all that mattered to him was he wanted this the most and he was going to get it. I love that focus about my son. I am so glad I have been given this opportunity to see my son in a different light and to let go in order for him to become independent. I know longer cared on what society thought about me as a mother but rather I valued the relationship my son and I had developed over the course of this experience.

Out the door he went. I did what many mothers do when they are nervous for their child and cleaned the house from top to bottom; I never do that normally! I had to keep myself busy, because I knew that if I thought too hard I would start to worry. This was becoming the longest two hours of my life. I had just finished the vacuuming when I heard my son.

I will never forget the moment when he walked through the back door.

> How did you go?

My heart was full of anticipation, just like any other 'normal' mother. But at first he did not respond, only gave me the longest stare. I knew that he was taking in the spotless kitchen – usually it is never that clean. My heart was in my throat. Suddenly, however, he announced in a loud voice:

> I got it! See, Mum, I told you and the driving instructor that I would get it, and I did! See, I didn't fail. I succeeded!

I cried the tears of joy. Not only had he received his driver's license, he had received his manual car license! I had not thought that this day would ever come, and now he stood in front of me, one step closer to independence and heading towards adulthood. It was time for me to let go and allow him to make his own mark on the world.

All my fear, uncertainty, and struggles were now becoming a distant memory. If he could do this, he could do anything. I just hoped that society would understand and accept him for him (Lauchlan & Boyle, 2007). I know society is not always that kind. But now I realised that my son would be able to show society what he can do rather than them seeing what he cannot do. He'll show them that the label does not define him: he is who he is!

CONCLUSION

Teaching my son to drive made me realise that previously I had limited expectations for my son. By analysing how I perceived him, I was able to identify my weaknesses as a mother and improve on them, in order to build a relationship with my son based on trust and independence.

This lived experience has also shown me the importance of positive thinking, in order to evaluate and change my mindset from 'fixed' to 'growth'. This transition of my own has been crucial in allowing me to be the best support possible for my son as he gains independence and transitions to adulthood.

Moving from understanding to accepting myself and my son has enabled me to see the bigger picture: my son can make positive contributions to society if I stop blaming everyone – especially myself – and focus instead on how lucky I really am. If I cannot accept and let go of my son, no one will have the chance to see my son's potential.

Everyone on this planet has something to offer society: we need to let them show us. I now have a better understanding of my role as a mother and its impact on every interaction with my son. No amount of research or knowledge can stop a mother from worrying, however. Motherhood is one of the hardest jobs I have ever had, and I have had many!

My son now makes most choices independently and is becoming more and more self-sufficient. I really never thought this day would come – and believe me, it may not have come at all, if I had not analysed my place as a mother in society. I wrote this narrative to raise awareness of Asperger's syndrome and to change attitudes in my local community and beyond. I wanted to provide a positive image of Asperger's, to show the world how capable my son can be, because so many people in the world still view this disorder as purely negative. I never expected that the experience would change me too!

Not only has my son received his driver's licence, but he has also travelled overseas. He planned the trip and organised how he was going to finance every step of the adventure. In the end, the travel agent only had to arrange the accommodation! I have learnt so much from my son – in fact, so much more than he has ever learnt from me. I feel such a sense of pride, knowing that whatever he wants to achieve, he will. I know that he will not let society dictate him, but instead he will show society what he is capable of in his own unique way. Son, I am so proud of you. Congratulations on all of your achievements!

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11. TECHNOLOGY USE AND TEENAGERS DIAGNOSED WITH HIGH-FUNCTIONING AUTISM

In and across Differentiated Spaces

INTRODUCTION

This chapter investigates how social uses of technology situated within specific differentiated spaces enable youth diagnosed with Autism Spectrum Disorder (ASD) to counter pre-conceived notions of autism as a form of limitation. In particular, we explore the richly layered, complex and creative lives that are enacted by young people who attend The Lab, an Australian-based technology club for youth diagnosed with High Functioning Autism (HFA) or Asperger's Syndrome (AS). In our discussion we employ Goodley and Runswick-Cole's (2011) work on disablism/ablism, posthumanism and their adaptation of Haraway's (1990) feminist analysis of the cyborg. Using such theory allows us to investigate, through the merging of bodies and technologies, the limitations of myths of 'organic history', via the emancipatory potential of online ways of being. By examining The Lab, we begin to understand that the extension of the self through technology does not occur in isolation but rather, flourishes in specific contexts. Hence, this chapter concludes that the uses of technology within physical, online and psychosocial spaces intersect to create unique hybridities that allow HFA and AS youth to construct their own narratives of identity, thereby challenging standardised notions of disability. These practices support Gillberg's (2002) notion of HFA as a source of new forms of creative thinking borne of a different cognitive style (Feinstein, 2011), as opposed to the construction of HFA as a form of imaginative deficit (Barnes & Baron-Cohen, 2012).

AUTISM AND TECHNOLOGY

Clinical definitions recognise ASD as a neurodevelopmental condition diagnosed on the basis of:

> … persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition to the social

> communication deficits, the diagnosis of autism spectrum disorder requires the presence of restricted, repetitive patterns of behaviour, interests, or activities. (American Psychiatric Association, 2013, p. 31)

Despite evidence that people living with autism are able to work and live independently, research in this field remains focused on 'solving the problem' (Baron-Cohen, 2000). For example, a systematic review of 381 peer-reviewed journal articles published in 2014 showed that 89 percent of autism studies related to diagnosis, prevention and treatment. The study found that only 43 (approximately 11%) of these articles did not deploy a medical research methodology (Ng, 2014). Most focused on identifying specific biological causes (e.g., gene, DNA and brain regions) or psychological research looking at how visual or audio tools may help people diagnosed with autism overcome social and communication deficits. The review highlights a lack of research on how living with autism may be enabling for some people, especially those diagnosed with HFA or AS (cf. Schutt et al., 2015). This gap in the literature invites research into the daily activities undertaken by people diagnosed with autism, including their personal use of digital technologies.

Existing research on autism and technology use has tended to focus on younger children and the development by research teams of single-user 'apps' designed to help individuals diagnosed with autism with daily task management, social skills development or language acquisition. Again, as mentioned above, we continue to see a deficit-based focus on problem solving, as well as a lack of attention given to young people older than ten. This is despite young people diagnosed with ASD being widely recognised as creative, keen and sophisticated users of technology (Wang & Spillane, 2009). It is in this context that we introduce The Lab, a network of technology clubs for young people between ages 10 and 16 diagnosed with HFA or AS. We begin by examining the literature that stimulated the foundation of the Lab and that helped to conceptualise its approach to working with young people on the autism spectrum.

THE LAB

The Lab was founded in 2011 as a not-for-profit after school and weekend program by a university technology researcher and a software developer. The program was based on the findings of a previous project run by the co-founders, which trialled innovative uses of technology with disadvantaged youth in urban and regional Victoria, including individual one-on-one software mentoring with HFA teenagers. Beginning with one location in Melbourne's inner west, the program has since grown to fourteen sites across five Australian states and territories (Schutt et al., 2015). Each site runs between one to three weekly two-hour sessions that each cater for 12 to 20 young people with an interest in computers Two software developers or designers work as mentors for attendees who either bring their own

laptops or are supplied with them. The Lab is now a registered national not-for-profit organisation.

The Lab takes a relatively unstructured and personalised approach to its activities, with a suite of free online programming/design lesson supported by individual face-to-face technology mentoring. This approach was developed in consultation with a number of advisors, primarily HFA youth involved in the co-founders' previous project. Young people at The Lab are free to engage in online/digital activity based on their interests. At a typical session, participants may play games such as Minecraft (sandbox game) or Team Fortress (first-person shooter multiplayer game) either by themselves or collectively. Roaming Lab mentors provide encouragement, demonstrations, introductions to other participants with aligned interests and one-on-one technical support for participants to create as well as consume technology. Depending on individual interests, this may take forms such as creating computer games, programming, establishing and running servers, building websites, constructing robots, generating and editing digital video or undertaking graphic design. Such activities are, however, never forced or mandated. Participants may instead choose to spend their time gathering around peers' laptops to watch videos or gameplays; the development of social skills and friendships is as important to the ethos of The Lab as the development of IT skills.

It was observed in an independent 2013 evaluation that the health and mental wellbeing of many Lab participants had vastly improved (Donahoo & Steele, 2013). Many Lab participants had been reportedly bullied at school and had found it difficult to make friends. In some cases, they had turned to self-harm or were prescribed anxiety medication. However, since attending The Lab, preliminary evidence suggests that participants had begun to socialise, make friends, were less inclined to self-harm and were less reliant on medication. While Donahoo and Steele (2013) identified a number of factors contributing to this positive outcome, they note that the key enablers were both the use of technology as a form of mediation, and the set-up of the Lab's physical space. Due to the parameters set on their study, the authors did not attempt to explain how and why these key factors enabled socialisation. Informed in part by this evaluation, and motivated by the dearth of research worldwide into adaptive uses of technology by HFA and AS youth, the current discussion offers a re-conceptualisation of the ways technology enables these young people to explore their psychosocial worlds via involvement in and across differentiated spaces.

THE CHILD AND THE CYBORG

Disability scholars Dan Goodley and Katherine Brunswick-Cole (2011) propose that Haraway's (1990) emancipatory feminist adoption of the cyborg can be further adapted to reconceptualise children living with disabilities. They claim that the cyborg – a hybrid figure that combines the machine and the body, merging social reality and fiction – offers potential for undermining the myths of 'organic history'

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(Goodley & Runswick-Cole, 2011, p. 3) that chain women to their biological forms. Goodley and Runswick-Cole present an existing scenario involving 'totalizing grand narratives which obscure the individual child and family' (p. 2) and facilitate everyday violence in the lives of children and their families through the forces of medicalisation and individualisation. They then present an alternative 'post able' world that avoids the myths of 'ableism' (Campbell, 2009), including the idea of a 'perfect' self and body, and embrace the potential of 'heterogeneity and multiplicity of the body and mind' (Campbell, 2009, p. 4). This is central to Haraway's argument, which presents the cyborg as a challenge to the notion of a 'unified, stable and normate' body (Goodley & Runswick-Cole, 2011, p. 5) and/or mind.

Of particular interest to us is the strong link between the cyborg and digital technologies, given the interests of the young people at the Lab. Indeed, Goodley and Runswick-Cole provide an overview of how children have been seen as connected to the future and technology, including notions of the cyborg child identity as fluid and temporal. We have witnessed this fluid identity in Lab sessions as young people follow their interests, skills and identities into and across online spaces. One Lab participant, for example, has used the 3D building platform Minecraft as a virtual theatre for embodying the roles of characters from action movies and comic series. Having downloaded Minecraft 'mods' (modification software kits) that turn the Minecraft platform into 3D simulations of game and film worlds such as the Matrix movie or Marvel comics, he has adopted a different persona on a weekly basis, adopting the voice of each character as he enacts scenes within the customised 3D world.

Such activities demonstrate Goodley and Runswick-Cole's conceptions of the extension and customisation of identity through modes of technology-facilitated communication. The kinds of technology uses described above allow children to create their own stories about themselves, to 'seize the tools to mark the world that marked them as other' (Goodley & Runswick-Cole, 2011, p. 6), and use them as 'not just an external tool but a natural aspect of the child' (p. 7).

Another Lab case study illustrates this further. Michael (a pseudonym) was a keen fan of the Super Mario Brothers game series when he joined The Lab at age 12. The Lab mentors introduced Michael to the Gamemaker software program, which he used to program his own Super Mario games. These games were then shared with other Lab participants in the Lab's physical space, and online with other Super Mario aficionados. Once Michael had begun to create his own games, he became interested in composing his own soundtracks to the games. His parents bought him Super Mario music scores and recordings, and he started to develop his music composition and digital editing skills. He also took up the violin at school so he could teach himself to play the Super Mario theme. At the same time, Michael made friends with another Lab participant who was an adept illustrator, animator and videographer, and who had his own popular YouTube channel where he shared his work. Michael was encouraged by his friend during Lab sessions to start his own YouTube channel. He did so, creating a series of 'quickdraw' videos that showed others how to draw Super

Mario characters, as well as videos of game reviews and designs of alternative Super Mario game covers. His channel also became popular, gaining positive feedback for Michael and leading to worldwide connections with other young people who shared his interests (Schutt et al., 2015).

Since then, Michael's interest in Super Mario has waned and he has moved on to other interests at The Lab. However, during the two-year period when this interest was strong, Michael was empowered through the deployment of digital technologies to build a hybrid identity that celebrated his interest in Super Mario and grew through it, to turn a pursuit that had marginalised him at school and 'marked him as other' into something which he controlled and from which he derived skill, satisfaction and connection to others who shared his interest. For young people like Michael, there is constant flow between the online and the offline, the real and the virtual - the essence of the cyborg. Indeed, it could be argued that a hard online/offline division is contrived, possibly generational, a story written by others who do not inhabit these same worlds. This division has consequences, as pointed out by Naseden's (2005) warning about the potential unintentional dehumanisation of autistic children through the reframing of their intelligence as 'artificial'.

We have observed that such judgement of 'artificiality' can be based on misunderstanding (or even fear of) what goes on when a young person with autism is sitting in front of a screen. The notion of artificiality is one that presupposes a state of non-artificiality, a delineation that the cyborg concept helps to breaks down. Participants at The Lab make highly sophisticated and multifaceted use of online technology to augment their sense of self and belonging, in ways that even their parents may not understand. The practices we have observed are integrated holistically into their lives in ways that blur the line between online and offline. At The Lab this varies greatly from participant to participant. We have seen two best friends sitting silently next to each other during Lab sessions while they collaborate on building technically complex game levels, using the game's messaging tools to chat freely 'in-world'. This is something these two participants could do as easily from home (either alone or at one another's house), yet they still choose to attend The Lab every week and sit in a room with fifteen others, even though they do not seem to interact with those fifteen others. Contrastingly, we have observed multiple participants collaborating in a participant-run Minecraft server by shouting across the room to each other and ignoring electronic messaging altogether. What the Lab continues to point out to us is that there is much work to be done in understanding the complexities and nuances of communication through technology. This form of technology-aided communication does not simply occur in any time and space but is rather situated in and across specific physical, digital and psychosocial spaces. We argue that it is through these multifaceted differentiated spaces that the concept of the cyborg emerges to challenge singular deficit-based definitions of disabilities such as autism. It is to further examination of these that our discussion now turns.

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DIFFERENTIATED SPACES

In this section, we look at how differentiated spaces facilitate technology-based communication and socialisation. The word 'differentiated' is used to recognise individual spaces as unique, serving distinct purposes in processes of communication. Yet, these differentiated spaces overlap and interconnect to form a culture of socialisation as seen within The Lab.

Gores (2000, pp. 13–14) suggests the notion of space:

> … refers to a number of both physical and abstract phenomena. On the most physical level, space designates the concrete materiality of books, canvases, ivory miniatures, buildings, and other aesthetic objects. However, space may also denote a kind of experience that these objects provide: for example, the microcosmic world of a novel, the vision of place created by a painting, or the shape of living space created through domestic architecture. Finally, space may describe the psychosocial realm in which individuals situates him- or herself in relation to culture and specific communities within it.

Here Gores adeptly articulates space as a fluid concept potentially involving material, metaphysical and psychosocial aspects. This conception of space is a complex resource for our thinking about social ontology. It is not concretised like realist ontologies, but encompasses and enables divergent and emergent processes.

We are interested in understanding how young people diagnosed with HFA and AS use technology to socialise and interact via situated interaction, especially within spaces that are differentiated, or specifically created by and/or them. Of course, these interactions are for the main part enabled by the use of language and other forms of communication. From a sociological perspective, socialisation is 'a process by which individuals learn to be functioning members of a society' (Grauerholz & Swart, 2012, p. 3). For our research, we focus on socialisation as a process of communication where individuals become part of society through exchanging embodied experiences and learnt behaviour within a given culture (Schwartz, 1980). In what follows, we examine three aspects of differentiated spaces – physical, online/digital and psychosocial – and how social ontological recognition of these helps us to re-envisage our understanding of youth diagnosed with HFA and AS.

Physical Space

There is currently a dearth of literature on the relationship between physical space and social and learning engagement by young people with disabilities, especially within autism studies. Our research seeks to understand more fully how the physical space of The Lab affects the way youths with HFA and AS interact and socialise. It also seeks to further Merriman's (2012) discussion about the relationship between physical and digital spaces enabled by mobile devices. Merriman argues that socialisation is no longer one-dimensional within the relative dimensions of

time and space but rather occurs simultaneously within multiple dimensions and spaces across different time zones. We suspect that The Lab is facilitating this form of multifaceted socialisation through technology and now turn our discussion to physical and then online/digital space.

Spatial semiotics studies meanings made of space in the form of signs or symbols (Halliday, 1978; Ravelli & Stenglin, 2008). According to Ravelli and Stenglin (2008, p. 355), spatial semiotics 'actively construe interpersonal relations within and around the space'. In their research, they primarily focus on physical spatial relations, looking at how buildings within public spaces alter the way we feel, communicate and interact. They suggest there are 'representational, interpersonal and compositional meanings' that construct human experience, including the expression of ideas and attitudes, and these enable us to organise meaning into coherent units of understanding about our society as a whole (Ravelli & Stenglin, 2008, p. 356–357).

The study of spatial semiotics leads to the study of spatial pedagogy that focuses on the set-up of space within a classroom setting, for example, navigating and changing the positioning and movement of teachers and students. Lim et al. (2012) suggest that 'specific spaces in the classroom take on certain meanings because of the nature of pedagogic discourse that occurs on the site and the positioning and distance of the site relative to the students and the teaching resources'. Hence, the structure of the space, involving the distance to objects (e.g., desks), students and teachers, has the potential to form a metaphoric panopticon that establishes control and power relations in a classroom via invisible surveillance (Foucault, 1979). Lim et al. (2012) outline four specific spaces in the classroom: authoritative, personal, supervisory and interactional. Authoritative space is said to be the area 'in front of the teacher's desk and in the front centre of the classroom…where the teacher is positioned to conduct formal teaching'. It is often the furthest away from the students, establishing formality between teacher and students. Hall (1974) hypothesised social 'distance sets' or more specifically 'proxemics' as the study of nonverbal communication through spatial awareness where the distance between people renders their relationship and communication. Hence, the contracted space created when the teacher is alongside the students' desks helps to reduce formality and facilitates interaction checking the psychosocial distance between teacher and student (Hall, 1974). It is also suggested that interactions within and between personal space (i.e., teacher and students) helps to alter power dynamics offering individuals more agency (Lim et al., 2012). While this chapter does not directly target classroom space, it seeks to illustrate that the physical set-up of and movement within spaces establish potentials for communication, socialisation and learning.

All Labs around Australia are predicated on the use of free community spaces with wireless Internet, in a bid to ensure that session costs for families of participants are kept as low as possible. These include donated out-of-hours office space, community centres, libraries, art studios and Returned Services League (RSL) clubs. This means that Lab spaces vary considerably in terms of their setup and level of flexibility, although, given the choices available, The Lab's managers deliberately opt for spaces

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with the highest degree of flexibility. This allows participants, who largely bring their own laptops to sessions, to retain a degree of control and arrange themselves in ways that make them feel most comfortable, an approach that is actively supported by Lab mentors.

All Lab spaces share two common characteristics. Firstly, a separate room is reserved for parents and family members during sessions so participants can take part in activities without family members, as one participant put it, 'cramping my style.' Secondly, Lab spaces are set up to be different to typical school classrooms. Indeed, The Lab's managers have avoided the use of donated classrooms specifically because of the negative connotations associated with school by some participants. Prior to the establishment of The Lab, its co-founders formally consulted with a number of young people diagnosed with HFA who advised that Labs should be 'cool tech clubs,' neutral, desirable spaces where young people would willingly choose to spend time – unlike schools which were seen as battlefields by many young people with HFA due to their experiences of bullying, isolation, unsuitable educational approaches, and a general lack of understanding of autism (Donahoo & Steele, 2013). This principle also extended to the name of The Lab. The name was chosen because of its neutrality, after the Lab's HFA advisors rejected names such as the "A+ Club."

Within the limitations externally imposed by each location's setup and fittings, each Lab environment is kept as informal as possible. Participants can arrange themselves in a variety of ways, from sitting alone in a corner to gathering in large groups. Mentors 'hover' and walk around the room, observing, helping individuals when needed and suggesting ideas. At the same time, a series of 34 online design and programming tutorials are available for participants to explore individually.

Research suggests that unstructured learning environments reduce power relations and encourage self-directed learning (Macleod & Ross, 2008; Radcliff et al., 2008). A formative influence for the Lab's co-founders was a teacher at a rural school for children with disabilities with whom they collaborated on a precursor project to The Lab. This teacher encouraged self-directed learning and set up his room as an unstructured learning laboratory, with live turtles and lizards in aquariums, musical instruments, computers, books, beanbags and art supplies in various areas of the room – much, it needs to be added, to the chagrin of the school's senior management. During their observations of activities in this room, The Lab's co-founders observed a high degree of student engagement to the extent that they observed former students pounding the door of the classroom with their fists in attempts to get back into the teacher's classes.

Online Space

The online/digital world as a space for social connection came about with the creation of the World Wide Web (WWW) in 1989 (Birke et al., 2014). Many theorists, including McLuhan (1962) and Giddens (1991), forecasted that media technologies

would change the way people socialise and interact. Although McLuhan (1962) wrote some thirty years before the beginning of the WWW, he prophesized the potential of web technology:

> The next medium, whatever it is—it may be the extension of consciousness— will include television as its content, not as its environment, and will transform television into an art form. A computer as a research and communication instrument could enhance retrieval, obsolesce mass library organization, retrieve the individual's encyclopaedic function and flip into a private line to speedily tailored data of a saleable kind. (cited in Guertin, 2012, p. 39)

He theorised that media technologies were increasingly becoming an extension of self rather than simply a passive, one-way communicative tool (McLuhan, 1964). He also foresaw new media not just as a database of content created for and by users but also a database of relationships mediated both locally and globally. Giddens (1991, p. 16) observed that while in pre-modernity, 'time and space were connected through the situatedness of place', the advancement of technology and global spread of modernity has led to the 'distanciation' of time and space whereby they are no longer relative. Instead, time is 'stretched over shorter or longer spans' independent from physical space.

While both theorists spoke of 'new media' prior to the popularisation of online media, they have helpfully informed theories about space in the 21st century. Henry Jenkins, an expert in the field of fandom, mapped the rise of the 'participatory culture' based on some of these observations. Participatory culture can be characterized as 'relatively low barriers to artistic expression and civic engagement, strong support for creating and sharing ones creations, and some type of information mentorship whereby what is known by the most experienced is passed along to novices' (Jenkins, 2006, p. 7). Bruns (2008) states that people become 'producers' – taking on both the roles of the user and the producer – as a form of 'resistance' or 'alternative' to other media content (Jenkins, 2010). Unlike physical spaces where roles, identities and status are more or less prescribed, the online space enables the choice of anonymity, or rather the illusion of anonymity, which breaks down power relations between users, encouraging them to participate in 'producing' (Bruns, 2008; Jenkins, 2006). It is important to understand that participatory culture is not simply equivalent to online culture but rather, is enabled through the online space (Jenkins, 2010). Some of the key enablers, as mentioned above, are its ability to store and broad- or narrowcast content and time-space compression – allowing people to share information across an abstract space not restricted by physical localities and time (Giddens, 1991; McLuhan, 1962, 1964).

Online and digital spaces also provide 'inexpensive tools for capturing, editing, organising' and publishing content that were previously unavailable in other media (Delwiche & Henderson, 2012). Most importantly, participatory culture fosters social relations through user production (Delwiche & Henderson, 2012; Jenkins, 2006, 2010). Writing a blog, tweeting or chatting over Facebook, for example, are

all processes of creating content that act as active forms of 'mediated interaction' that substitute 'orality' and enable information exchange within interest groups (cf. Castells, 2010, p. 392; Delwiche & Henderson, 2012; Thompson, 1995). In sum, the online space enables socialisation in a form of 'participatory culture' because of its lower barriers to entry, lower costs, time-space (ir)relativity, availability of tools and spaces for specific interests.

A large volume of research around online space and participatory culture has involved young people. This is because there is a higher uptake of new media technologies by youth in comparison to adults as they grew up within the digital environment (Buckingham, 2008; Maczewski, 2002). For example, research has found that civic engagement and socialisation among youth occur largely online (Bennett, 2008; Buckingham, 2008; Flanagan & Metzger, 2008; Maczewski, 2002; Sefton-Green, 2006). However, as we have been highlighting, relatively little research has examined the social use of digital technologies by young people with autism. Instead, most research into this group's use of online technology has focused on learning skills such as digital storytelling, speech, identifying social-emotional cues and game design (Anwar et al., 2011; Dorsey & Howard, 2011).

Psychosocial Space

As mentioned earlier, we consider psychosocial space to incorporate how an individual 'situates him- or herself in relation to culture and specific communities within it' (Gores, 2000, p. 14). It is 'manifold and is constructed imaginatively by each individual, both conscious and unconsciously' (Gores, 2000, p. 14). The concept includes reference to 'a person's psychological development in, and interaction with, a social environment' (Segen's Medical Dictionary, 2012). Hence, attention to psychosocial space helps to explore how a person constructs his or her own identity through interacting in, and with others, in differentiated spaces. Note that identity, in this case, is understood as fluid and changeable in relation to social environments and differentiated spaces. A valuable addition to theorisation of identity and meaning making in contemporary life is the idea of third space to which we now turn.

The notion of third space has been influenced by postcolonial and sociolinguistic theory (Bhabha, 1994). Bhabha refers to it as 'a challenge to the limits of the self in the act of reaching out to what is liminal in the historic experience, and in the cultural representation, of other peoples, times, languages, texts' (Bhabha, 2009, p. xiii). While there are multiple interpretations of third space, in this chapter we specifically draw on Guitierrez's (2008, p. 152) view of third space as a 'transformative space where the potential for an expanded form of learning and the development of new knowledge are heightened'. Here, third space helps to facilitate an understanding or translation that becomes new knowledge specific to those individuals involved in psychosocial interaction (Corcoran, 2012). Meaning making is understood within the 'locality of cultural translation' (Bhabha, 2009, p. xiv). Third space can therefore be understood as transitional space or even a process where meanings

are created through individual and collective psychosocial development (Bhabha, 2009; Guitierrez, 2008). Thus, we envisage third space to entail fluid and hybrid interactions between people and the spaces they inhabit e.g., psychosocial and online spaces/psychosocial and physical spaces (Soja, 1996).

Our research is interested in understanding how psychosocial spaces involving youth with HFA and AS interact with other spaces of The Lab. In other words, the project aims to investigate how individuals situate themselves in differentiated spaces. Richly layered, complex and creative identities and relationships are formed and performed by young people diagnosed with ASD who, to observers – including, in our experience, many parents – may appear to be simply staring at a screen. Online environments have the potential to offer third spaces where a sense of belonging is generated and coding, design and animation skills are tested, shared and celebrated through activities such as 'fanon', or the fan-based creation of images and films based on canonic tropes or interests, as outlined earlier by Lab participant Michael. The digital era has enabled such multimodal and interlocking forms of social connection and skills development, where young people can demonstrate, and are judged by, their technical skills and knowledge (as opposed to their appearance or social behaviour) in ways that allow them control, autonomy and anonymity if they choose.

Research into Internet and games cafes, although not focused specifically on autism, reinforces this view, with attendees motivated by factors including the desire to perform, belong and spectate (Taylor & Witkowski, 2010), to connect socially and to learn about games (Jansz & Martens, 2005). Beavis et al.'s (2005, p. 1) study of school-aged gamers identified such cafés as "liminal spaces situated at the margins of Australian culture and located at the junctions between home, school and the street, online and offline spaces, work and play."

CONCLUSION

Disability studies complicate the notion of ableism whereby the self and the body are made to conform to stringent 'species-typical' standards regarding human beings (Campbell, 2009). Living with impairment can, from normative perspectives, designate a person as less human, thereby resulting in the withholding of developmental opportunities individuals may otherwise have. As illustrated above, The Lab provides a context for challenging conventional thinking about disability. The use of technology within and across the Lab's differentiated spaces enables youth diagnosed with HFA to excel in specific types of creative activity, overthrowing the myth that autistic individuals suffer from imaginative deficit (Barnes & Baron-Cohen, 2012). Thinking about the Lab and its participants is also aided by the concept of the cyborg; specifically how hybrid technological-corporeal opportunities emerge for HFA youth to construct their own narratives beyond the constraints of normative reality. This line of thought disputes the notion that the body and/or mind are 'unified, stable and normate' (Haraway, 1990) and presents

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us with potentials for heterogeneity and multiplicity, working towards a more inclusive society. Finally, the hybrid nature of third space challenges concretised and static notions of personal identity, helping us to better understand how collective involvement may enable socialisation by HFA youth.

This chapter is part of a larger project looking to understand how The Lab, a technology focused community-based club, enables youth diagnosed with HFA to interact and challenge ideas about people living with disability. Apart from explorations involving novel theoretical applications, some of which have been introduced here, we are also keen to develop innovative methodologies to match these process-oriented perspectives (Corcoran, 2014). This is one way our research pushes conventional thinking beyond the restrictions of reductionism, where diversity equates to abnormality and normativity is pervasive. Instead, working together with the young people accessing the Lab, we aim to celebrate their difference for the intrinsic value this adds to our understanding of human complexity and diversity.

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12. SIGNIFYING DISABILITY AND EXCLUSION

Tales from an 'Accidental Activist'

INTRODUCTION

In this chapter a story unfolds about the management of disability and its effect on a student undertaking a university degree at an Australian university. Readers are presented with the dilemma faced by River and family when unexpected and long-term illness interrupted academic studies and completion of a degree. River's story has been hidden in interpersonal and individual interpretations of academic policies, procedures and regulations.[1] Through reflections on River's circumstances, the objective of this chapter is to identify alternative ways to challenge disability discourses outside those predominantly understood at the macro level of legal instruments and institutional procedures.

This chapter is structured as two stories. The first relates to River's circumstances and the implications of reasonable adjustment in relation to academic considerations and the intentions of disability standards in education. The second represents the mother who became the 'accidental activist', critic and advocate. I offer an approach known as 'ecosocial semiotics' when examining academic policies relating to elite student athletes and students with disability. A comparative analysis supports my contention that more research is needed into the ways that corporeal practices within universities reproduce disability in policy rhetoric. I end with the question of 'what would you do?' to invite researchers to continue challenging scripts of failure attributed to the educational outcomes of students with disability in university.

Writing about these experiences is not an easy balance between the personal and the need for scholarly reflection and analysis of key incidents, observations and problems that emerged in River's story. Such stories need to be told to empower family members to advocate on behalf of adult students with disability when their rights to participate and complete a degree are compromised. I accept responsibility for my interpretation of events that led me to the conclusion that maternal intervention is necessary for mobilising change.

Preface

We need to be reminded of the normality of social rituals such as the 'rite of passage' that signals the annual flight from school to university. This is an important time in

the lives of young people, their families and the nation when thousands leave home to further their education and employment prospects. Rightfully this is a time for celebrating success and achievement. These young people and their families have bought into the economy of social advantage that university education is held to represent, as well as the mythology that hard work, persistence and opportunity will be rewarded. Having a university degree is crucial for individual, economic, social and political mobility and represents an asset of considerable value. The Australian public sees universities as valuable institutions necessary for economic and national growth and for educating students for professional careers and skilled employment. In contrast to pragmatic considerations of universities, 'soft' needs such as diversity, learning, universal access, disadvantage, tolerance and openness, rank particularly low (Universities Australia, 2013).

It is no surprise that as Australian and international universities steer towards more active engagement with the economy and industry, and adoption of corporate managerial styles of governance, that "the participation of students with disability is not highly prioritized in higher education policy" (Brett, 2014, p. 49). River's story is prefaced by the selling of dreams through social rituals, schooling cultures, and institutional and political systems that demand educational success.

RIVER'S STORY

River began studying as an undergraduate and was optimistic that the degree would be finished within the required time frame. The plan that began in hope changed to despair when River's academic progress was interrupted due to intermittent bouts of illness. With the illness not fully diagnosed by various medical practitioners, River's health declined significantly over the coming months. Months of serious illness morphed into two and more years. River missed attending the first graduation ceremony to receive a previous degree. Over time River lost connections with friends and former university colleagues. At the most serious stages of the illness, River gave up hope on being able to complete university studies or having any optimism about the future.

The path to adult independence was compromised with the formerly able and independent River returning to the parental home to be cared for. At the worst stages of the illness, River required full time care and could not be left alone. River's parents did not experience the supposed freedoms of the 'empty nest'. They became full-time carers because there were no other people to do the job.

Although continuing to be compromised by episodic and latent effects of illness, River decided to resume studies believing that the university could negotiate a return to study plan so that outstanding subjects could be completed albeit modified to the requirements for reasonable accommodation. The critical issue for River was the right to continue studying. The next section narrates the pursuit of that right.

Negotiating the Right to Continue Studying

The right to an education is enshrined in the *International Covenant on Economic, Social and Cultural Rights* and further endorsed in the *UNESCO Convention against Discrimination in Education.* As the right to education is perceived as a lawful entitlement, states are accordingly obligated to facilitate such rights through national policies and instruments. That appears to be the intention implied in UN conventions and protocols until questions are raised about whether these reflect arbitrations for universal access or whether the right to a basic education is an unequivocal human right (Spring, 2000). In taking the view that the right to education is justifiable and important for the development of a person's full potential and personality, it would appear that the Australian Human Rights Commission endorses that pre-emptive human right. Rights to an education are not excluded to persons with disability and are acknowledged in *Disability Standards for Education,* Australia, 2005. It is illegal for any educational authority to refuse, deny benefit, cause unjustifiable hardship, expel or subject the student to any other detriment, or develop curricula that excludes the person from participation. Universities Australia (2014) support flexible modes of study and emphasise the need for universities to generate a policy environment that enables students from all backgrounds and abilities to participate and succeed at university.[2]

Legislative principles and conventions on equality frame policies and procedures relating to the management and accommodation of students with disability in universities. Generally, such students apply to the respective university disability or equity services department with accompanying medical evidence on the nature and level of disability, illness or condition and the impact on academic capacity *before* decisions are made about entitlement to support services and resources and adjustments to academic programs. Each university sets the policy environment, conditions and requisite procedures according to interpretations of legislative compliance. This is the environment that contextualises the practicality of negotiating the right to continue studying.

River followed the procedures for registration as a student with disability and provided medical evidence on time so that the request for reasonable accommodation could be processed before the start of the semester. River was informed that the respective academic or subject co-ordinator needed to have full information on the condition and that resuming studying was conditional on academic approval of the request for reasonable accommodation. The semester was well into the fourth week with no resolution or contact and advice from the disability advisor's department. Lack of action on the request for reasonable accommodation appeared to be subsumed in an environment of disinterest or inadequacy to address what originally was a relatively uncomplicated request. The original request was for flexible mode of delivery via online and alternative participation instead of attending face-to-face

lectures and tutorials. River's illness made it impossible to sit, travel or stand for long periods without adequate rest and recovery. River subsequently had to withdraw from the subject as the semester was half way completed without resolution and in the light of institutional refusal to consider alternative methods of delivery of curriculum and assessment. In another instance, an alternative examination venue was organised more than forty minutes drive from River's home despite medical documentation indicating the likelihood of deterioration in River's condition. Like a self-filling prophecy, River's health was severely impacted to the extent of needing urgent medical treatment.

River's body may not have been fully functional but it did not mean that River lost the intellectual ability to read, write and *participate* in a different format of learning. The disability condition meant that it would take longer time to complete individual subjects. River may have overestimated the effect of the illness by returning to study too soon. Combined with student debt, medical costs, and time limit for completion of the degree, the choices were to withdraw or continue. Returning to study meant a return to normality and the hope that university staff would be amenable to flexible delivery of curriculum and alternative assessments.

The first year of returning to study could only be described as a disaster in terms of the powerlessness of self-advocacy to establish a meaningful dialogue with institutional stakeholders. Subsequent completion of subjects was not without challenges. River had to continually re-negotiate previously agreed to approvals for reasonable accommodation which had either not been recorded or forgotten about, or, resupply new medical evidence apart from that which had been already supplied.

 River's situation is not new as findings from disability research studies confirm aspects of this story (Fuller et al., 2004; Goode, 2007; Vickerman & Blundell, 2010). Alan Hodkinson argues very powerfully that students with disability are subjected to deliberate and systematic erasure communicated through "negative attitudes towards disabled people" (2014, p. 125). Other researchers find that biases and stereotypes contribute to regimes of negativity associated with people with disability (Borland & James, 1999; Areheart, 2008; Williams et al., 2014). It is almost impossible to change reasoning on the ways that bodily differences are used to justify, deny rights and discriminate by setting up artificial hierarchies and barriers between people (Wolbring, 2008). *Ableism* is so dominant in social thought and practices and become normalised as a strategy to exclude and systematically manage any forms of aberration and deformity as part of the social contract (Hubert, 2013; Goodley, 2014).

Incremental policy and legislative changes may suggest positive movements towards becoming a more inclusive society. A salient and continual problem is that "motherhood statements of commitment to equality and elimination of discrimination" rarely address the degree to which institutions and society are committed to implementing socio-democratic participation and equality (Gaze, 2002). Disability tends to activate anxieties, fears, phobias and threats of contamination, much like panics that existed in history, and in the ways that popular cultural images and

literary and media representations of the grotesque and the abnormal continue to reproduce discourses of disablement (Rubin, 2012; Sharloo & Kaptein, 2013).

In River's case, individuals believed that they were doing the right thing at the time but may not have fully understood the effects of their actions on the health of the student or whether alternative procedures could be put in place without detriment to the university and other students. Some individuals were more amenable and approachable and provided considerable support. Each year meant more rounds of negotiation to remain in the academic program. Uncertainty added to the considerable stress of managing the medical condition.

Although River passed subjects, slow progress appeared to signal concerns about River's calibre as a student at that university. While not overtly stated, River sensed that moves were afoot to discontinue enrolment regardless of whether River's academic results were comparable or better than other students. Fears of expulsion in the later stages of the degree brought into focus whether the core values of inclusivity and diversity promoted by the university were meaningful. River had not breached university policy, conduct rules and regulations nor was identified and notified as a student at risk. Such fears of expulsion were substantial as there was a high risk that a decision would be made to exit River from the course.

River's story revealed vulnerabilities within university procedures that added to the challenge of completing a university degree. Ambiguity around meanings of reasonable accommodation and unjustifiable hardship raise concerns about whether a student with disability can have confidence in university policies and procedures in terms of institutional compliance to anti-discrimination legislation and disability standards in education. This next section asks whether River's situation was an aberration or a casualty of an inexact science.

Rights and Obligations: Disability Standards in Education

Australian disability standards in education supplement anti-discrimination law by clarifying and elaborating legal obligations for education providers to comply with in meeting the needs of students with disability. Disability standards also set out rights, measures and actions that can be taken to facilitate legislative intentions.

There is the recognition that students with disability should be able to participate and use facilities on the same basis as other students. However, there may be situations where students with disabilities are unable to participate on the same basis or can be treated in the same way. Legal obligations are said to be met if the interests of all parties are properly considered, not impacted on unreasonably, or cause unjustifiable hardship, including the student with disability and the education provider. What becomes critical to this discussion and to River's situation is consideration of the effects of reasonable adjustment on the student's ability to achieve learning outcomes and participate equitably on the same basis as other students. Disability standards legislation suggests that rights to be educated are supported and that all reasonable efforts should be made to facilitate that right on the same basis as other students.

A student with disability may feel reasonably assured, that, given positive policy conditions, progressive attitudes of universities, and in view of legal considerations of equality and anti-discrimination that they at least have "an equal chance…not as the less fortunate to be left behind...and achieve...personal quest for influence and social position" (Rawls, 1971, pp. 106–107). In Kiefel v State of Victoria [2013] FCA 1398, Justice Tracey commented that, "well-meaning parents have wrongly been led to believe that redress is available under the DDA for what they perceived to be deficiencies in the manner in which educational services have been provided to their children" (6). This is an interesting comment because of the suggestion that complainants may have little or limited success if they claim administration inefficiency on the part of education providers in dealing with students with disability.[3] Equally, literal interpretations of anti-discrimination laws may not provide equitable outcomes.

Legal instruments may not be sufficient in advancing protections against discrimination in cases of reasonable accommodation. Disability standards for education legislation appear to present a paradox inasmuch as "there is no requirement on providers to make unreasonable adjustments" (Australia, 2005). Education providers can be exempted if reasonable adjustment incurs costs or is considered to have no benefit to the provider. An issue would be whether education providers experience the same level of unjustifiable hardship as that of a student with disability. It would require legal clarification of the meanings of unreasonable adjustment and unjustifiable hardship to understand the implications of these differences. Defensible discrimination can be allowed thus adding another layer of complexity to negotiations of reasonable accommodation.

At the macro level, Australian legislation supports the rights of students with disability to an education and has guidelines on compliance measures for education providers.[4] The Garrett review in 2010 into disability standards legislation noted continuing ambiguities relating to determining reasonable adjustment, consultation, curriculum related issues of access and mode of delivery. Reported cases conciliated at the Australian Human Rights Commission suggested that education providers, including university and tertiary sectors, were not as proactive in complying with disability standards. The Garrett review and subsequent self-help fact sheets issued by the Australian Department of Education and Training unfortunately err in assuming that matters of disability in education are predominantly encountered in school settings. There is a considerable information gap on how individuals, parents and care givers can address issues relating to disability in higher and tertiary education sectors.

River's story indicated relatively inefficient processes in terms of the accommodation of a student with disability at a university. The story is valuable for illustrating that anti-discrimination legislation may also be porous when it comes to education rights. As cited research indicates, disability is not simply a body function problem but is made more difficult as an issue of reasonable accommodation.

THE MOTHER'S STORY

Advocate or Provocateur?

As indicated in the preceding section, River had to return to the parental home for care and support. River was an adult therefore issues encountered in this story were different to those relating to school age students and their parents. With minors, parents have the assumed right to speak and advocate. Intervention may not necessarily be welcomed by medical and other experts. Mothers are seen as meddling or interfering or overprotective although they have reason for intervening and challenging authority. Parents, and particularly mothers, are seen as to (a) exacerbate or (b) ameliorate medical conditions; or (c) problematise the management of illness by medical professionals (Logan, Simons, & Carpino, 2012). Opinions vary on the efficacy and effectiveness of parental and or maternal intervention but there is consensus in sociological, educational and medical literature that parents have rights, have input and that parental intervention can affect outcomes and change protocols.

An important difference here is that university students generally are of adult age. Whether parents and families can intervene in educational matters at universities may not be the norm. It would assume that consent needs to be given and that universities agree to disclosing information to a third party. Consideration would need to be given to privacy laws and obligations of tertiary education providers in relation to disclosure.

Action plans issued by the Australian Human Rights Commission for use in tertiary education sectors support the need to gather information through external resources and databases but do not give explicit guidelines or advice that relevant information could also be collected from families.[5] I raise this issue in relation to the requirements that "all circumstances are taken into account" when considering the effects of decisions made by education providers that may compromise educational opportunity (Section 10, *Disability Standards in Education,* 2005).

I identify a problem relating to who has the right to speak and advocate for adult dependants in situations such as those that River experienced. The person most likely to step into the role of advocacy is the mother (Yates et al., 2010). Intervention has risks and centralises society's most difficult issues with images of mothers and symbols of motherhood. As Patrice DiQuinzio (1999) observed:

> ... being a mother and being mothered are both imbued with tremendous social, cultural, political, psychological, and personal significance. Everyone has a stake in the social organizing of motherhood... (p. viii)

DiQuinzio iterates the complexities of motherhood in western industrialised societies in terms of the effects of ideologies of individualism and the rationalisation of binary categories of nature and gender. Mothers are essentialised as organic subjects sharing homogenous traits of reproduction, social roles and equivalent gender identity.

As Rothman articulates, mothers, motherhood and mothering are replete with ambivalent meanings that "place you on the outside of your own experience, leaving you with extraordinary contradictions between what you are experiencing and what you are thinking about" (2000, p. 13). Venturing outside dominant constructs is to take on the risk of not performing to social and cultural expectations. Because mothers are often called upon to care, protect, advocate for others, the role of activist appears to be a normal characteristic of the experience of mothering. This duty of care or obligation is imposed or expected of mothers and assumed as a condition of motherhood regardless of age, occupation, or social status.

Panitch (2012) describes situations where mothers are brought into roles of advocacy, not by choice or because of their actions, but because it was necessary to challenge decisions made by experts that affected her child's rights. Panitch calls such mothers 'accidental activists' to distinguish this role category. Michael Apple uses the term *activist selflessness* to indicate that mothers can mobilise maternal discourses as justification for taking actions that potentially can be reconstituted in the public sphere (2010, pp. 145–154).

I do not seek justification for actions that I took in River's situation but to indicate the problematic constitution of mother in the context of intervention referred to in this section. This then raises the question of who is this mother and what are her credentials to speak? Quite simply, it is the writer of this chapter. As feminist theorists and sociological research indicate, mother is not a composite, nor an *a priori* category. This mother is a member of the academy and worked as a lecturer in educational studies thus providing her with the knowledge and symbolic capital to exercise and mobilise academic skills of inquiry. My intervention describes an unpacking of discourse terms and policy rhetoric that depend on corporeal metaphors and signification of bodily difference that are not expressed *on the same basis* for students with disability.

Disability advocates and researchers iterate desires to uncouple historical legacies and medico-anthropological constructs of disability. The methodological problem is to gain insight into the experiences of disability without disabling such persons through unintended but consequential definitions and categories (Goodley, 2013; Slee, 2011). As students with disability are vulnerable in their interactions with education providers, new ways need to be found to change institutional practices. Research praxis itself may be such a stumbling block even if philosophically and ethically motivated to promote inclusion (White, Drew, & Hay, 2009; White & Drew, 2011). Mariotti (2012) also asked whether advocacy in contexts of disadvantage belied unconscious desires for recognition in a particular disciplinary field rather than fully addressing the needs of people experiencing disadvantage. Such ethical considerations underpin disability research studies and place some demands on researchers to find appropriate methodological approaches.

The methodology serves to clarify maternal intervention in this context. It is adapted from Paul Thibault's work titled *Brain, Mind and the Signifying Body: An Ecosocial Semiotic Theory* (2004). His work sits outside disability research;

however, it is considered ethically and methodologically appropriate for discovering insights into signifying, semiotic and linguistic-discursive practices of universities and for expanding the 'social' modelling of disability.

Identifying Paul J. Thibault

Paul Thibault is a professor in linguistics at the University of Adgar, Norway with an extensive publication record over the past thirty years. His theory of 'ecosocial semiotics' links very clearly to the unpacking of 'meta-grammar'; 'value-making distinctions'; and 'metafunctional ' hypotheses that are assembled and produced in meaning-making activities (2004, p. 47). To Thibault, such systems of meaning realise, produce, and regulate particular realities and their outcomes. More critically, signifying processes and linguistic structures invoke, invite, locate, position and align bodies as specific entities associated with those realities. In following a key point made by Vygotsky, Thibault recognises that language and cognition are not separate and discrete categories. Meaning-making activities are situated in social environments and in "interaction with others ... [that]... both precedes and guides and shapes the transition to the forms of 'inner' dialogue that we conventionally call 'thought'" (p. 49). The issue is to identify the 'seat of consciousness' that contains such thoughts (Thibault, 2004, p. 176).

> ... only through the attempt to understand the constitutive inseparability of these semiotic-discursive and physical-material cross-couplings and dynamics that we can adequately theorize our own and others' embodiments, our subjective experience of our ecosocial environments, our perceptions of our inner states and sensations and the meanings we attribute to these... as well [in] interactions with others. (pp. 9–10)

While Thibault does not provide a template, I intend to compare policy approaches adapted by universities relative to elite student athletes and those used for students with disability. I anticipate that this comparative analysis will serve to demonstrate the significance of the relationality and rationality of linguistic practices, symbolic meanings and cognitive interpretations of corporeal metaphors and signs. In keeping with the theme of 'accidental activist', it was in the context of maternal intervention that such policy and procedural differences were identified. The comparative analysis follows.

Corporeal Metaphors and Realities

Perhaps because it is so normal that we forget that university students and higher education institutions are made up of physical bodies. University regulations augment codes of behaviour and conduct required of academics, students and the public. Texts proscribe and describe procedures, policies, curricula, assessment alongside material and technological apparatus and regulations of governance and

compliance. Therefore when considering Thibault's conceptualisation of 'ecosocial semiotics', I identify universities as textually rich depositories constitutive of particular metaphorical and metacognitive applications deployed in meaning-making activities. I conceptualise River as a scripted body linked into semiotically and linguistically determined meanings and activities associated with university protocols, procedures and policies.

Using a sample of literature from university programs and policies, and compliance guidelines issued by the Australian Institute of Sport (AIS), I identify policies relevant to elite student athletes. I now explain the role of the AIS. The AIS is an Australian government funded athletic institute which was established in 1981. Its purpose was to recover Australia's sporting reputation and performance in international competition. The AIS now has a number of centres distributed throughout Australia and caters for an extensive range of sporting activities and is acknowledged as a centre of sports science excellence.[6] It has since added athletes with body differences.

Elite student athletes undertaking university studies require affiliation to specific sports organisations, institutes or bodies and must be participants in nominated elite athlete programs. Student athlete does not mean a recreational athlete or sportsperson. The AIS identifies these athletes and has a set of guidelines for universities to follow. Australian universities nominated as Elite Athlete Friendly Universities (EAFU) commit to AIS principles relating to the provision of flexible study and assessment options.[7] These are compared with those for students with disability.

DISCUSSION

In relation to assessment, enrolment and course related needs, AIS principles and guidelines suggest that EAFU nominated universities take on a reciprocal obligation to ensure that elite student athletes are not inconvenienced by university schedules, mode of delivery of curricula and assessment requirements. Recommendations include the ability to negotiate assessment deadlines, sit examination externally, including at hotels or wherever travelling, and have access to online materials and class notes for missed tutorials and practicals.[8] Substitute or make up alternatives over summer and or ability to swap between online and on campus modes are also offered depending on sporting commitments. Elite student athletes can take several leaves of absence when there are increased commitments to sporting events such as the Olympic Games and other forms of elite sports competition.

Language descriptors emerge discursively and semiotically as pre-conditions by which elite student athlete bodies are given high status in policy reasoning. In the context of elite student athletes, the policy context is framed as an *enablement* discourse directed by AIS recommendations. Requirements for *flexibility* are embedded reciprocally between the objectives of the AIS to maintain Australia's sporting reputation and the onus placed on universities to commit to national pride by modifying AIS academic programs to accommodate sporting commitments and

sports competition. I raise the question of whether students with disability are treated *on the same basis* as elite student athletes.

In terms of policy reasoning and procedures relating to the accommodation and management of students with disability, there are subtle but distinctive differences. Assessment, course and enrolment related needs are communicated through what may be described as an authority-power dynamic in which students with disability are required to plead for approval. Using language terms such as determined, dependent, subject to approval, submission of documentation, authorised medical or registered practitioners are written into sign systems of authoritative legalist power.

Attention to these subtle differences in policy framing and procedures illustrates that respective tones of language are very different. I hypothesise that what is being revealed linguistically is a subconscious bias peculiar and particular to Australian national ideology. Known as a 'sporting nation', this ideology is purportedly reflected through sports achievement. The AIS supports the national endeavour by supplying physical specimens that reflect the nation's self-image. Thus co-opted as state and political apparatuses, the AIS and universities represent sites of reproduction of state hegemony. Bodily different athletes are also inculcated into national discourse by their sporting achievements and by what their bodies signify and represent symbolically in projecting the ideals of a collective nation.

Disability discourse is framed in medico/legalistic/bureaucratic language in contrast to the less formal language used in AIS guidelines. Students with disability MUST provide original medical evidence to qualify for registration as well as submit other evidence from qualified professionals if disability is related to sight, sound or learning issues. The elite student athlete supplies evidence of participation in a sports competition or program. Notwithstanding that procedures are presumed to apply equally, the onus of proof appears to be more rigorous for students with disability. They must obtain certified medical documentation by registered practitioners as evidence of the health condition to prove it exists and has an effect on academic performance. The standard of proof does not appear to be as formal for elite student athletes in consideration of evidence required when applying for reasonable accommodation. AIS assurances suggest that elite student athletes will have positive outcomes because access to alternative modes of curriculum, delivery and resources is demanded. Although *commitment to equality* is signified in value statements, procedures and processes that universities endorse, students with disability must continually prove the status of their disability, including being made subject to further examination by university nominated medical or other qualified personnel should further proof be required.

I am not arguing that elite student athletes should not have access to flexible study arrangements but am pointing out discrepancies that suggest that there are discrete methods of accommodating student bodies. It then follows that policy reasoning differentiates athlete and non-athlete bodies on the basis that some are more equal and some are not equal than others. I am suggesting that evidentiary standards are

not applied equally if students with disability incur hardship in order to comply with requests for reasonable accommodation. The limitations of the chapter do not allow for an analysis of the legal status of compliance to AIS principles and guidelines and those indicated in the previous section. Further research may determine whether these parallel structures of administration and regulation of student bodies constitute discrimination. As Thibault indicated, particular activities and pre-conditions are constituted through metaphorical, metacognitive and metacorporeal signs and symbols which are articulated in hierarchies of difference. The 'seat of reasoning' in policy infers that procedural differences affect outcomes differently. Read in the context of River's experiences and disability standards in education, the core problem that maternal intervention identified is the issue of whether universities treat students with disability *on the same basis* as elite student athletes. Different procedures appear to compromise the spirit and intentions of disability standards to enable students with disability "to achieve learning outcomes; and ability to participate in courses and programs" *on the same basis* as other students.

This mother did not anticipate that different standards, programs and policies could apply to conditions for reasonable accommodation and that these are determined and justified by differentiating the status of student bodies. While education providers can cite unjustifiable hardship as an exemption in disability standards in education legislation, it does not address a situation where EAFU universities may endorse discriminatory practices despite statements of equality.

River's circumstances drew this mother into an invisible landscape of the management of disability in a university setting. In drawing attention to the relational status of student bodies, this intervention provided an alternative methodology to unpack policy reasoning in demonstrating how discursively and linguistically relayed texts of difference and disability are constituted. Intervention also demonstrated a need for further inquiry into non-democratic practices in universities that perpetuate discrimination through the justification of difference associated with physical bodies. The conclusion is purposeful in asking an open-ended question.

What Would You Do in this Circumstance?

Given reluctance to intervene in the first instance has led this mother to a different view on the accommodation and management of disability by education providers. The role of 'accidental activist' opens up opportunities to develop further inquiry into university policies and procedures and challenge scripts of failure attributed to students with disability.

NOTES

[1] River's story is authentic but fictionalised to safeguard individual and institutional anonymity. River's gender, age and type of degree undertaken are not revealed.

[2] Universities Australia (2014). *The Voice of Australian Universities.* ACT: Canberra. https://www.universitiesaustralia.edu.au/uni-participation-quality/students#.VOQXBS7fVIp

[3] Appeal by Kiefel on costs was dismissed. Mortimer, J. (2014). Kiefel v State of Victoria [2014] FCA 604. Federal Court of Australia: Melbourne.
[4] Department of Education and Training (2014). Australian Government. Canberra: ACT. http://education.gov.au/disability-standards-education
[5] Australian Human Rights Commission (2014). *Disability Discrimination Act Action Plans: A Guide for the Tertiary Education Sector.* https://www.humanrights.gov.au/disability-discrimination-act-action-plans-guide-tertiary-education-sector
[6] Matthew Eggins (2011). The AIS – An Icon for Excellence in Sport. http://www.ausport.gov.au/ais/about/history
[7] Australian Institute of Sport (2014). *Guiding Principles for Implementation of the National Network of Elite Athlete Friendly Universities* Canberra: ACT. http://www.ausport.gov.au/ais/personal_excellence/university_network/guiding_principles
[8] Australian Institute of Sport (AIS) Canberra: ACT (2014) http://www.ausport.gov.au/ais/personal_excellence/university_network/guiding_principles

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PART 4

THEORISING

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13. A TROUBLED IDENTITY

Putting Butler to Work on the Comings and
Goings of Asperger's Syndrome

INTRODUCTION

In this chapter I want to trouble Asperger's Syndrome (AS) just as Judith Butler and the scholars she has inspired have troubled any and all fixed identity categories. In particular, I want to queery Asperger's Syndrome and untether it from the foundationalist assumptions of a taken-for-granted 'ab/normal' body. I will use a selection of Butler's theoretical tools – performativity, intelligibility and discursive agency – to present a different version of Asperger's Syndrome, one viewed through the necessary constraints of subjectification and the predictable sorts of trouble that follows for those located within a politics of fixed embodiment. Specifically I will put Butler to work to interrogate an excerpt from a diagnostic interview in which a young boy was diagnosed with Asperger's Syndrome as well as a selection of posts to a discussion board thread at the Asperger's community support website WrongPlanet.net. Both of these data sources formed part of my PhD research, for which all appropriate ethical clearances were granted. The interviewed transcript and archived texts from WrongPlanet.net are subject to a discursive analysis using Butler's theoretical tools of performativity, intelligibility and discursive agency.

   Butler has not been widely taken up in critical disability studies, although scholarship such as Shildrick's (2009) queerying of 'leaky bodies', Samuel's (2006, 2002) intersectional studies of disability, race and gender and Corker's (1999) Deaf Studies have worked with her ideas around performativity to de-stabilise what is routinely and unreflexively considered to be an 'impaired' and 'disabled' body. Butler's work is reputed to be theoretically obtuse, unapproachable and difficult, although I suggest that it is the deeply radical threat that the notion of performativity poses to the ontological integrity of 'disabled embodiment' that may more accurately account for her virtual absence from disability theorisation and research. Butler's ideas around materialisation and the discursive constitution – and not mere mediation – of human bodies, seriously challenge the taken for granted a priori existence of disability via disabled and/or impaired bodies. In some very important ways, Butler's notion of performativity and its antifoundationalism challenge not just the 'reality' of disability, but the viability of disability identity and the larger rights-based, identitarian project of disability studies itself.

This chapter's work of troubling Asperger's Syndrome is vital given its uncritical yet widespread take-up as a category to name and know difference across the Global North in the last thirty years and its material effects in the lives of individuals and institutions alike. Its rapid popularisation contrasts sharply to its removal from the latest version of the DSM (APA, 2013) after only twenty-years short as a separate clinical diagnosis. This rise and fall is instructive in light of the Western sociocultural reliance, misplaced it would seem in the case of Asperger's Syndrome, on psychological diagnosis as a way of negotiating human difference. In this chapter I demonstrate how usefully Butler can be put to work to trouble this coming and going of Asperger's Syndrome and to provide novel and genuinely critical insights in the field of critical disability studies.

THINKING ABOUT THE BODY WITH BUTLER

Performativity is perhaps Butler's most influential idea and I will begin this reconsideration of Asperger's Syndrome by elaborating what this notion might mean for 'disabled bodies' generally and Asperger's Syndrome in particular. Butler's theory of performativity has profound implications for disability theorisation and disability identity because of its re-conceptualisation of embodiment, including 'disabled' embodiment, as a process of discursive materialisation. At the outset it is important to note that Butler's focus in the key texts articulating her theory of performativity (Gender Trouble, 1990; Bodies that Matter, 1993; Undoing Gender, 2004) is on the sex-gender binary and the heterosexual matrix that renders it intelligible, and not 'disability' or 'impairment'. Indeed she has paid little explicit attention (so far) to 'disability'; however, I suggest that since her theory of performativity amounts effectively to a theorisation of embodiment, it has obvious and important implications for the field of critical disability studies. This relevance for a critical study of disability is latent in Butler's thinking about liveable and grieveable lives and the normative discipline that is, in effect, the counting of who matters as 'human'. Consider this statement from Butler (1997) for example:

> How does materialisation of the norm in bodily formation produce a domain of abjected bodies, a field of deformation, which in failing to qualify as the fully human, fortifies these regulatory norms? What challenge does that excluded and abjected realm produce to a symbolic hegemony that might force a radical rearticulation of what qualifies as bodies that matter, ways of living that count as 'life', lives worth protecting, lives worth saving, lives worth grieving? (p. 15)

Interestingly in this excerpt, as in all of her key texts articulating performativity, Butler is not referring to disability or impairment, even though to a reader and student of disability studies it may seem that she must be and could only be through her use of words like "deformation" and "abjected". But this exclusion of 'disability' from even Butler's consideration of the "domain of abjected bodies" is indicative of

the disciplinary power of compulsory abled-bodiedness (McRuer, 2002), ableism (Campbell, 2009) or what might be dubbed, from a Butlerian perspective, the ableist matrix, and it remains true that disability as such has not (yet) figured in Butler's theorising about sex, gender, race and lately, religion. Yet, given that 'disability' and 'the disabled body' have been the spectres in excess, the constitutive outside, that police the boundary of 'worthy' human life, I argue that Butler's notion of performativity can and should be put to work to deconstruct the idea of 'disability' within the hegemonic ableist framework that structures dominant understandings of *which bodies* matter, *and who* comes to count as 'normal' and 'not normal' with/out the promise of liveable and grieveable lives. Given its almost profane popularity but sudden recent demise in DSM5 (APA, 2013) as a separate diagnosis and category of developmental disability, Asperger's Syndrome seems to provide a perfect opportunity to undertake this Butlerian task.

With this rationale in mind, it is timely to further clarify Butler's notion of performativity, specifically her arguments for discursive materialisation, for the necessary and inescapable realisation of embodiment through discursive normative frameworks. For Butler (1993), materiality "is bound up with signification from the start [although] to think through the indissolubility of materiality and signification is no easy matter" (p. 30). Butler is sometimes accused of being an idealist (see Fraser's and Benhabib's critiques in Benhabib et al. (1994) and for not adequately accounting for corporeality in her philosophy. This is, however, a misrepresentation of her position, as Butler (1994) makes clear when she states that she does

> not deny certain kinds of biological differences. But I always ask under what conditions, under what discursive and institutional conditions, do certain biological differences – and they're not necessary ones, given the anomalous state of bodies in the world – become salient characteristics of sex. (p. 34)

Barad (2003), who takes up and re-works Butler's notion of discursive materialisation in her own thesis of posthumanist performativity, also makes this point when she argues that a

> performative understanding of discursive practices challenges the representationalist belief in the power of words to represent pre-existing things. Performativity, properly construed, is not an invitation to turn everything (including material bodies) into words; on the contrary, performativity is precisely a contestation of the excessive power granted to language to determine what is real … performativity is actually a contestation of the unexamined habits of mind that grant language more power in determining our ontologies than they deserve. (p. 802)

Butler acknowledges corporeal bodily existence but insists that any understanding of what we come to know and how we come to count the *mattering* of bodies is a sociocultural and historical act situated and realised within power: knowledge configurations. As Jagger (2008) concludes, Butler's argument is "not that the

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materiality of bodies is nothing but a linguistic product, but rather that the concept of materiality is inescapably bound up with signification" (p. 62). For Butler (1993) language is crucial in this process and regarding the body she argues that

> It must be possible to concede and affirm an array of 'materialities' that pertain to the body, that which is signified by the domain of biology, anatomy, physiology, hormonal and chemical composition, illness, age, weight, metabolism, life and death. None of this can be denied. But the undeniability of these 'materialities' in no way implies what it means to affirm them, indeed, what interpretive matrices condition, enable and limit that necessary affirmation … We might perhaps want to claim that what persists … is the 'materiality' of the body. But perhaps we will have fulfilled the same function, and opened up some others, if we claim that what persists here is *a demand in and for language.* (pp. 66–67; italics in original)

Our bodily realisation is only possible, therefore, through the normative criteria sedimented in language and operationalised as discourse and Butler refers to this irreducible process as discursive materialisation. As she states "every effort to refer to materiality takes place through a signifying process which, in its phenomenality, is always already material" (Butler, 1993, p. 68). As I have already stated, Butler is not denying corporeality nor is she arguing that bodies are mere discursive constructions. Rather she is arguing that we can only apprehend our own (and others) bodily materialisation through discourse. Butler's discursive materialisation thereby denaturalises the body and removes 'abled' and 'disabled' bodies alike from taken-for-granted 'common sense', including the culturally authorised common sense that is the Diagnostic and Statistical Manual of Mental Disorders (DSM) – in any of its iterations. By centring embodiment – that is to say both theories about bodies as well as accounts of and 'experiences' of bodies – within fields of power-knowledge, Butler is able to explain not only the discursive materialisation of bodies but their very common sensical appearance as prediscursive, 'natural' and prior to culture. Butler (2003) writes that

> 'Materiality' designates a certain effect of power or, rather *is* power in its formative or constituting effects. Insofar as power operates successfully by constituting an object domain, a field of intelligibility, as a taken-for-granted ontology, its material effects are taken as material data or primary givens. These material positivities appear *outside* of discourse and power, as its incontestable referents, its transcendental signifieds...When this material effect is taken as an epistemological point of departure…this is a move of empiricist foundationalism that, in accepting this constituted effect as a primary given, successfully buries and masks the genealogy of power relations by which it is constituted. (p. 34–35; italics in original)

By denaturalising the body, Butler collapses the distinction of *biological* sex from *cultural* gender back into the field of power: knowledge. However, it is important

to re-iterate that she is also folding the material and the discursive into each other, as irreducible, if also incommensurable *and* mutually constitutive. Butler (1993) writes that

> what is at stake is less a theory of cultural construction than a consideration of the scenography and topography of construction. This scenography is orchestrated by and as a matrix of power that remains disarticulated if we presume constructedness and materiality as necessarily oppositional notions. (p. 28)

PERFORMING DISABILITY? DISCURSIVE MATERIALISATION AND 'THE DISABLED BODY'

For Butler (1993), "ontological weight is not presumed, but always conferred" (p. 34) and this conferral must apply equally for 'disabled' bodies as any other sorts of bodies because "a body schema is not simply an imposition on already formed bodies, but part of the formation of [all] bodies" (p. 54). In this way Butler demonstrates the ways in which performativity, as a citational chain within a field of intelligibility, links the process of discursive materialisation with subjectification, although this description implies a separation between materialisation and coming into being that is artificial and better understood as culturally and ontologically compelling: "the subject and the repetition of acts are not separable … [and] the body is performatively produced as such through the sedimentation of 'corporeal styles' in a 'stylized repetition of acts'" (Jagger, 2008, p. 53). This brings us to the nub of Butler's (1993) theory of performativity as "not a singular or deliberate 'act', but, rather, as the reiterative and citational practice by which discourse produces the effects that it names" (p. 2). Crucially, for the oppressed and disadvantaged, it is within this very chain of citations and performative re-iterations that agency and change are made available. Since discursive materialisation produces bodies from within the hegemonic morphological imaginary – but only performatively, through the repetition and reiteration of discursive norms – citational backfires are possible and the reiterative signifying practice at the heart of Butler's notion of performativity also offers, simultaneously, the possibility for re-signification and re-embodiment. For Butler (1993) existence requires us to be signified – that is aligned along the grids of intelligibility that prevail in any given sociocultural context – in order to be recognisable to ourselves and others, and while these normative discursive frameworks—the grids of intelligibility—precede us, Butler (1993) argues that opportunities for discursive agency arise when, as they occasionally do, these chains of signification backfire, providing moments of agency within an overall field of constraint. It follows from a Butlerian perspective that it is through our participation in these performative acts, these citational chains that configure our subjectification that opportunity for re-signification and thus alternative embodiment, can arise.

As Butler (1993) argues "the radical difference between referent and signified is the site where the materiality of language and that of the world which it seeks to signify are perpetually negotiated" (p. 69) and the "constitutive demand" (p. 67) for being *signified* that is satisfied through performativity, opens discursive norms to alternative imaginings and revision, even if the outcomes of attempted re-signification are not determinable in advance. This conception of embodiment is interesting to take up in relation to 'disability', which is where we now turn in order to analyse, from a critical disability perspective, alternative explanations for the comings and goings of Asperger's Syndrome.

<p style="text-align:center">ASPERGER'S SYNDROME: THE REGULATORY IDEAL</p>

Asperger's Syndrome was spoken into existence in the early 1980's by British psychiatrist Lorna Wing (1981) in her appropriation of the clinical work of the Austrian paediatrician Hans Asperger (1944), most notably his doctoral study of 'autistic psychopathy' undertaken in Vienna in the 1940's. However, its genealogy reaches back to the Enlightenment at least. It is a complex history, bedded into sociocultural conditions and discursive figurations that, although worthy of scrutiny, largely lay outside the parameters of this chapter. Yet in order to deconstruct Asperger's Syndrome as a regulatory ideal, some of this history needs to be canvassed, if only briefly. Much as Lenard Davis (1995) has argued about Deafness in his chapter *How Europe became Deaf in the Eighteenth Century*, I argue that Asperger's Syndrome is also historically contingent and its emergence in the West in 1940's Vienna and reinvention in London some forty years later, was no coincidence. Rather, the time was ripe for 'Asperger's Syndrome', as its popularity as a diagnosis of choice in the Global North and its take-up in popular culture make evident. My argument here builds upon the work of Nadesan (2005) and Waltz (2013), and before them, Nikolas Rose (1996), in locating the emergence of Asperger's Syndrome within a wider discursive field, as a culmination of the Enlightenment project and the requirements of modern institutions to manage and domesticate the differences of large 'unruly' populations. I don't have time in this chapter to go into detail, suffice it to say that 'Asperger's Syndrome' as a category for 'knowing' and technique for disciplining difference, was unnecessary and culturally inconceivable in the West before the rise of the 'psy' sciences, the birth of the clinic and the instigation of compulsory mass schooling. It is no accident that all of Asperger's and many of Wing's case studies were referred to their clinics for assessment and intervention by head teachers and other teachers at schools, troubled by the behaviour of these unhappy students.

Asperger's Syndrome became available as a medically authorised diagnosis with its inclusion into the Diagnostic and Statistical Manual of Mental Disorders in DSM IV in 1994 (APA, 1994), just a decade after Wing's resuscitation of Asperger's original work. It rapidly gained popularity as a diagnosis of choice for young boys (typically of aspirational, middle class parents) who were referred for assessment and treatment to developmental psychologists and other clinical experts by teachers

and guidance officers because of the ways in which their behaviour *appeared* to cause particular sorts of school trouble. By the turn of the twenty-first century, just a decade on from its inauguration in DSM IV, Asperger's Syndrome was represented in popular media as an 'epidemic', sweeping through the young male affluent populations of the Global North. As a diagnosis and category of 'difference', it has always had an uneasy relationship with Kanner's autism, the diagnosis it often polarises (in more ways than one) on the reified spectrum of autistic disorders. But this is a different story for a different chapter.

As a regulatory ideal, Asperger's Syndrome normalises a particular apprehension of behaviour that represents certain people as obsessive, aloof, anti-social, uncommunicative, unempathic and generally disinterested in 'normal' human affairs. Hans Asperger (1944) described, "the shutting off of relations between self and the outside world" (p. 39) as the "common denominator" (p. 39) shared by his autistic patients. He typifies his autistic patient as, "like an alien, oblivious to the surrounding noise and movement, and inaccessible in his preoccupation. He is irritated only if someone breaks into his isolation" (p. 78). This metaphor of 'aliens from another planet' has been taken up and reworked by people identifying themselves with Asperger's Syndrome, as will be discussed in an upcoming section of this chapter. The regulatory ideal that Asperger instigated is so pervasive as to be instantly recognisable: Asperger (1944) incites this unmistakability when he writes that

> Once one has properly recognised an autistic individual one can spot such children instantly. They are recognisable from small details, for instance, the way they enter the consulting room at their first visit, their behaviour in the first few moments and the first few words they utter. (p. 68)

Asperger (1944) figured autistic psychopathy as a type of "personality disorder" (p. 87), albeit "an inherited disposition" (p. 86) incorporating "genetic and biological factors" (p. 84) and it was on the basis of his assessment of the four children who constituted his case study cohort – V. Fritz, L. Harro, K. Ernst, and L. Hellmuth – that the template for Asperger's Syndrome was originally mapped. Asperger (1944) describes

> a particularly interesting and highly recognisable type of child. The children I will present all have a common fundamental disturbance which manifests itself in their physical appearance, expressive functions and, indeed, their whole behaviour. This disturbance results in severe and characteristic difficulties of social integration. In some cases the social problems are so profound that they overshadow everything else. In some cases, however, the problems are compensated with a high level of original thought and experience. (p. 37)

This template remains recognisable, unsurprisingly, in Wing's (1981) figuration of Asperger's Syndrome produced in the early 1980's, although her map is oriented along the following seven axes: speech, non-verbal communication, social interaction,

repetitive activities, motor coordination, skills and interests and experiences at school. Although Wing disputes two aspects of Asperger's original profile – about the acquisition of spoken language in relation to walking and secondly regarding propensities for originality and creativity – she endorses his work so strongly as to name her re-appropriation of his original work in his honour, as Asperger's Syndrome. So while Lorna Wing modified Asperger's original formulation and renovated it to better fit the cognitive, neurological and genetic theories of human behaviour dominant in the early 1980's, it remains true that the edifice of what we now know as 'Asperger's Syndrome' was built upon only ten clinical case studies – six from Wing's clinical account augmenting Asperger's original cohort of four. According to Wing, and to nearly all of us who believe we encounter it, Asperger's Syndrome can be recognised

> as a lack of empathy; one-sided or naïve interaction; difficulty with friendship formation; pedantic repetitive speech; poor nonverbal communication; intense preoccupation with certain subjects; and poor gross motor coordination, regardless of intelligence. (Burgoine & Wing, 1983, p. 261)

This work of instant recognisability, this discursive realisation of Asperger's Syndrome as a regulatory ideal, was taken up conscientiously by many recruits in various fields of practice throughout the Global North over the last thirty years. Indeed not only did Asperger's Syndrome become a popular diagnosis, it was so popularised by public media as to become a pervasive (and instantly recognisable) trope in popular culture. The troubled, difficult oddballs of Mark Haddon's (2003) *The Curious Incident of the Dog in the Night-Time* and Jodi Picoult's (2010) *House Rules* and the nerdy geeks *of The Social Network* (Fincher, 2010), *House M.D.* (Shore, 2004–2012) and *The Big Bang Theory* (Cendrowski, 2007)*, to give just the most 'successful' examples, illustrate the pedagogical effects of the regulatory ideal as they are played out in popular culture.

Popular culture, however, is just one facet of the public pedagogies instrumental to the institutionalisation, reification and commercialisation of Asperger's Syndrome. The psy-sciences remain central to the authorisation of the popularity of Asperger's Syndrome, despite the increasingly distributed nature of diagnostic expertise (largely to teachers and other producers of culture) and the variety of instruments for self-diagnosis available readily on the World Wide Web, like Cambridge University's Asperger's Quotient Test (The AQ Test, 2014). Yet clinical authorisation remains necessary to access government support for Asperger's Syndrome (like 'special' treatment/education in schools) so we shall now turn to a series of excerpts from a transcript of a diagnostic interview conducted in 1998 by perhaps the leading international clinical expert in Asperger's Syndrome to demonstrate just how easy it is to be captured and subjectified by a regulatory ideal.

CAPTURING *BEING CAPTURED* BY THE REGULATORY IDEAL

This interview was conducted in 1998 by a clinical psychologist who had by that time established himself as a leading international figure in the field of Asperger's Syndrome. This clinician had trained in clinical psychology in England, qualifying with his undergraduate degree in 1975, and had subsequently completed his doctoral studies into Asperger's Syndrome in London under Uta Frith (at that time herself a dominant figure in the psychiatric understanding of autism), in the wake of Wing's resurrection of Hans Asperger's original clinical research. He had also, in the same year as the diagnostic interview, published a guide to AS for parents and professionals, a best seller that was reprinted four times in its year of publication alone. This clinician was making regular appearances on television and radio and had a rapidly growing clinical practice specialising in Asperger's Syndrome, indeed the family had to wait many months before an appointment was available to schedule their interview. Also, by this time, Asperger's Syndrome had been ratified as a pervasive developmental disorder, separate from autism, in the DSM IV (APA, 1994) as well as the ICD 10 (WHO, 1990) and diagnostic rates for Asperger's Syndrome throughout the global north were being reported as having 'skyrocketed': it was an increasingly popular and popularised diagnosis and this clinician was at the key nodes from which this popularity was emanating.

The family consisted of a boy aged five, the subject of the interview, and his parents (mother and father). The five year old was currently enrolled at a state preschool in preparation for entering Year One the following year. It was part of this clinician's practice to undertake an audio recording of his diagnostic interviews, which was then provided to the family for their information and review. It is a transcript of this initial diagnostic interview that provides the data for this analysis. Both the family and the clinical psychologist gave their written consent for the author to use the interview transcript for research purposes and this permission was governed through institutionally granted ethical clearances. The interviewed transcript was subject to a discursive analysis using Butler's theoretical tools of performativity, and intelligibility as highlight how the event of diagnosis was also a process of subjectification for the child in question. The interview lasted for approximately one hour and was conducted in the psychologist's office, housed within a suite of medical professionals.

The boy's father undertook most of the child care and home care work and his mother, who worked as a primary school teacher, earned the family's income. The process that culminated in this interview was triggered by the child's preschool teacher, who had expressed concerns about his social behaviour at school. She told the parents that the child reminded her of another student she had taught the previous year who *"also"* had been diagnosed with Asperger's Syndrome. She strongly encouraged the parents to agree to her request for an initial Guidance Officer assessment with a

view to scheduling an appointment with the clinician, whom she nominated, to take advantage of the proximity of his expertise. Time, it seemed, was of the essence and action was needed, now. So, the regulatory ideal of Asperger's Syndrome the normative discursive framework that rendered it (instantly) recognisable and intelligible, was already being brought into operation by the diagnostic reflex (Harwood & Allen, 2014) of this child's school teacher, even before the child was assessed by one of the school district's assigned Guidance Officers. As conscientious parents, committed to their son's wellbeing and development, and trusting in the professionalism of their son's teacher, they supported her actions and provided the appropriate formal consent. Subsequently, the Guidance Office visited the child's preschool, observed the child and conducted a series of standard intelligence tests, concluding that the boy had 'a profile' *typical* of AS. She endorsed the preschool teacher's view that an appointment with the clinician should be scheduled as soon as possible since an official diagnosis would be necessary to address the child's 'special learning needs' in primary school. A report (including the test scores), prepared by the Guidance Officer in consultation with the preschool teacher, was forwarded to the clinical psychologist in advance of the family's scheduled appointment. I describe this lead up to the interview because it demonstrates the distributed nature of the regulatory ideal and how significant diagnostic allies are dispersed throughout likely zones of appearance in order to activate the process of pathologisation. The preschool teacher was positioned to be alert for children whose behaviour or pattern of development differed from 'normal children' and she was authorised – not just by her professional duty of care, her employing authority Education Queensland, but also implicitly by the child's parents – to access the resources and instigate the interventions that this child's apparent differences appeared to necessitate. The Guidance Officer, who was specifically trained in educational (child) psychology, was recruited to provide the evidentiary rationale (via the observation checklist and IQ scores) for this intervention. The clinical gaze, noted by Rose (1996a, 1999), was here taken up by all participants in the (already diagnostic) process – except the child himself – so that a diagnosis of Asperger's Syndrome had already been unofficially conferred by the oversight of others. All that remained was the disciplinary seal of the notarised expert. This is not to suggest a conspiracy of intent, rather, to illustrate the pervasive power of circulating discourses.

The interview transcript begins with the psychologist speaking knowingly, familiarly of the child. His opening statement begins with:

> I'll just go through a few things. First of all Evan is he looks like any other kid. There's nothing that physically distinguishes him and certainly he's intelligence is brilliant, from the testing. But it does show quite clearly that there are unusual aspects of his socialising, in his language development in a way and in some aspects of his play. On the social side, it's quite clear that for Evan sometimes he's more interested in what we're doing than in how we're socialising. It's what you produce rather than how you cooperate and

when he's interested in something, he's entranced by the activity rather than the opportunity to play with somebody.

Although the psychologist did spend the first twenty minutes of the hour long interview 'playing' with the child, it was on the basis of this restricted interaction and the Guidance Officer's report alone, filtered through his expert knowledge and experience with the diagnostic framework (the regulatory ideal) of Asperger's Syndrome, that he confidently summarised and pronounced these essential and 'disordered' aspects of the child and his behaviour. Within moments of his previous statement, the psychologist re-iterated these key features as indicative of the child's differences. He said

> His profile is unusual, in a number of ways. So basically what we've got is somebody who is who looks normal, no physical features, intelligent, but socially is a bit aloof, who seems to enjoy his own company, wants to probably control the activity and do it his way so that when he's playing with other kids, if they're being flexible and in different directions, he's probably going to be not very comfortable with that because he's got his own thing in mind and he probably wants to do it his way.

The child, by virtue of his 'profile' and its similarity to the template 'Asperger's Syndrome' is quickly disciplined, and his past, present and future ordered via the psychologist's expertise and techniques. At this stage of the interview, the psychologist had not asked the parents any questions or requested any information from them about the child. He privileged the Guidance Officer's report and his own knowledge. Through his speech, the psychologist is representing the child as always having had AS, implying from the outset, that the purpose of this interview was to draw into public awareness, including the institutional domain of the school, an existing 'reality' about the child. The past was telescoped into the present so that the child's likely future could be mapped and the child himself disciplined into intelligibility through the subjectification of Asperger's Syndrome.

From the interview's outset, the psychologist works to fit the child's behaviour into the existing category of Asperger's Syndrome and reframes the child's "shyness" as problematic because apparently 'developmentally inappropriate' and a typical. He says

> It's also clear that at times in the social interaction, he is hesitant because he's unsure of how to relate to strangers. Ah he's a bit cautious of what they may do so he's not robust or confident in the social side of life. It's also apparent that when we are interacting, he doesn't look as much at others as you would expect. *Now it's not just simple shyness.* (Italics added)

This is despite the child's consistently polite behaviour and well-mannered but otherwise unremarkable play during the interview, as evidenced in the original audio-recording and subsequent transcript of the diagnostic interview. Several

similar indicators of 'normal' behaviour and development are ruled out through the psychologist's efforts to make the diagnosis of Asperger's Syndrome stick. The child's awareness of and interest in being observed during the interview, as well as his attempts to involve the psychologist in his ongoing block play, are interpreted through the clinical lens as a problematic shyness and an abnormal wariness of strangers. The psychologist states

> So um, it's noticeable that although he's playing constructively he's made he makes reference to you when he was anxious that I was a stranger, for emotional support, but what he's not doing quite so much is the showing off, the 'Look at me Mum, look what I'm doing' that I would normally expect at this stage. So in other words, once he becomes entranced with what he's doing, it's like people disappear and the activity overrides everything else and he is almost in his own little world when doing those activities.

Other interpretations of these behaviours are available, but the psychologist prefers to read them as indicators of Asperger's Syndrome, as aloofness and obsession, both classic autistic tropes, rather than as acts of sociability and efforts to engage with others to receive support and acknowledgement. The five year old and his family left the hour long interview with a diagnosis of Asperger's Syndrome and the regulatory ideal accomplished its effects of recognisability, intelligibility and subjectification. Asperger's Syndrome had been discursively materialised; the five year old is subjectified and now embodied a pervasive developmental disability, of unknown cause and uncertain, contentious 'cure'.

BECOMING ASPIE: DISCURSIVE RESIGNIFICATION?

As Butler (2004) makes clear, performativity is an uncertain matter, and makes matter (and mattering itself) uncertain. The history of Asperger's Syndrome also makes clear that the citation of regulatory ideals can play out unpredictably and this is evident in the ways in which Asperger's Syndrome has been performed differently in other sites and spaces, like the World Wide Web. People who identify with Asperger's Syndrome have actively taken up the opportunities for contact and community that cyberspace provides and it is arguable that in its liminality, the internet is an "interruptive, interrogative and enunciative (space) where new ways of being and innovative kinds of cultural meaning can be brought into existence" (Russell, 2006, pp. 3–4). In this section I turn to a particular website, WrongPlanet.net, as an example of how the nexus between recognition and intelligibility and the *re*-citation of a regulatory ideal can realise different performances of Asperger's Syndrome and perhaps even its re-signification, given the affordances of a very different space. A selection of text-based postings to the archived discussion board thread *Why is Asperger's such a negative thing?* at WrongPlanet.net throughout April 2007 are analysed discursively using Butler's theoretical tools of discursive resignification and discursive agency to demonstrate how Asperger's Syndrome was made to *matter* differently, in a different,

non-clinical space, through a different performance by people identifying differently with Asperger's Syndrome.

WrongPlanet.net describes itself as an online resource and community for individuals with autism and Asperger's Syndrome, includes a chat room, a number of general and special interest forums, a dating section as well as articles advising how to deal with day-to-day issues (WrongPlanet.net). The website claims to have over 80,000 registered users and its emblem is a small green sci-fi 'alien' sitting atop an unfamiliar planet (WrongPlanet.net). On WrongPlanet.net another regulatory ideal comes into play and is made explicit: Many posters to the website draw attention to the abled/disabled binary by referring to neurotypically developing persons, people who in other venues may be called 'normal people', as "neurotypicals' or "NT's" for short. In relation to these NT's, many posters to WrongPlanet.net identify themselves as 'aspies', a moniker of pride and affiliation with Asperger's Syndrome that is now widespread. In responding to the discussion thread *Why is Asperger's such a negative thing?* Sallyandjack reply by reframing the question itself with "A better question would be 'Why do people treat Asperger's like such a negative thing?" Other posters reposition themselves as aspies in other than disabled ways and indeed many posts articulate a counter-hegemonic view to 'normal' ability as being deeply flawed and imperfect, thereby conspicuously inverting the abled-disabled binary. Merle, for example, posts that "I have noticed instant hostility from some NTs … they react to it like a magnet reacts to iron … they really can't understand what goes on inside of us. They just don't have the capability." Sinsboldy posts along similar lines to the same thread arguing that it is neurotypicals (but perhaps not the regulatory ideal itself) that have the problem when s/he writes, "Humans (or at least NT's) are naturally wired to dislike those who are different from them. They cannot comprehend something as different from them as autism or Asperger's, so they view it as defective." Stevo_the_Human's contribution problematises and criticises the behaviour of NT's while still avowing the biology-driven genetic discourse that underpins its regulatory ideal when s/he posts

> NT's for the most part are driven by their instinct, not all of them, but most of them are deeply prejudiced and non-thinking robots, slaves to their baser automatic thought processes that they are scarcely aware of … All humans on the whole in my estimation are little more than glorified bacteria running ancient survival programs that are not designed for our modern technological world, they are petty and tribalistic, its small wonder that the world is filled with war and poverty.

Whilst it is unclear if Stevo_the_Human is including aspies within the category of 'humans', regardless, this is a strident othering of "NT's", typical of the binary inversion that is represented in this WrongPlanet.net discussion thread. The regulatory ideal of 'normal human development' is deployed in unexpected and revisionist ways by these poster as they perform 'Asperger's Syndrome', and themselves as

'aspies', as different (to normal others), but not disabled. Through their re-citation of both these regulatory ideals, 'normal 'neurotypicality and 'disabled' Asperger's Syndrome are re-signified, and 'aspie' is, as an effect, performed in new and interesting (if still problematic) ways.

The discursive agency demonstrated by the posters to this discussion board thread on WrongPlanet.net queries, or at least makes seem queer 'neurotypicals', whilst leaving the normative discursive framework that supports the regulatory ideals of both 'normality' and 'Asperger's Syndrome' in the frame. By simply inverting the binary, by manoeuvring oneself in relation to the polar opposite so that one is positioned *to other*, rather than *be othered*, the grounds of intelligibility and recognisability are unrenovated. But while Butler (1993) notes that the effects of resignification cannot be known in advance, she does remind us that hope (for us all) remains in a persistent and pervasive queering of *all* identity categories when she writes that "'queerness' might be understood not only as an example of citational politics, but as a reworking of abjection into political agency that might explain why 'citationality' has contemporary political promise" (p. 21). Presumably this is regardless of who is abjected and who is abjectifying. Chris, perhaps of all the posters to this WrongPlanet.net thread, queeries the regulatory ideal of Asperger's Syndrome in the most profound way, not by othering "NT's" but by troubling what Asperger's Syndrome can be through his/her own discursive materialisation of it. Wing's version of Asperger's Syndrome is *not* 'instantly recognisable' as Chris posts

> You will find NT's will not take to you as well as AS people will, with some exceptions … it seems all NT's seem to dislike or are uncomfortable around those who are different. Just because (we) see things differently, and it's not what NT's come to expect, which is sad, as they need to acknowledge us and understand us, one issue with AS is the lack of awareness from NT's, they expect everything to be like them. However as much as they wish to find a so called 'cure' for us. I say you need to stand tall, you are not diseased, and you may feel that AS has its issues, when I was first diagnosed at 13, I first saw AS as a big problem, however five years later, I am more at ease with it as I have discovered much more about it, thanks to books, Wikipedia and WP, you are a unique person ☺ you have a unique viewpoint which only we can understand, people should not expect you to change, you should expect them to get used to you, as you have done nothing wrong, and it's only NT's fault if they can't understand, I'm not being hostile to NT's as I have met some really nice ones who want to give others a good chance. But you have a very interesting view of the world, and we should not expect you to change, you are unique, and it's cool ☺believe me, I value the fact that AS gives me independence, I don't require to stay by the crowd, I don't need to rely on big groups of people, I can be content and manage by myself, and you can to. ☺ Just hold you head up

high, and say you are different, and proud of it, and besides, do you really want to be like everyone else? ☺

I hope that helps ☺

Chris.

CONCLUSION: UNDOING ASPERGER'S SYNDROME? BEYOND THE DSM

In the latest version of the DSM (APA, 2013), Asperger's Syndrome was removed as a separate diagnosis and it is anticipated that it will also be removed from the ICD (WHO, 2010), which is also currently under review pending the publication of a new edition. This was a highly contentious if well telegraphed change and the APA has devoted a lot of money and time to spruiking its 'necessity' on 'scientific grounds', arguing that it was a long overdue tidying-up of an historic anachronism, since any difference between Kanner's autism and Asperger's Syndrome was merely nominal, brought about by history, geography and the interference of a pesky world war (Murray, 2008; Nadesan, 2005; Wing, 1997). In any case, both have been overridden in the latest version of the DSM, the DSM5, by the now reified spectrum of autism *disorder* (singular). Regardless of the rationale, it is a socioculturally significant move, especially given the industry and commerce – 'scientific' and cultural – that Asperger's Syndrome has generated. Massive future profits have seemingly been sacrificed in order to reign in a diagnosis that seems to have taken on a life of its own. Asperger's Syndrome, as a phenomenon, has been disciplined by the APA and will no longer, it seems, be allowed to travel so loosely, so promiscuously, so unpredictably in the world. What will not be admitted is the risk to psychiatric authority (and to the pursuant ownership of categories of difference and the licence to apply them) that the re-signification of 'Asperger's Syndrome' through 'aspie' identification and community, posed. By removing Asperger's Syndrome, the APA has shored up their industrial monopoly as well as their categories and their categorical imperative to diagnose. In this way, aspies troubled normalcy (Davis, 1995) itself and have been disciplined for it by the recapture the framework of intelligibility and the renaming of the regulatory ideal of 'autism disorder'.

Of course, the trouble with Asperger's Syndrome is far from over, as the burgeoning neurodiversity movement demonstrates. It is also far from problematic as is made clear in Runswick-Cole's (2014) analysis of the politics of the 'us and them' binary at the heart of the current neurodiversity movement. She cautions about the ways in which this re-configured, but not radically re-constituted polarity, dovetails with neoliberal agendas, constraining creative coalitions grounded in a different, open politics of becoming. This recent cultural experience of the diagnostic annihilation of Asperger's Syndrome is a reminder of the trouble with *all* fixed identity categories, especially those requiring particular sorts of embodiment, specific sorts of mattering, including re-signified ones like "aspie" and "NT" that

appear, on the surface at least, to offer an escape from negative subjectification. As Butler (2009) suggests, "it is on the basis of this question 'who counts as a subject and who does not?' that performativity becomes linked with precarity." While posters to the WrongPlanet discussion board may come to matter differently because of their re-signification of the regulatory idea of Asperger's Syndrome, while they may perform Asperger's Syndrome in this space in new and interesting ways, this re-signification, any re-signification based upon self-identification, was bound to be felt as a challenge to the authority of the APA (representing Psychiatry) to own and authorise the taxonomies and the technologies for determining, officially, what will count as 'Asperger's Syndrome' and who will determine, through properly authorised diagnosis, precisely who has 'it'.

The challenge remains for us all to trouble normalcy (Davis, 1995) for ways to live within the constraints of discursive subjectification, ways that allow as many people as possible "to live in new modes of existence, ones that are not finally recognisable but still allow us to live" (Butler, 2009). To this end, in what ways can critical disability scholars, advocates and allies in coalition with people who identify as neurodiverse, work together to challenge the hegemony of the APA's revised regulatory ideal 'autism spectrum disorder' to make the most of its citational misfires and to open up new spaces for becoming and mattering differently, together? Butler (1993) argues that we are all discursively signified and that we are embodied through our placement within the grids of intelligibility that constitute our very existence as subjects. It would seem therefore that critical, creative work at the very sites of recognition and intelligibility, such as the education and ongoing professional development of teachers and psychologists, working to capitalise on the misfires of the new DSM5, are a couple of handy places to begin. That is more than enough good trouble to be getting on with, since as Butler (2004) also asserts, "Let's face it. We're undone by each other. And if we're not, we're missing something" (p. 19).

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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

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.

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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15. A HIDDEN NARRATIVE

Reflections on a Poster about Young People with
Health Conditions and Their Education

INTRODUCTION

The purpose of this chapter is to examine how ideas are communicated, particularly regarding children and young people who live with serious health conditions. The research artefact of interest here is a poster displayed and presented at the American Educational Research Association – Disability Studies in Education 2014 Melbourne conference (DSE conference). Issues underlying the preparation, presentation and reaction to that academic poster are discussed throughout this chapter, which is structured into three main sections. Following a brief consideration of creativity and knowledge production processes, the first major section provides contextual information about the poster development and the students under discussion. Secondly, research about this cohort of young people with serious health conditions is connected with political context and theoretical perspectives within disability discourses. Finally, the communication success of the poster is examined, concluding that the provocations contained in the poster did not provoke anticipated reaction. Turning the analytical lens onto the poster itself, rather than the intentions and aims of the authors or the conference and its delegates, resulted in the realisation that what it failed to provide was narrative connection for those reading the poster.

CREATIVITY AND KNOWLEDGE PRODUCTION

Many theoretical conceptions about creativity exist, but it is Feldman, Csikszentmihalyi and Gardner's (1994) notion of creativity as the process of 'going beyond' that offers something of interest for this discussion. By moving beyond the safe and the known, researchers advance knowledge and research practices through fresh explorations and explanations, articulating concerns and perspectives beyond what is familiar. The abstract submission deadline for the DSE conference prompted me to wonder if an academic poster might offer more in terms of creativity, communicative possibility and contribution to knowledge than the preparation of another twenty-minute conference presentation.

   The production of knowledge tends to advance slowly through academic communities with the scholarly publication of journal articles and books often

beginning with spoken conference presentations. While it is possible to communicate in many different ways, the usual main course at the conference table is a spoken presentation with the ubiquitous PowerPoint slide show adding salt and pepper. Ideas were presented at the DSE Melbourne conference in various spoken forms including keynote addresses, themed symposia, panel discussions, formal question and answer sessions following individual paper presentations, as well as informal conversation and interaction. It seemed that many of the presentations at this conference focused on specific impairments or conditions, with binary medical versus social models of disability still retaining currency. In their keynote presentation, Dan Goodley and Katherine Runswick Cole shook things up a little by employing contemporary theory and communication tools like Twitter and images to advance theoretical conceptualisation and their activist agenda. Athina Zoniou-Sideri's senior scholar address in English was a triumph and Ben Whitburn, who won the conference Junior Scholar award, won the hearts and minds of delegates with his engaging and challenging keynote. Our poster, however, stood alone and remained isolated at this conference.

CONTEXT FOR THE POSTER

My co-authors of the poster (see acknowledgement) brought both research and practitioner perspectives. We had already collaborated on many projects and, together, our knowledge and passion about this group of children and young people and their education is strong. The practitioners among the group have worked for many years in education support programs, hospital transition programs, advocacy and management of national support services. Academic perspectives come from educational and sociological research, specifically about these young people in Australia. However, we were not sure how these ideas would be received at the DSE conference.

We decided early on that the main function of the poster was to provide a summary of important educational concerns about these students and we hoped that moving away from the standard presentation format might assist in evoking a response. However, because we were so preoccupied with negotiating such clear wording and choosing the right images for the poster, I suspect we forgot to pay attention to how the poster would be 'read' and whether we were communicating key ideas.

Ours was the only poster at that conference and while delegates tended to be polite and positive, few engaged with the ideas presented, beyond mild interest as they walked past on their way to collect their lunch. The authors had imagined the poster would be provocative and spark interest leading to dialogue and debate. In contrast, the response was decidedly lukewarm.

The first aim of the poster presentation was to provide information to raise awareness about this growing group of students and their educational entitlements. The second aim was to provoke reaction to the key idea that students with health conditions needed to simultaneously (a) be included in disability discourses and (b) to also stand apart in order to be noticed.

COUNTING STUDENTS WITH HEALTH CONDITIONS

Alternative terminology about the young people in question includes 'serious illness', 'chronic illness' or 'disabled'. More often these young people are referred to by their diagnosis: 'the kid with that weird immune system problem', 'the one with cystic fibrosis' or 'the kid who is away from school a lot'. I have chosen to use the term 'health conditions' as it is consistent with terminology in disability policy and doesn't beg questions like: Who decides what a serious illness or significant medical condition entails? And what criteria should be used to determine this? The term 'chronic' implies long-term, but for some young people—like those who survive cancer—the illness might over in a couple of years, but implications for educational performance remain. Depression for young people with health conditions is reported as common in the literature from medical, health and psychological fields. For education, however, medical details should not be the main concern. It's how the health condition impacts on the young person's capacity to attend school, participate and to achieve that should be of interest within educational policy, systems, schools and classrooms.

The different health conditions, with which the students in question live, tend to be difficult to manage on many discursive levels. 'Health conditions' are not usually grouped together, even though this makes sense for education, which is why talking about a cohort of students is important. And while disability policy and discourses include those who live with health issues, they do tend to be tacked onto the end of lists, possibly as a 'politically correct' afterthought. Those children and young people, who live with health conditions, do not usually have any obvious visible signs of their conditions and often don't realize they have a legitimate place within disability. They are frequently the only student in their school with such challenges and can be easily overlooked, with many trying to 'pass' as an ordinary student, because being ordinary is such a novel experience for them (White, 2014; Yates et al., 2010).

Extraordinary achievements in biomedical science in recent years have meant that the lives of many children and young people have been significantly extended. Those who would have previously died are now living longer, well into adulthood. Childhood cancer, for example, although a very small part of this cohort is nevertheless astounding as it nowadays has such a high survival rate (90%). These students are absent from school for between six months and two years, but this is not typical of the overall cohort, where very different patterns of absence from school are seen (White & Rosauer, 2015). Those born with cystic fibrosis nowadays are no longer expected to die before they are 20 or 30, with most living into and beyond middle age. Students in this cohort have many other health conditions (about 200 at last count) like diabetes, organ transplants, stroke, Crohn's disease, scoliosis, anorexia nervosa, chronic fatigue syndrome and immune system disorders. Indeed, I compiled this particular list of conditions by considering, one-by-one, the 10 young people I grew to know over a three-year period, during a large Australian study (Yates et al., 2010) in which knowledge about these young people's lives was sought

from educational and social perspectives. As a cohort of students who lived with serious and challenging health conditions, these medical labels proved to be of little use for education.

Medical estimates indicate that between 12% (Sawyer et al., 2007) and 20% (Smith et al., 2013) of school-aged children and young people live with chronic and serious health conditions. Interestingly, substantial increases in the prevalence of long-term and debilitating health conditions, commonly referred to as 'chronic', has led to the emergence of new medical specialisations, acknowledging the need for attention to this growing and complex field. In the education sector, however, students living with health-related challenges tend to be viewed as isolated and rare medical aberrations, rather than a burgeoning cohort of students.

Using Sawyer et al.'s (2007) figure of 12%, I used official figures on school enrolments (Australian Bureau of Statistics, 2014) to try to quantify how many school-aged students with health conditions live in Australia. The extraordinary figure of 500,000 was the result (see White, 2015). However, it has not been possible to verify this figure as education systems in Australia do not monitor these students and it appears unlikely that they will be included in the data about students with disability that the Australian Government has committed to accumulate during 2015 (Department of Education, 2014).

Education has not kept pace with the significant changes that have occurred in medicine in recent times, and education has not yet developed systems and processes to include and appropriately accommodate this burgeoning group of students (White, 2015). A recent study (White & Rosauer, 2015) demonstrated that these students are located in all parts of Australia, in each different types of school (government, Catholic and independent) that are found in all the Australian States and Territories. It should be noted here that since 1901 when Australia became a federation, individual Australian states retained control of education. This means that there are eight separate and individual government educational systems in operation. Add to this the Catholic and independent sectors, and the complexity of talking about 'Australian education' as a single entity becomes apparent. For the students under discussion here, this means inclusive school-level practice requires policy change within at least 20 school systems and in each of the 9,400 schools currently operating in Australia. So it is fair and reasonable to note that these students do not presently count in Australian school level education.

Clearly the estimate of half a million Australian students, living with health challenges, and enrolled in Australian schools is somewhat startling. And conceptualising this large number of individual students, as an educational cohort, is an important first step to acknowledging their existence and accommodating them in schools. Another important and related concern is how health issues affect learning. Specifically, how frequently students are absent from school and patterns of absence as well as the capacity to attend to lessons when present, is important. Research tells us that this is different for each individual (White & Rosauer, 2015), but that there are common concerns (Yates et al., 2010). The name of the health

condition reveals very little about an individual and even less about how they will fare in education. Rather than medical diagnoses and labels, the most important concern for education should focus on how learning may be affected and what support would be of most use.

Epidemiologists have expertise in identifying and quantifying health populations, but they too find it complex and highly problematic to estimate numbers of school-aged students with serious and chronic health conditions (For further discussion, see Ireys, 2001/2013; White & Rosauer, 2015). However, most research about these children and young people points to educational inclusion as the most significant problem. Education of these students is reported as a major concern in the health disciplines of paediatric medicine, public health, paediatric nursing, medical sociology, psychology, psychiatry, oncology and other medical specialist areas. Strangely, the field of education remains mostly silent about these students.

POLITICAL CONTEXT FOR FUNDING, PROGRAMS AND ENTITLEMENT

Bureaucratic alarm over education funding in Australia is expected to override other concerns, until assuaged. Eyes will no doubt be averted when the education of children and young people with health conditions is raised as a serious and new concern, as additional funding demands will inevitably be assumed. To be fair, however, education bureaucrats have good reason to be nervous about funding, with Australian GDP spending on education being noticeably lower than other OECD countries (Middleton, 2012). Since the Howard Government era, significant levels of government funding have been allocated to the operational costs of all schools, including very wealthy private schools. Government funding also supports Catholic schools, and this has been the case since the late 1970s. Therefore, education coffers are never full enough, particularly in the eight government school systems. Disability funding is never adequate and government education departments have developed stringent criteria for funding eligibility and support that excludes many students.

Most young people with health conditions consulted in an earlier study (Yates et al., 2010) reported on the substantial difficulties with teachers in their schools recognizing the existence of their health conditions and how this affected their learning. Parents also reported that they found schools very unhelpful regarding accommodating their children and this was a major source of frustration. Further, both groups did not report that they sought additional funding or resources. Instead, they desperately wanted the teachers to understand the challenges faced by these young people and to make allowances regarding assignment deadlines and homework completion. This is the 'reasonable adjustment' sought. It should be noted here that little cost is associated with teachers noticing and accommodating individual students with health challenges in their classrooms. Communication with and within schools was identified as the greatest concern identified by young people and their parents (Yates et al., 2010) regarding health conditions and learning. Funding is not the answer to this issue either.

Government departments of education continue to fund special schools and services associated with paediatric hospitals that prioritise bedside teaching, but these are somewhat out-dated as they do not meet the needs of the majority of students under discussion here. To illustrate, the average length of stay overnight in a paediatric hospital is typically brief, less than three nights (based on data from the Royal Children's Hospital Health Information Service). However, these special schools only accept students into programs if they remain in hospital for longer periods of time. Usually, hospital special schools and associated services do not accept responsibility for students once they have left hospital. Contemporary medicine no longer requires long periods of convalescence in hospital. Therefore, education systems are not currently accepting responsibility for most of the cohort of students with health conditions while they spend long periods of time recuperating alone at home. This can be for periods of months or even years.

Nor do hospital special schools usually play any role in supporting students back into their regular schools, with philanthropy stepping into this breach. As figures are not available about the extent to which the hospital special schools service this cohort of students, it is difficult to accurately evaluate their relevance. A sceptical interpretation might lead to the conclusion that it is a convenient arrangement for those employed within these special schools and an economically attractive one for government departments of education, who are perceived to be serving the needs of students with health concerns.

Most school-aged young people with challenging and serious health conditions in Australia do not appear to be aware of their entitlements under disability legislation (Disability Discrimination Act, 1992; Commonwealth of Australia, 2005), particularly within the educational sphere (see White, 2015). Educational outcomes have serious consequences for economic independence and wellbeing of these students as they are now expected to live well into adulthood. Government departments of education are short-sighted, if they to continue to fail to notice these students as their numbers are expected to grow, as medicine continues to improve.

POSTER DEVELOPMENT

The authors of the poster chose to report what is known about these students from practice and research perspectives. The production of this knowledge has not yet resulted in Australian education systems accommodating or including these students. Therefore the poster was designed to raise awareness about this cohort and several key concerns about education for this group, rather than to report on any specific project or program. This general aim of raising awareness about these students and their education was accompanied by a second aim of discussing why these young people need to (a) fit within disability discourses, and (b) be considered as a stand-alone group, and this was one of the poster's main communication points. As seen in Figure 1 below, the trope of an umbrella was used to try to convey this key point. For

Figure 1. Photograph of the poster

good measure, the words of 'sheltering under the disability umbrella', was added. As the conference focus was disability studies in education, it seemed an appropriate audience with whom to raise this idea.

Having participated in development of a poster that was well received at a health conference and having used this genre with success for Masters level assessment tasks, I had assumed that the poster format would be useful, as ideas and information could be readily communicated. I also thought that the images used on the poster would be important and that depicting health-related disability and education, without resorting to clichés, would offer a challenge to the group.

The history of collaboration between the seven authors was long-term and continuing. Two of us had worked as researchers on the large study funded by the Australian Research Council that investigated identity, social connection and education for young people aged 11–18 with chronic illness (Yates et al., 2010). Six had been involved in practical information sessions about post-school options for young people with health conditions. Four of us were currently working on a funded project analysing the contents of a database and review of the literature about these young people and their education (see White & Rosauer, 2015). And in various combinations we had co-authored grant applications, book chapters, journal articles, conference papers and now this poster.

We worked for several months to develop the poster which required us to address the issues of how we would articulate what we had to say, and how we would indicate and signify illness. Wanting to be seen as being an ordinary school student, eschewing special treatment and the importance of social goals, was something that emerged from the earlier study (Yates et al., 2010). That research had employed ethnographic, visual and narrative approaches to investigate identity, friendships and connection to education for young people with health conditions. At the conclusion of that project we put together a report for the young people that summarized the conclusions and used many of the photographs taken by the young people (see Walker et al., 2009). The striking thing about that collection of images from that study was the lack of reference to health conditions and the keen pursuit of being an ordinary and regular teenager.

Following extensive negotiation, we agreed on the wording of each panel of text and made decisions about how the poster would be structured and what it should attempt to convey. This was a far more complex undertaking than we had anticipated and it was time-consuming. We decided on three main panels of information and several images of young people to serve the first aim of raising awareness about this cohort. Our second aim was addressed by provision of a list of provocations about the importance for this group to belong within disability discourses and yet to also be considered a stand-alone group. The entitlement of this group to be included within disability policy and programs was indicated with a series of dot point references.

We opted to list information about three important studies and projects we had been involved in on the left panel. As it was prepared for an academic conference, locating the issue within other funded and published studies was considered

important but, as mentioned earlier, reporting on specific studies was not the overall purpose for the poster authors.

Working under the belief that the central panel would be the most likely to be read, and to keep to our first aim of raising awareness about these students, we chose to list distilled knowledge from our reading of several bodies of literature, or practical knowledge learned by program presentation and from previous research. Below this, we identified major concerns about this cohort and education as simply and clearly as possible, under the heading 'But the problem is…', attempting to quickly cue poster viewers into our rather concentrated point of view. References didn't fit onto the poster, so they were contained in a handout. We agonised over suitable images and settled, in the end, by trying to depict the diversity of children and young people with health conditions and by focusing on education. The only indication of a health condition was one of the students wearing a thin, but nevertheless noticeable, oxygen tube in one of the images.

THEORETICAL AND POLITICAL POSSIBILITY

There are many different theoretical possibilities and political realities regarding this particular group of students. Knowledge and theorisation about disability has advanced considerably into many different directions with social and political perspectives (e.g. Slee, 2011) being developed, employing contemporary social theory (e.g. Goodley, Hughes, & Davis, 2012). Drawing upon social, feminist, queer and crip theory (see McRuer, 2006; Peers, Brittain, & McRuer, 2012) and the opportunities afforded by intersectionality (Erevelles, 2014; Cho, Crenshaw, & McCall, 2013), have been influential and support insight into the intent behind critical disability studies (Goodley, 2013, 2014). Consideration of those with health conditions fit—but not obviously—within these theoretical discourses.

Health related disability receives little attention and can often be the afterthought or the odd one out, rather like the conference poster. Transnational disability policy (e.g., United Nations, 2006; World Health Organisation, 2014) clearly indicates that health related conditions are included within the acknowledged disability sphere and this has been reflected in the policy of individual nations. However, as so many different health conditions fit within this broad term, it tends to muddy the waters, leaving those with health related disability not usually depicted in any collective way. As discussed earlier, this is particularly important within school-level education where students with health challenges would benefit from being considered as a group or cohort. Within the health sector, individuals are grouped according to their diagnosis or disease, but as already discussed this makes little sense in education.

Invisible disability is a useful, but somewhat slippery concept. Mullins and Preyde (2013), for example, assert that students with invisible disabilities receive less overall attention than those with visible disabilities. The focus of their study, however, was Canadian university students with ADHD, Dyslexia and mental illness. Students with health conditions were not included. I am not advocating here

that any other conditions deserve less, just that those with health conditions tend to be systematically overlooked. Valeras (2010) uses the term 'hidden' rather than 'invisible' disability, implying individual agency in identity performance. Like Davis (2005), she raises the issue of living with societal doubt about genuine disability status.

> When individuals are not "seen" as having a disability, it can be more difficult for them to secure the assistance or accommodation they need to function effectively. Because they are not clearly identified, those whose disabilities are invisible must often bear the burden of securing the assistance they require… those whose disabilities are invisible may also have to convince other people that they really are disabled, not seeking some special—unfair—advantage; thus what they must do is meet a burden of proof. They thus face a double bind: either they forgo the assistance or accommodation they need—and thus suffer the consequences of attempting to do things they may not be able to do safely by themselves—or they endure the discomfort of subjecting themselves to strangers' interrogations. (Davis, 2005, pp. 154–155)

Therefore, concepts of invisible or hidden offer generative possibility in research about this cohort of students. Similarly, contemporary theoretical concepts such as assemblage, hybridity and intersectionality offer much to support thinking and conceptualisation about complex social processes. Sociological investigation focuses on connecting individual histories and larger concepts like disability, class, gender and race. But increasingly defining and subdividing categories like disability into a further category of health conditions, and subcategories of that, result in unnecessarily fragmented and highly individualised conceptualisations, serving nobody's purpose. But this is how this cohort is conceptualised. For this group of children and young people in education it would be far more powerful to acknowledge the interwoven nature of oppressive categories that exclude. And intersectionality theory would support this, along with how these categories strengthen or weaken each other (see Crenshaw, 1989; Winker & Degele, 2011). The obvious danger of categories and subcategories, however, is the reduction of political impact and disability reform. And for this group especially, it is a problem as they are viewed within education as individual aberrations. The powerful ideas and attitudes inherent in crip theory, critical disability studies and inclusion need also to be put to work in relation to these students.

Children and young people with health conditions have been systematically overlooked in education, particularly within Australia (White, 2014, 2015). In part this can be explained by their invisibility. In part, it should also be acknowledged they do not usually come to the fore within disability discourses, programs or education funding arrangements. In part, it seems that many students with health conditions do not identify with disability, having no visible sign of bodily impairment. Or perhaps they do not feel entitled, as Davis (2005) and Valeras (2010) have suggested. And in part, the 200 or so illnesses and health challenges included in a general 'health

conditions' group can tend to see themselves separately. There are for example, childhood cancer organisations, associations for paediatric diabetes and cystic fibrosis groups, to mention just a few.

Politically this keeps 'health conditions' splintered into many different directions with some conditions attracting more funding and attention than others, e.g., childhood cancer. This relates to the second of the two major points of our poster. The first being to raise awareness about this group of students and the second being the need to simultaneously belong within disability and to be recognized as a stand-alone group for political and educational purposes. However, there appears to be about 200 stand-alone groups at present, which is undoubtedly important in health and social support networking, but is not helpful within education. There is therefore a clear political dimension to encouraging identification as a united and specific 'health conditions' cohort in order to attract much-needed attention, particularly within education systems and schools.

Many research papers in the disability field refer to bodies and image and research texts are available that have examined semiotic systems and how they relate to disability (see for example Schormans, 2014; Bogdan, Elks, & Knoll, 2012). However, the young people under discussion here, who have invisible disabilities, are not usually noticed. A recent film serves as a useful illustration. The Fault in Our Stars (Boone, 2104) is a romantic comedy based on Greene's (2012) bestselling teen novel that traces the interactions and adventure of two American teenagers who live with cancer. While it does depict the lives of these young people beyond their medical conditions, their illnesses are always present throughout the film. What was of particular interest to me, however, was how this illness, the invisible disability discussed in this chapter, was visually represented to ensure that the viewer knows that this person has a medical condition, with the nasal oxygen tube being the signifier. Most of the school-aged children and young people under discussion here, who live with health-related disability, do not have signifiers like this.

DISCUSSION AND CONCLUSION

The provocations so carefully crafted for the poster did not provoke anticipated reaction. Indeed, the responses to the poster were tepid, with conference delegates smiling encouragingly and murmuring polite comments as they ventured past our display. Those of us standing by—ready for bracing and robust discussion—remained perplexed. How had we failed to communicate? Perhaps we didn't supply sufficient information? Or possibly the problem lay in the way the information was presented? Our images were deliberately subtle, perhaps too much so? Or was there just too much text to read? But most academic posters consulted did tend to be crammed with more text than this one.

Connor (2014) recently drew together a history of DSE conferences and their significance in bridging disability and education. He described the DSE conference tradition as one that provided a minority space that offered safety and support for

participants, stating that the conference provided "emotional sustenance for far flung educators" and "The DSE conference has kept me grounded, informed, hopeful, motivated, equipped, stimulated, and challenged in terms of my job: teaching educators how to work with all children." Perhaps this indicates the purpose and expectations of this academic community?

Dipping a toe into the complex world of communication and semiotics has shown how significantly choice of text, image, fonts, colour and layout impact on communication. And this apparently applies to academic posters. Who knew? As one of the reviewers pointed out quite rightly, publications about the complexity of communication in this form have existed for some time (e.g., MacIntosh-Murray, 2007; D'Angelo, 2010). And this is certainly worth further exploration, particularly in terms of semiotics. I wondered also whether the academic culture of the DSE conference was not accustomed to poster presentations? Or did conference delegates tend to retain their focus on a sub-genre of disability, tending to affirm inclusion in general, like motherhood, but reserving interest for the version of disability in which they were particularly interested?

Struggling to understand why the poster did not succeed, I was provoked to read more broadly about how social theory has been employed within critical disability studies. And the aim of raising awareness about this cohort of young people and provoking response from conference delegates was no longer enough. There is much more to write and discuss about these students and how they fit and might participate further within disability discourses.

However, a more obvious and straightforward explanation for the failure of the poster to connect with conference delegates has become clear. We became focused on distilling what we knew to be important information to be included in the poster. We also became preoccupied with the wording, layout, colours and image selection. And in the process, we forgot that facts just aren't interesting in themselves. What was missing was any narrative element. Like the young people themselves, our purpose remained hidden. The world revolves around stories and this applies in all academic disciplines (Richardson, 1990). We failed to include any stories of real people and thought, naively, that the facts would just speak for themselves.

If a standard conference presentation had been prepared instead, individual stories and connection would have inevitably been included. This is a familiar genre and one that demands narrative in order to make and clarify points, whether they are theoretical, political, educational or personal. Comparing the poster for a film (see: http://en.wikipedia.org/wiki/The_Fault_in_Our_Stars_(film) with our poster demonstrates the importance of story most clearly. The film poster depicts a love story with tragic elements, and humanity has always told itself such epic narratives. The academic poster, by contrast, is a technical exercise and a bundle of information. And like unpleasant-tasting medicine, it is only with willpower and discipline that it can be taken into the system and absorbed.

To return to knowledge production and creativity theory, the DSE conference connects valued colleagues who meet each year to tell each other stories and to

try out emerging ideas regarding their work and lives. At first the reaction to our poster seemed to indicate a lack of interest and I felt wistfully regretful of the time involved in its production. By examining the intense focus on the technical aspects of producing the poster, as well as speculating about why it was received in such a lukewarm manner, 'going beyond' the known became required. If the poster had been enthusiastically received and robust argument had ensued, then 'going beyond' would not have been required. The dual aims of raising awareness and provocation would have been achieved.

Instead, struggling over the bland reception of the poster led to further thinking about the communication of ideas and how realities are constructed. Writing this chapter without my colleagues has been a useful and somewhat unavoidable project. Each day as I arrive at work, I walk past that poster, as it stands tall looking down on the kitchen at The Victoria Institute. It manages to communicate its presence to me each day, but it has not succeeded in communicating the passionate ideas and commitment of its authors, as its virtues are merely technical ones. Simply put, the poster lacks a story and it lacks heart. By stepping away from the familiar conference presentation genre, a more interesting way to communicate was sought. Instead of opening up ideas and possibility, however, largely because of discomfort and unfamiliarity with the medium, the poster became a technical, rational, factual and dull communicative device. And that is no way to communicate a new story with an experienced audience.

Knowledge production is slow and can be painful but theory does help us to think about research findings as well as social and educational concerns. Social theory and critical disability studies has much to offer research about the education of children and young people with health conditions. Further hard work of conceptualisation and theorisation is now required, and thinking about this poster has brought this point home. Creativity theory serves to remind us that it is venturing into unknown territory that is important. Taking risks, as a central element in creativity, is important for the production of knowledge. And this is more important than the presentation of polished, comfortable products or performances, even if these are well received.

on various related projects, with the most recent being a research project funded by Victoria University and the RMLP (see White & Rosauer, 2015).

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16. THINKING ABOUT SCHOOLING THROUGH DIS/ABILITY

A DisHuman Approach

INTRODUCTION

In this chapter, we develop and draw on an emerging approach – which we entitle the DisHuman – to explore how disabled children's lives are enabled *and* limited by their construction as simultaneously both 'different from' and 'the same as' other children. One institutional setting in which the child becomes known in their relationship with the dis/ability complex is the school. We write this chapter in the light of our wider thinking about 'sameness' and 'difference' in the lives of disabled people. This is an approach that we have characterised as DisHuman Studies (Goodley & Runswick-Cole, 2014; Goodley et al., under review). We explore how the presence of dis/ability has the potential 'trouble, re-shape and re-fashion' the conventions of schooling (Goodley & Runswick-Cole, 2014: 1). We remain hopeful that all members of school communities (children, parents, teachers, local authorities, wider community members) will continue to take the opportunity to disrupt the status quo and to become open to the possibilities unlocked by an awareness and acceptance of the DisHuman reality that plays out in schools.

In English schools, the category of "child with special educational needs and disabilities" is used to label children whose learning profile is considered to be atypical when compared with children without these labels. Membership of the category of "child with special educational needs and disabilities" (SEND) is determined by an assessment process, involving the child or young person, parents, or those with loco parentis, and practitioners. Inclusion into the category is determined by the extent to which children:

- have a significantly greater difficulty in learning than the majority of children of their age;
- have a disability which either prevents or hinders them from making use of the educational facilities of a kind generally provided for pupils of the same age in schools within the area of the local authority (DfE & DoH, 2014: 15–16).

Despite the rapidly changing policy context for disabled children in England over the last thirty years (Goodley & Runswick-Cole, 2011a), this definition of SEND has not changed significantly since the publication of the 1996 Education Act (HMSO,

1996). Indeed the definition has recently been reiterated in the Children & Families Act (HMSO, 2014) that sets out a series of legislative changes described by the Coalition government as heralding the biggest reforms to special education since the Warnock Report (DES, 1978). Despite calls from inside the inclusive education movement, and from critical disability studies, to move away from within-child models of special educational needs (Skrtic, 1991; Barton, 1997; Runswick-Cole & Hodge, 2009; Goodley, 2014) the focus remains on the difficulties the child 'has' and what they 'cannot do'. The categorisation of a child "with special educational needs and disabilities" (note the child first language and the label appended afterwards) can only be made in reference to the norm. For example, a child has a 'SEND' if the child "has a disability which prevents or hinders him or her from making use of educational facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions" (DfE & DoH, 2014: 274). This suggests that although children with SEND are considered to be children, perhaps even children *first*, they are, at the same time different from other children and are identified as needing different "educational facilities" through a recognition of the co-existence of impairment which is deemed to be attached to their personhood. Implicit within the category of child with SEND is a claim to both sameness (in the use of children first language – they are children too) and difference (in the making of the category as a departure from and in reference to the "general"). Hence, any conception of the disabled child refers to those young people who are living at the intersections of childhood and dis/ability. The term dis/ability is chosen because, as we know, whilst some children are given labels denoting lack (disability) there are others that occupy the category of gifted and talented (ability or in some cases hyper-ability).

As we have noted elsewhere (Curran & Runswick-Cole, 2014; Goodley & Runswick-Cole, 2012), stories about disabled children's lives have often been told in ways that cast children in an unfavourable light in comparison to norms of childhood. Children whose lives are perceived to deviate from these norms, for a myriad of reasons (dis/ability, sexuality, race, class, gender), have historically been pathologised and seen as 'the problem' within education settings (Slee, 2001). However, while we acknowledge the ways in which the hegemony of the norm casts a shadow over the lives of disabled children, here we extend our analysis to consider how disabled children's lives are both enabled and limited by their construction as simultaneously both 'different from' and 'the same as' other children. Those living at the intersections of dis/ability and childhood are often viewed as being like any other child (they are children first) whilst also inhabiting spaces of difference: where their diverse educational needs, as expressed through categorisations associated with disability and impairment, are also illuminated.

One institutional setting in which the child becomes known in their relationship with the dis/ability complex is the school. The focus of this chapter is schooling, we use the term 'school' rather than education because we see schools to be communities in which a host of activities take place including: teaching, learning, friendship-making and relationship building. Schools are sites where being constructed as both

simultaneously 'different from' (dis/abled) and 'same as' (child) other children plays out in the lived experience of disabled children. And we also recognise that each category of child and dis/abled brings with it social, political and cultural histories that are drawn upon in ways that make each category known and reacted to. We write this chapter in the light of our wider thinking about 'sameness' and 'difference' in the lives of disabled people. This is an approach that we have characterised as DisHuman Studies (Goodley & Runswick-Cole, 2014; Goodley et al., under review). We set out our thinking in relation to the DisHuman in more detail below.

DISHUMANISM

DisHuman studies is a response to what we see as a DisHuman reality:

> one which, we contend, simultaneously acknowledges the possibilities offered by disability to trouble, re-shape and re-fashion traditional conceptions of the human (to 'dis' typical understandings of personhood) while simultaneously asserting disabled people's humanity (to assert normative, often traditional, understandings of personhood). (Goodley & Runswick-Cole, 2014: 1)

Like the feminist philosopher Rosi Braidotti's (2013), we have become disillusioned with these narrow versions of the 'human norm that stands for normality, normalcy and normativity' (p. 26). And yet, we do not wish to abandon the category of the human in the lives of dis/abled children, young people and adults. We suggest that it is possible to remain *critical* of the category of the human, while, at the same time, making a *claim* for the human in the lives of disabled children.

In our thinking about the DisHuman, we have suggested a number of bifurcated concepts that illustrate the pervasive reach of the DisHuman condition: DisHumanism.

To this list, we would add the DisChild (Goodley et al., under review). Our conception of the DisHuman seeks to recognise the practical and often political ways in which it is necessary, indeed desirable, to emphasise the *ability* side of the dis/ability binary whilst also wanting to attend to the disruptive work done by the presence of *disability*. In ways that are in tune with the deconstructionist tendencies of poststructuralist writers such as Michel Foucault and Jacques Derrida – and in response to the recent postconventionalist interventions of writers such as Rosi Braidotti, Gilles Deleuze, and Felix Guatarri – our engagement with the DisHuman condition seeks to recognise the work done with, for and against the disruptive qualities of disability and ability, difference and normality, the deviant and the human. For instance, we might want to emphasise the *child* side of the binary when we think about the DisChild in education and schooling (Goodley, Runswick-Cole, & Liddiard, under review). Here, it seems important to be able to claim that disabled children are *children* too, that they have a right to education because of their status as *children* under, for example, the United Nations Convention on the Rights of the Child (UNICEF, 1989). However, disabled children have not always been included within the category of children who should be educated in schools;

Table 1. DisAbility studies: Becoming DisHuman and other possibilities

DisAbility studies		
DisHuman	DisChoice	DisYouth
DisLife	DisDevelopment	DisFamily
DisCitizenship	DisAblement	DisMedicine
DisAutonomy	DisLabour	DisPopulate
DisNeoliberal	DisAdvocate	DisRecognize
DisNormative	DisQualify	Dis/Reason
DisNormal	DisScience	DisAdult
		DisCapitalism

(Adapted and developed from Goodley & Runswick-Cole, 2014: 6)

until relatively recently, responsibility for 'handicapped children' in England was with health rather than education services. This situation only changed as a result of the 1974 Education Act. The 1981 Education Act, following the influential Warnock Report (DfE, 1978), was the beginning of a move towards the integration of disabled children to be educated in their local schools alongside non-disabled peers. However, it was not until the 1990s that the idea that disabled children should be 'normally' educated in the communities in which they live became more widely accepted in England and part of inter/national law (UNESCO, 1994).

While it is clearly important to continue to assert that dis/abled children are children too, it is also necessary to recognise, to claim and to celebrate the *dis* side of the *Dis*Child binary: '[a DisH]uman 'position means that we recognize the norm, the pragmatic and political value of claiming the norm, but we always seek to trouble the 'norm'' (Goodley & Runswick-Cole, 2014: 5). Emphasising the *dis* allows us to call into question normative categories of child, youth, adult and family and to celebrate difference and diversity. The presence of the phenomenon of disability disses (or disrespects) the normative tendencies inherent in traditional and hegemonic conceptions of childhood. We would argue that the inclusive education movement (Barton, 1996; Ainscow et al., 2006; Allan, 2006; Baker, 2002; Barton, 1997) has advocated for accommodations and practices that are inclusive of disabled children's perceived differences while claiming their status as children like any other, who have the right to be educated in their local communities. While a DisHuman approach recognizes that disability and humanity are always in friction, we have argued that they often rub against each other in ways that are productive and revealing of dis/abled children's potential (Goodley & Runswick-Cole, 2014). This frictional potential of the DisHuman condition is something that we think permits us to think again how we understanding notions of the human, dis/abled, child, learner and educational institution.

Our commitment to exploring the possibilities of DisHuman studies in schools is driven by our professional and personal engagements with the lives of dis/abled children and young people. Over the past ten years, we have worked alongside dis/abled children and their families and allies in research. We describe the research projects in more detail below. Our understanding of disability is guided by Carol Thomas (2007: 73) who defines disablism as: 'a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being'. We argue that dis/ability studies allows us to 'acknowledge the theoretical, practical and political work that takes place either side of the binary, a binary denoted by the presence of '/' (the slash)' (Goodley & Runswick-Cole, 2014: 3). We remain painfully aware that "many disabled people have been denied the opportunity to occupy the position of the modernist humanistic subject: bounded, rational, capable, responsible and competent" (Goodley & Runswick-Cole, 2014: 3). In dropping the slash of dis/ability and dis/human and replacing them with the elided concepts of DisAbility and DisHuman we seek to further recognise the dynamic ways in which the Dis and the Ability or Human rub up against each ways in potentially productive ways that might be of use to those interested in furtherering inclusive education. Moreover, by fusing Dis to these concepts, we seek to foreground the importance of those working the dis/ability context (or DisAbility) whilst recognising that one often has to appeal for recognition in a space rife with Ability. Ableism refers to those social, political and cultural practices that uphold a narrow conception of the citizen tied to idealized notions of independence, autonomy, rationality and cognitive progression. Capitalist and neoliberal societies are increasingly ableist places: where the role of welfare and government are rolled back and in their place emerge self-sufficient individuals who are capable of looking after themselves as part of the meritocratic architecture of our contemporary ideological times (Goodley, 2014). One place in which ableism is rife is the school.

We have written elsewhere (Goodley & Runswick-Cole, 2011b; Runswick-Cole et al., under review) about the ways in which disabled children and young people are routinely subjected to de-humanising practices. In our research with disabled children and young people, we have repeatedly found examples where disabled children have not been offered the opportunities and aspirations afforded to so-called 'typically developing children' in play, education, and in leisure activities (Goodley & Runswick-Cole, 2010; Runswick-Cole, 2011; Hodge & Runswick-Cole, 2013). Historically, disabled children have been characterized as monstrous (Runswick-Cole et al., under review) and in education, in particular, their leaky, uncontained, uncontrollable and unpredictable bodies are troubling for schools under pressure to conform to the demands of marketisation, inspection regimes and the requirement to move disabled children as close as possible to a mythical ableist norm (Runswick-Cole, 2011; Goodley, 2014). One way in which we might think of disabled children's impact on educational contexts is in terms of their disruptive potential. Disabled

children often demand places such as schools to rethink their priorities, their usual modes of operation and their cultural foundations.

In this chapter we ask how does status of a 'child with special needs and disabilities', and their categorisation as both 'same as' and 'different from' their 'non-disabled peers' play out in the schools? What impact does this have on children and families and their experiences of schools? And how might these experiences inform wider understandings of schooling? We are especially interested to ask – when is ok to follow the normative workings of schools and in what ways do children and families 'dis' schooling?

THE RESEARCH PROJECTS

Our engagement with the DisHuman child is informed by the three recent research projects described below. More information about each of the projects can be found by visiting the links to the projects.

1. *Economic and Social Research Council (Grant No. RES-062-23-1138). Does every child matter, post Blair? The interconnections of disabled childhoods. 2008–2011* (http://www.rihsc.mmu.ac.uk/postblairproject/) (summary taken from Goodley, 2014: xx).

This project was based at Manchester Metropolitan University, Manchester, UK in collaboration with the University of Newcastle-Upon-Tyne, UK. The aim of the project was to understand what it meant to be a disabled child growing up in England during a time of policy change. The study was based in the north of England and ran from September 2008 – April 2011. The participants included disabled children aged 4–16, their parents/carers and professionals who work with disabled children, including teachers, third sector workers, health workers and social workers. Data collection included interviews using multi-media methods. The interviews were open-ended and covered a range of issues including children and young people's experiences of health, social care, education and leisure. A period of ethnography involved attending children's birthday parties, bowling, shopping with families as well as attending impairment-specific leisure activities, including an autism specific social club, parent groups, and user consultation meetings set up by local authorities, services and professionals to access the views of families. Finally, the research also included focus group interviews with professionals ranging from teachers, social workers, speech pathologists, advocates, and leisure providers (https://doeseverychildmatterpostblair.wordpress.com).

2. *Resilience in the lives of disabled children across the life course (Scope) 2012–13*

The aim of this project was to ask what resilience means in the lives of disabled people across the life course. As part of the project we worked with ten disabled children and young people using a life story approach. As might be expected,

their experiences of school were a key part of their life story narratives. For more information about the project visit: http://disability-resilience.wordpress.com

3. Economic and Social Research (Grant No. ES/K004883/1); *Big Society? Disabled People with Learning Disabilities and Civil Society, Economic and Social Research Council 2013–2015* (Summary taken from Goodley, 2014: xx).

The project runs from June 2013 to June 2015 and is a partnership between four universities (Manchester Metropolitan University, the University of Sheffield, the University of Bristol and Northumbria University) working with three partner organizations (Speak Up for Action; the Foundation for People with Learning Disabilities and independent living consultants) in the UK. The overall research question asks: how are disabled people with learning disabilities faring in Big Society? The research is being carried out through seven overlapping and interconnected phases including interviews and ethnographic encounters. [More details available at: http://bigsocietydis.wordpress.com/]. As part of the project we worked with young people in England who were in a transitional period as they moved from child to adult services in education, health and social care.

THE ANALYSIS

In our analysis for this chapter, we revisited the narrative of children, young people and parents and family carers from Study 1 and 2, and Katherine's ethnographic notes from studies 1 and 3. In re-reading the data, we adopted a DisHuman lens, looking for moments where each side of the binary was emboldened or diminished and paying particular attention to the ways in which both sides of the binary are held in tension and rub up with one another. In re-visiting the narratives and ethnographic accounts, our aim was not to force the data to fit with our DisHuman approach, but rather to see what a DisHuman reading of the stories might add to our understanding of the lives of disabled children, family-carers and allies.

THE DISHUMAN SCHOOL

Disabled children and young people demand us to think in ways that affirm the inherent humanness in their lives (and their alliances with other children) but also allow us to consider their disruptive potential (as an antidote to some of: the typical and normative ways in which schools do their work). We suggest that the DisHuman child demands a DisHuman school. We draw on our research projects to explore a number of moments in which our *Dis*Human and Dis*Human* schools become visible. First, we explore moments where the *Dis*School emerges and disability provokes productive responses in schools. Next we consider when the Dis*School* appears in moments where the requirements of ableism expose, marginalize and exclude children. We conclude by thinking about the implications of our findings for children, families, schools and wider communities.

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The Dis*School*

> Now he's just started GCSEs[1] because [David] had not option but to do GCSEs but what he does now, we select the subjects so he's doing science subjects, drama and geography then on top of that he'll do PE and PSHE, so that works out at part time and we've done that all through secondary which means he hasn't done Maths for years because we weren't getting anywhere with Maths so … Claire (mother, Participant 1, Study 1)

Claire describes the *Dis*School. While there may be no other option for her son "but to do GCSEs" (Dis*School*) through a mixture of part-time schooling and home education David is doing the subjects he enjoys, and he's given up Maths because he 'wasn't getting anywhere'. In this brief vignette, the significant level of work done by Claire, David's mother, to push for the *Dis*School to be appear is hidden but, nonetheless, Claire and David, and the presence of *Dis*Ability, have disrupted the conventions of schooling, which require students in England to study Maths until sixteen and to study in school full-time. Claire's DisHuman approach is further evidence by her admission that:

> as a parent I aspired for my child to be independent and have a job and relationships, and I didn't aspire for him to have GCSEs. Claire (mother, Participant 1, Study 1)

While Claire's aspirations for David to be independent, to have a job and to be in a relationship reveal very *human* desires for David, *Dis*Ability disrupts her aspirations – she no longer has any desire for him to achieve GCSEs.

Parents are often key players in setting up the *Dis*School. When, thirty years ago, William and Penny's son Neil was refused a place at their local village pre-school, they set up their own:

> we opened our own playschool, so I could take Neil and Samantha [his sister] and they would both be part of the community. William and Penny (father and mother, Participants 6, Study 2)

Imogen described how she campaigned for post-16 provision for her son in their local area:

> As soon as Jonathan started at secondary school, I knew that we'd have a problem post-sixteen. There was nothing in our area of children with complex needs who had been through mainstream school. My vision was a post-sixteen where young people could follow their interests … fortunately someone in the local authority[2] agreed with me. Imogen, mother, Study 2, Participant 8

Kirsty also worked with her local authority to push for a *Dis*School to emerge:

> The mainstream secondary school was unsure about accepting my daughter. The head said: "she doesn't write she doesn't read or speak", and we've had people who don't do one of those things, but we've never had anyone who doesn't do all three. But the local authority was really supportive and the special school head teacher was too, and in the end, the school didn't have a choice. Kirsty (mother, Participant 5, Study 2)

While parents' contribution to the creation and maintenance the *Dis*School was often crucial, the presence of disabled children in schools was sometime enough for the *Dis*School to emerge. William and Penny explained that in Neil's primary school:

> I mean it reached a point where the school teachers had to have a rota set up because some of the kids had starting to get into fights over who was going to support Neil each day. William and Penny (father and mother, Participants 6, Study 2)

As Imogen's story reveals, sometimes parents and practitioners worked together to create the *dis*/school. Certainly, teachers play a key role in the production of the *Dis*School as this vignette demonstrates:

> The science teacher was constructing a display that would use lighting to move from day to night and different creatures would emerge throughout the day. This was alongside his construction of the solar system which glows under UV lights. He uses projectors to display moving pictures of animals and UV paint to bring to life a huge spider. He explained how he had used a projector to take the children to Mars and that they had asked 'where are we?' then speculated on the fact that they couldn't live there because there was no water. He said that there was no way his pupils could have learnt this looking at books. The science teachers from the mainstream school had said 'why can't we teach science like this?' (Katherine's ethnographic notes, Study 1)

As we have argued, the *Dis*School emerges when the presence of dis/ability disrupts normative practices in schools. In Claire and David's example, the *dis* disrupts normative notions of the curriculum content and curriculum choices and even where and when education might take place. While we do not wish to condone the exclusion that provoked Penny and William to set up their own pre-school for Neil, we suggest that the disruption caused by the presence of the *dis* was productive in setting up an inclusive pre-school for the whole community. Here is disability and humanity rubbing up against each other in sometimes difficult but also productive ways. The role of parents and practitioners is clearly important in creating *dis* schools, but children and young people are not passive in this process as the story of Neil and his friends illustrates above. For us, *Dis*Schools are places full of potential both disrupted by and enhanced by the presence of DisAbility.

The *Dis*School

We saw above that as a small child Neil was excluded from pre-school. We know little detail from William and Penny's narrative about the pre-school, only that it wouldn't accept Neil, so they set up one that did. We can imagine, however, that this pre-school was a dis/*school:* one in which to be accepted, even at the age of three, it was necessary for a child to match up to some hazily articulated image of the 'human norm that stands for normality, normalcy and normativity' (Braidotti, 2013: 26). Sadly, children and young people and their family-carers frequently encountered the Dis*School* in each of our research projects.

Gail explained her first meeting with her child's new class teacher in primary school:

> "I [the teacher] was terrified of having him, absolutely terrified, but he's ever so good you know he just sits in the corner quietly," and I [the mother] thought, "Well that says everything." Gail (mother, Participant 2, Study1)

The teacher's terror harks back to the image of the monstrous disabled child we alluded to above. For the teacher, difference is a threat to the requirements of an ordered classroom, to the progress of the 'other' children and to her own well-being. The *Dis*human child has to be managed, by sitting quietly in the corner, while the 'real' work of educating the 'normal' children goes on around him. Imogen describes a similar story of exclusion:

> I asked the [primary school] teacher why she never read with Jonathan. She said he had a teaching assistant to work with him and she had twenty-nine other children to think about … I wrote a letter of complaint to the head teacher.

Jonathan's failure to be included in the category of the twenty-nine 'other children' reveals the persistent re-articulation of 'the human norm' in schools. To be included, you have to match up to standards of achievement and behaviour expected of the "majority". In the Dis*School*, children who fail to do so are relegated to the margins – to being quiet in the corner or to work apart from the other children with a teaching assistant. Often, in the Dis*School* there is what parents described as a 'lack of will' to include DisAbled children:

> [Mainstream primary school] had to be able to fit Larry in with their timetable, you know it had to be something that you know Larry could participate in, you know sand play or water play, so both timetables had to fit in… there was really just a lack of will [to include him]. (Susan, mother, Participant 4 Study 1)

Patsy described the lack of flexibility that meant that even in the hospital school was emerged as a Dis*School* – lacking in flexibility or support for disabled children:

> When I'm in hospital, the teacher comes round. They teach everyone whatever their intelligence, level, age or whatever – the same thing. The brought me a

copy of the *Rainbow Fish* [a picture book]. The hospital teachers got in touch with my school then and school wanted the hospital teacher to help me write this Greek myth but I hadn't done any of the work and so I couldn't do that either because it was too hard. (Patsy, aged 13, Participant 2, Study 2)

For Patsy, the Dis*School* was also in evidence in her regular mainstream school, and she explains how ableist assumptions underpin not only approaches to teaching and learning but also to friendships and relationships:

I have the same amount of friends as everyone else, people assume I need help to make friends, like I need friendship groups and things, but I don't, not really. At break time, I have to sit in a room with all the disabled children. I don't really know why because, well, I used to have to go to the toilet at break, but I don't now. It seems like they're trying to club all the disabled children together, we're not *ordinary* friends, if I made an enemy of one of the people in there or something, if I had an argument with one of them, I'd still have to sit in there with them. (Patsy, aged 13, Participant 2, Study 2)

Sadly, the preoccupations with conformity and normality of the Dis*School* are evident beyond the classroom door seeping into the playground and contaminating relationships between parents and children in the school community, as Maria's story demonstrates below:

And nearly every day [my son] comes out of school and says: "Can so and so come round for tea?" and I can see their mother looking at me going: "Please no! Please no!" so I have to make up a hundred and one excuses all the time about why they can't come. (Maria, mother Participant 7 Study 2)

The Dis*School* is a difficult place for disabled children. Their status as same, but not quite (Shildrik, 1996) renders them vulnerable within the Dis*School* as their unruly bodies and minds unsettle the veneer of ableist normativity.

CONCLUSION

What does our DisHuman analysis bring to the table in discussions about the inclusion of disabled children in schools that has not been said already? The systemic, material, relational, attitudinal barriers to the inclusion of disabled children have long been the focus of research and publications (Ainscow et al., 2006; Allan, 2006; Baker, 2002; Barton, 1997). We already know a lot about the discrimination that disabled children face in schools. Academics have spent a lot of time looking at the lives of disabled children, but a DisHuman approach has allowed us to see something different. We have been able to reveal both the tensions and potentials that emerge when a child is seen as same but different. Being 'same, but different' offers up a challenge to school communities to respond. As we have seen, school communities react differently, some exclude in order to maintain the sense of order that the Dis*School* requires

in order to manage its anxieties about league tables, inspections and performance. On the other hand, the *Dis*School's response is productive, and orientated toward change rather than maintenance of the status quo.

We remain hopeful that all members of school communities (children, parents, teachers, local authorities, wider community members) will continue to take the opportunity to disrupt the status quo and to become open to the possibilities opened up by an awareness and acceptance of the DisHuman reality that plays out in schools.

NOTES

[1] General Certificates of Secondary Education (GCSEs) are standardized tests taken by most sixteen-year-olds in England.

[2] The 'Local Authority' refers to the responsibility that local councils have for delivering education services to all children in England.

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AFTERWORD

Cultivating a Global Disabilities Studies in Education

INTRODUCTION

The Disabilities Studies in Education (DSE) Conference began in 2001 in Chicago with approximately thirty-five people in attendance. The host organizers at National Louis University had taken a chance to *begin* a formal conversation within an informal conference structure about seeking alternative frameworks to special education's conceptualization and operationalization of disability. For me, this event changed my academic life. As a doctoral student who had substantial experience in working as a teacher within urban high school settings, I had observed injustices toward students identified as disabled on a daily basis. As a result of working in New York's school system segregated by disability, I had become a strong advocate for inclusive education. At the same time, the limited scripts within special education that invariably pathologized and stigmatized children always frustrated me. It was at this conference that I met a range of seasoned and emerging scholars, teachers and other doctoral students, who shared an interest in *talking back* to a powerful system that we had experienced as a disservice rather than a service to countless children, youth, and adults with disabilities.

The inception, growth, and significance of the DSE conference has been described elsewhere (Connor, 2014), so I will only make one important point here. It took us several years to develop the "what" to talk back with. I recall conference attendees being concerned about not wanting to impose a new rigid dogma that would claim to speak for all and inhibit the exponential growth of creative thinking around the paired topics of education and disability. To cut a long story short, as an informal network without a membership-type organization, we met annually to develop our thinking, culling from two more sources. One source was Disability Studies, and the interdisciplinary scholarship that had arisen largely in the USA and UK since the 1970s. The other source was the work of critical special educators such as Len Barton, Douglas Biklen, Lous Heshusius, William Rhodes, Tom Skrtic, Steve Taylor, and Sally Tomlinson who had questioned and challenged the foundational knowledge of the special education field, as well as its policies and practices.

Once we "married" education to disability studies, and began to write about DSE as an alternative way to rethink and reframe disability and education, sometimes in *relation to*, sometimes *outside of*, and sometimes *within* special education—

we noticed that some educational researchers were erroneously using DSE as synonymous with a superficial synonym for special education akin to having a ("sexy"?) makeover. To counter that trend, we decided to bite the bullet and state what DSE was, recognizing that we had organically began by stating what DSE was not. To provide access to all members of the scholarly community who were interested in developing a definition, we held a yearlong discussion on line. The result was a series of DSE tenets and examples of DSE utilized within research, policy, and action that were presented, discussed, and modified in a public forum at that year's conference. To "launch" a more formalized framework for DSE we engaged with Roger Slee, editor of the *International Journal of Inclusive Education*, who allowed four members of our community to guest edit a special double edition in which we shared DSE's tenets and examples (Connor, Gabel, Gallagher, & Morton, 2008). Since then, this framework has helped distinguish DSE as an entity in itself and, more importantly, a conceptual tool that can be put to work.

Another two aspects of the DSE story that bear mentioning is that its legitimization, so to speak, was also in part because of the formation of the Disability Studies in Education Special Interest Group (SIG-DSE) within the auspices of the American Educational Research Association (AERA) *and* the continuation of its own annual conference. The DSE-SIG has meant research on DSE has been a staple feature of the USA's largest educational conference, providing opportunities for expanding the discipline and further growing a network of scholars who share similar interests. The annual conference shifted from being national to international when hosted by the University of Ghent, Belgium in 2010, the University of Christchurch, New Zealand in 2013, and…The Victoria Institute in Melbourne, Australia, in 2014.

Holding the annual conference in countries around the world signifies a global interest in DSE, creating local, regional, national, and international connections among researchers and members of the wider community who share an interest in expanding historically limited understandings of disability and actively creating a world that is accessible to all. As an attendee of all DSE conferences to date, I was personally thrilled that it was being held in Australia, and (after several very long flights) very curious to engage with presenters about their work. Perhaps the best way to provide a snapshot of the conference is the following report that I was asked to provide to the DSE-SIG for their spring 2015 newsletter.

DSE CONFERENCE IN "THE LAND DOWN UNDER":
A REPORT ON MELBOURNE, 2014

The 14th Annual Disability Studies in Education Conference was held at Melbourne's Victoria Institute, part of Victoria University, in Australia. In keeping with previous years, the conference ran for three days over the weekend of July 25th–27th. Senior Research Fellow Tim Corcoran, was the convener of the conference, working closely with Roger Slee, Director of the Victoria Institute and Editor of the *International*

Journal of Inclusive Education. The conference was a truly international event with representatives from Australia (of course), Fiji, Germany, Greece, Japan, Nigeria, Papua New Guinea, New Zealand, South Korea, Taipei, the UK, and the USA.

The Senior DSE Scholar Award was given to Professor Athina Zoniou Sideri of the University of Athens whose presentation was called *Inclusive Education, Neoliberal Plans and The Economic Crisis in Greece.* The Junior DSE Scholar Award was given to Ben Whitburn a Ph.D student at Deakin University, Melbourne. His presentation was titled, *Attending to the Potholes of Disability Scholarship*. Professor Dan Goodley from the University of Sheffield, England, and Dr. Katherine Runswick-Cole, Research Fellow from Manchester Metropolitan University in the U.K. were keynote speakers, co-presenting *Disability Studies in Education: A Posthuman Manifesto*.

Each of the three days was filled with interesting panels and presentations from what is likely the most "international" DSE to date. As usual, there were ample breaks between sessions with time enough to catch up with old colleagues from distant lands as well as meet new colleagues from other far-flung places. The content of sessions ranged from perennial favorites such as critiquing current educational policies and school systems, to practical suggestions of working within inclusive classrooms, from engaging with parents to garner services for their children, to facing the global *zeitgeist* of "accountability" and high stakes testing.

Social times during the evenings meant opportunities for dining and drinking, both considered serious pastimes by Australians. Melbourne itself is a beautiful, multicultural city—not unlike Vancouver, Canada—with a very high standard of living, including numerous neighborhoods with their own distinct "flavor," incredible Victorian and modern architecture, wonderful museums, and endless options for exploration. The people were open and friendly, always very helpful if asking for directions or recommendations.

During the plenary session we collectively shared our thoughts, experiences, and impressions of the three days. There was a sense that the DSE conference continues to provide a welcome respite from other academic venues by allowing an open atmosphere for exploring ideas about dis/ability and education, as well as related areas and fields of interest. Attendees were eager to hear about possibilities for next year's conference, and expressed a desire that it be held in the United States again. I said I'd take the message back, and the US-DSErs will collectively try and grant their wish! … more on that topic to follow soon.

It was clear from the presentations that many DSE articles and chapters are about to be published, have hit the press already, or are shaping up as you read this. Furthermore, there will be a collection of articles based on presentations of this DSE conference in a forthcoming edited volume coordinated by Tim Corcoran. In closing, I'd like to say that the Aussies did a brilliant job in not only maintaining the quality of conference we have come to expect, but also expanding the very discipline of DSE. Thank you Tim, Roger, and the 2014 DSE Conference Committee.

COLLECTED WORKS FROM THE 2014 DSE CONFERENCE

The forthcoming edited volume mentioned above has materialized into *this* wonderfully diverse collection of chapters by conference participants. Being invited by the Editors to have "the last word" was both an honor and an offer I could not refuse. It has allowed me to engage with the presenters' work at a deeper level, and reflect upon ways in which DSE has grown in places, spaces, and communities I had only imagined at best. In other words, although I was familiar with many of the issues addressed at the conference, learning about them in different contexts provided me with a greater, oftentimes more nuanced, perspective.

In the remainder of this chapter, I will cull elements from the work of each contributor with view to foregrounding ways in which it (1) resonates in some way with the tenets and examples of DSE in theory, research, and action, and (2) reveals ways in which DSE continues to grow in global contexts. For those who are interested, the tenets of DSE can be found on the webpage of AERA (http://www.aera.net/SIG143/DisabilityStudiesinEducationSIG143/tabid/12121/Default.aspx) as well as in the editorial, *Disability Studies and Inclusive Education—Implications for Theory, Research, and Practice* (Connor, Gabel, Gallagher, & Morton, 2008). If my math serves me correctly, of the sixteen chapter contributions, eleven are from Australia, two from New Zealand, with one each from Bangladesh, Nigeria, and the UK. This makes for a welcome diversification from the usually US dominated works at DSE conferences, although it is worthwhile to note that the majority are still "Western." Taken together, they make a strong argument for the universal need for DSE to continue its work; taken separately, they each raise questions that promote exponential thinking as integral to DSE and the way forward in dismantling the hegemony of normalcy.

Jenene Burke's *Not Just for the Fun of It: Children's Constructions of Disability and Inclusive Play Through Spatiality in a Playspace* is an example of research that "contextualizes disability within political and social spheres" (AERA, n.d.). Her chapter features a discussion of the social model of disability that, while familiar to many, is still crucial for the world outside of disability studies. Burke investigates forms of social (re)production in play spaces or, as she explains, "… how social roles and relationships are defined and understood by children" based upon their shared experiences. The issues raised in this work include the degree of acceptance by children toward human diversity in contrast to the possibilities of hostility and rejection. The author recognizes that social relations are linked to power relations, i.e. relations that can signify short and long term political struggles. She writes, "Children construct social norms and their understanding of social positioning from their observation and knowledge of cultural practices." Burke's exploration of children's perceptions of difference achieved, in part, through personal photographic scrapbooks consisting of smiling, sad, grimacing faces, allows us into the world of six to ten year olds. The work raises questions about well-intended gestures in the spirit of accessibility that fall far short of universal design. In describing her son, a parent notes, "He just wants to be normal like everyone else," raising the

specter of normalcy and the host of problematic assumptions on which it is built. That said, in this instance if we relate normalcy to accessibility ("normal" access to the attractions of a playground), we see ways in which segregation occurs when "The Liberty Swing" precludes utilization by all children. As one nondisabled boy notes, "Wheelchairs have to play on it. It's their swing." The "Restricted Area" sign for "User and Carer" is still, for all intents and purposes, segregation. Thus, children do read spatial messages socially, and social messages spatially when it comes to disability.

In *Teachers' Aides' Perceptions of Their Training Needs in Relation to their Roles in State Secondary Schools in Victoria,* Dianne Gibson's work is linked to how DSE "supports the education of students labeled with disabilities in non-segregated settings from a civil rights stance" (AERA, n.d.). The inclusion of children and youth with disabilities into school systems has been achieved, in part, through the employment of teacher's aides (TAs) to help support students. Gibson's research focuses on a group of professionals who are relatively "unseen" in educational research yet serve a crucial role in collaborating with teachers in inclusive settings. Much of their work is described as trial and error, as most TAs have some post-school training but no experience working in schools before this particular role. As a result, TAs are generally unprepared, unclear about their role, but are viewed as integral to implementing inclusive practices. Interestingly, TA work can be viewed through the lens of gender, age, and social class as 19/20 are female, 14/20 are over 50 years old, almost all have low wages (I am assuming based on similar patterns in US and UK) and, arguably, may view themselves as primarily "caring" versus educating. The demographic raises questions about qualifications and certifications in regard to professionalization into (special) education, the skills required of TAs, as well as their dispositions toward human differences. Over half of the participants self-identified as needing training in: basic and instructional remedial strategies; implementing the IEP; using appropriate technology to assist student learning; working with students who have refugee background, and; executing behavior management programs. This list reveals the complex nature of the job and, by implication, the expectation that the responsibilities of the qualified teacher are delegated to the unqualified TA.

Kate Holland's *Celebrating the Voices of Students with Hearing Impairments in New Zealand Secondary Schools: Celebrating the Voices of Students* is an obvious connection to how DSE "privilege[s] the interests, agendas, and voices of people labeled with disability/disabled people" (AERA, n.d.). The work focuses on Kelly and Cody, students with hearing impairments (and one with a learning disability) in a NZ secondary school. Deaf students have been seen as a challenging group in terms of access, as the Deaf community have claimed their own language and often advocate for separate programs. The research was participatory with Holland noting, "Kelly and Cody were encouraged to discuss whatever they wanted people to hear about their educational experiences, in whatever manner they wished to share their voice." One finding was that there is "… a common desire for students with learning impairments who wish to emphasize their similarity, rather than

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their difference to others." Pivotal to this point is the degree to which each teacher makes students feel differently from or similar to their peers. For instance, the art teacher provides additional time and flexible ways in which assignments can be produced. Other teachers either cannot or will not, although it is sometimes difficult to discern which is the case. Holland notes, "The extra time and alternative teaching practices required to ensure Kelly can comprehend appears to be sacrificed for the learning of the rest of the class, indicating a more neo-liberal, cut-throat approach to teaching." Here, the author brings up the increasing globalization of education as a commodity. The competitive market has multiple implications for citizens who are less capable but require more money to be educated. This clash of discourses provides the backdrop for Kelly and Cody's educational experiences, and is related to the disturbing instances of bullying. Interestingly, and directly related to the previous chapter, both students see their teacher aides are a good fit, "… [they] felt that their teacher aides greatly shaped their education experiences. Without them, both agree that their educational opportunities would be severely limited." That said, their inferior education compared to nondisabled students suggests forms of attrition exist within schools—ranging from subtle to blatant—that are, by and large, still under the radar and tacitly accepted. As Holland concludes, "Kelly and Cody's voices demonstrate the gap between what is a sufficient education for a 'normal' child and a child with a hearing impairment or other disability may be exceptionally wide and seemingly unjust."

In *Inclusive Education in Bangladesh: Stumbling Blocks on the Path from Policy to Practice,* Masud Ahmmed's contribution connected to DSE's intention to "promote social justice, equitable and inclusive educational opportunities, and full and meaningful access to all aspects of society for people labeled with disability/ disabled people" (AERA, n.d.). The chapter widens the discussion so far to encompass perspectives from countries beyond the "Western World." At the same time, however, we see how *many* patterns resonate around the world, as successful inclusion "depends on the willingness of teachers and factors such as infrastructural adequacy, prejudice and skills in addressing special needs." Incidentally, this point was prevalent in numerous presentations on inclusive education at the World Education Research Association held in Edinburgh, Scotland in November of 2014, featuring studies from diverse locations as Belgium, China, Iceland, Italy, and Nigeria. Ahmmed's research questions were straightforward and of interest to us all, including: (1) What are your views about the inclusion of students with diverse needs/disabilities in the regular classroom? (2) How confident do you feel in teaching students with special needs/disabilities in regular classrooms? Additionally, other questions were posed about support needed, factors as to why schools include or exclude, and potential barriers. The work recognizes inclusive education as a social responsibility *and* also portrays the reality of educators in Bangladesh. On respondent shared, "Our class time is only 35 minutes. How can I handle those children [having special needs] with extra care alongside 60 to 70 other [students without disability] within this [short] time?" Indeed, it is clear

that even for the most empathetic teacher a combination of overcrowding, lack of knowledge about disability, and no additional adult support makes them ask: How much can a single professional realistically do? The proposal of an adviser/educator/supporter to counter a "disability unfriendly environment" is well taken. In addition, it is imperative that "the old ways" of society's response to disability be changed, so begging is not the only choice (or most lucrative future) for disabled children, replete with connotations of social hierarchies, charity, pity, and ultimately the association of disability with a devalued life.

Peter Walker's *The Privileging of 'Place' Within South Australia's Education Works: A Spatial Study,* like many other chapters in this volume, relates to DSE's practitioner support of "Disability and inclusive education" (AERA, n.d.). Like the work of Burke, Walker's focus is on the significance of space and its production of social meanings. In brief, he explores what do certain spaces *signify*, particularly in relation to educational establishments, and educator understandings of human difference? He evokes the notion of three spaces: the real, the imagined, and the "3rd space" – an interaction of the previous two, purposefully used as a conceptual place where everyone belongs. Walker's work calls attention to the ironies and (mis)namings present in our field, such as "special education facilities being called 'centers' given that special schooling, and disability in general, exists on the fringes …" The building under scrutiny is The Eyre Center, with architecture akin to a hospital and distinct spatial divisions that signify—and reinforce—segregating practices. Walker culls from the observations of Slee, including the importance of differentiating how we conceptualize difference in the name of inclusion:

> … inclusive education presents challenges to schools that have long sought to homogenize the student body. Building on this, consider that student bodies may be perceived either homogeneously (we are all alike) or heterogeneously (we are all different). In the first instance, inclusion is the instrument 'to make normal.' In the second, there is 'no normal': difference is the norm. (Slee, 2013, p. 11)

Of course "difference is the norm" within DSE's vision of inclusive education. Walker's evocation of space and what is signifies is important for every educator to consider as they configure their own classrooms and have input into the configuration of their educational establishment. He encourages educators to think of themselves (among other things) as "spatial planners and constructors of their own sites… [and] consider deeply the implications of spatially protecting students and how this might ultimately serve to compromise a student's participation and citizenship."

In Amy Claughton's *Choosing Time: Supporting The Play of Students With a Dis/Ability,* the author "challenges research methodology that objectifies, marginalizes, and oppresses people with disabilities" (AERA, n.d.). She is vociferous in her critique of control groups and limited norms within educational research that serve to disable students. Instead, she calls upon what may be perceived as a radical form of DSE. As Claughton explains,

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> The disability studies perspective is enabling, suggesting through its very nature that it is time to stop comparing children when assessing. It is time to stop comparing children with dis/ability, defining their ability in relations to another's ability and acknowledge their independence and agency.

In her view, DSE helps provide her with a framework to critique existing established methods of research and validate new approaches. Claughton challenges the widespread notion that children with disabilities play "inappropriately," asking *according to whom*? She writes, "In using a disability studies lens, we need to question the notion of 'appropriate' play. What exactly does it mean? It seems that…play is an 'able-bodied' concept—something understood and observed only in relation to typical development." Eschewing the mythical norm, Claughton sees play as in *play*, play for fun, play as something organic and natural, spontaneous, pleasurable, exploratory—while presuming competence in the individual child, and recognizing that play helps shape the child's emerging identity. She notes her approach of allowing children to play resulted in greater motivation and engagement that she believes is due to them "being acknowledged as independent, choice making and trusted learners." In line with this, the author challenges the prescriptiveness of the current curriculum in regard to something that is, essentially natural and organic. Claughton cautions, "By redirecting children away from certain types of play, those in power are making value laden judgments on how they should be engaging in play and dismissing the individual agency at achieving their personal goals." In sum, she does a fine job of using DSE as a conceptual framework that fits her study, replete with its reframing from a traditional medical to a social grounding, while advocating for necessary change in how we perceive of children with disabilities and subsequently do research about them.

In *Inclusive Education for the Disabled: A Study of Blind Students in Nnamdi Azikiwe University, Awka, Nigeria,* Bentina Alawari Mathias "adheres to an emancipatory stance … working with people with disabilities as informed participants … not 'subjects'" (AERA, n.d.). This mixed methods study set in the most populated country of Africa provides insights into the experiences of Blind college students, their instructors, and their peers. The theoretical orientation is equity theory, and compatible with the notion that blind students should have equal opportunities with sighted students. Mathias' sentiment is that of DSE, although it is not explicitly named as such. She notes how improved educational opportunities are needed because "… people with disabilities also have invaluable roles to play in national development, and to be able to do this effectively and meaningfully, their education needs to be given proper attention." The study yields interesting findings, such as 11% of able-bodied faculty respondents thought blind students should not be in same classroom as "… they distract the class by asking too many questions thereby making the lecturer to be slow in teaching to enable them benefit from the teaching." In contrast, all blind students interviewed preferred inclusive education vs. specialized school placements (though they saw the value of learning Braille,

learning to type, and how to use their walking stick, all of which they had learned in a special school). Like the previously discussed works of Burke and Holland, the chapter featured voices of disabled students who share their unique knowledge an experiences. For example, one student stated, "When people see you as a blind person, they avoid you, they don't help you when they need help. So in order to make good friends, I pay for most of the services I receive," while another shared, "Our reading materials: the tapes, recorders, brail, Brail machines and typewriters are all very expensive. Most of us cannot afford them." Here we see the realities of blind African college students in negotiating a world that routinely marginalizes and excludes them.

The multiple authored chapter titled *Managing the Barriers in Diversity Education that We Create: An Examination of the Production of University Courses about Diversity,* witnessed the power of perspectives when a doctoral candidate from Bangladesh, veteran teacher over 40 years experience, a parent of child with autism, and a doctoral student in field of autism were united in their interest of researching a diversity course they all taught for first-year university students. Barbara Garrick, Satine Winter, Mahbuba Sani, and Lynn Buxton's collaboration resulted in a provocative piece that raised many questions about the place of disability in diversity curricula. As such, the piece resonated with the DSE approach to practice, namely "Disability culture and identity as part of a multicultural curriculum" (AERA, n.d.). One of the authors expressed a deep desire to see DSE featured throughout the university, "Her [Buxton's] years as a Head of Special Education have reinforced her desire to see diversity and disability studies break the bounds of the field of special education and faculties of special education to become mainstream and part of teacher training courses." Interestingly, the authors sought to actively reshape the conceptualization of, and therefore teaching of, autism from a social model perspective, despite formidable challenges. They note, "The ideas that lie around our views of disability and diversity are open to contestation by powerful forces that control the agenda." That said, they actively sought to "trouble the diagnosis through arguments that the disorder exists primarily discursively and has been talked into being each and every time regulatory norms are used to shape and define the diagnosis." In doing so, the authors critique the meaningfulness of assessment courses in relation to understanding human diversity, such as the label of autism. They know that statistical analysis and the reduction of individuals to numbers is not "real." Garrick et al. focus on their peer who has a child with autism, commenting, "… the scores *told her nothing about what the first year course achieved for the preparation of pre-service teachers and her child*." The authors raise many important points in this chapter, one of them being the inadequacy of a mathematization of human complexities. Another is their observation that "The control and quality agendas override the equality agenda," referring to the deprofessionalization of educators by the constant imposition standardizing knowledge under intense surveillance. The scripted curricula prompted one author to lament the relentless reductionism within standardization, leaving her to conclude, "I could be teaching about cabbages!" It

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is with great irony that the authors reveal how the new curriculum on diversity has actually contradicted itself and exacerbated inequalities, leading them to advocate for a more rights-based approach to including disability as diversity.

Gill Rutherford, Leigh Hale, and Denise Powell's chapter "*We Put a Few Ramps in Here and There, That's About It:" The Need to Ramp Our Minds in Academia* is related to the DSE advocacy of practice in which "Disability is primarily recognized and valued as a natural part of human diversity" (AERA, n.d.). They begin with a triumvirate of quotations from college students that read like blows to the stomach: (1) "Of course you'd terminate a pregnancy if test results indicated Down syndrome—why wouldn't you?"; (2) "Those kids [labeled disabled] are not my problem," and; (3) "Yeah, we use the word *retarded* all the time with our mates—I probably wouldn't say it in front of someone who has, though." The prevalence of ableism in all college students, including future educators, is always astounding and clearly illustrated in these three statements. In their quest to dismantle the hegemony of normalcy, the authors seek to "ramp our minds" in academia. Rutherford et al.'s objectives were to explore topics that are of general interest to everyone who works in universities: (1) To understand and describe identified good teaching practice that raises the awareness of disability in general, and; (2) To provide recommendations of how teaching and learning activities could be to enhance awareness of disability issues via both content and accessible delivery. Their findings captured the importance of values and beliefs of lecturers, specific practices for student engagement, barriers to the inclusion of disability matters as an integral part of university studies, and possible ways of addressing these issues. Importantly, the authors also provide a useful heuristic of heart (values), head (disposition), and hand (practical skills) that allows faculty members to engage themselves in a reflective manner with disability issues. One participant shared how he encourages "… thinking beyond what's habitual and normative. We want them to think, to not assume the normative all the time … you're always thinking critically about the ordinary assumptions." In sum, it is a *must* for university educators to rock the boat, think out of the box, and cross established lines of understanding. A second professor-participant conveys the potential of thinking flexibility, commenting, "I changed for the one and it improved the three hundred." In sum, Rutherford et al. rightly raise questions about the responsibility of higher education, leaving us to ponder what will be each university's legacy as a result of how disability is taught in its courses and practices, conveyed through the dispositions of all faculty members?

In *A Mother Caught in Two Worlds: An Autoethnographic Account of a Mother's Mindset and Perception when Teaching Her Son with Asperger's to Drive,* Ruth Cornell's poignant account of her relationship with her son fits with DSE's claim that we "assume competence and reject deficit models of disability" (AERA, n.d.) . This chapter reveals a the emotion-laden, compelling voice of a mother in describing her child's transition to a young adult through the act of independently driving a car. At the same time, the narrative parallels her own increasing awareness of the need

to transition from deficit-based assumptions about disabilities to one that presumes competence. She writes,

> I was so ashamed that I had failed my son as a mother and teacher because I was too caught up in his diagnosis. The 'Asperger's label had made me over-analyze the situation, and prohibited me from allowing him to show me what he could do. I felt like such a bad mother.

The fact that her son kept his sunglasses on when in a tunnel was his choice, his comfort level, his identity, his decision, *not hers*. Cornell is left to conclude, "My son was not a replica of myself." Having realized this, she shares, "Suddenly, I didn't feel as though I needed to analyse his every move. Instead, I allowed him to plan independently what he was going to do," concluding, "After all, that is what he would have to do if he was in the car without me." As a result, her son's meltdowns were reduced, their relationship improved, and he drove with self- assurance. While a simple narrative, arguably conveying the universal parent-child negotiation of autonomy, this chapter conveyed the importance of parental understandings of strength-based understandings of a child in context, as opposed to DSM-5 deficit-driven characterizations.

Lye Ee Ng, Stefan Schutt and Tim Corcoran's *Technology Use and Teenagers Diagnosed with High-Functioning Autism: In and Across Differentiated Spaces,* "recognizes and privileges the knowledge derived from the lived experience of people with disabilities" (AERA, n.d.). The authors note that 89% of research in autism is related to diagnosis, prevention, and treatment, emphasizing the medicalized framing of disability while neglecting ways in which living with autism can be enabling, and in keeping with a DSE orientation. In addition, they note a lack of research worldwide into adaptive uses of technology for youth with autism. To counter this, the authors study technology in "The Lab" as key to exploration and education, allowing youth with autism to inhabit multiple virtual worlds as different characters with view to researching their engagement and creativity. They write, "By examining The Lab, we begin to understand that the extension of the self through technology does not occur in isolation but rather, flourishes in specific contexts … impacting the identity of youth with high-functioning autism." Indeed, The Lab serves as a safe space for youngsters with Asperger's Syndrome. Within it, they "… make highly sophisticated and multifaceted use of online technology to augment their sense of self and belonging, in ways that even their parents may not understand." The multiple spaces created in a technological spanning of time zones creates a form of "multifaceted socialization," a third space (echoing the principle also used by Walker in this volume) that opens up possibilities for new ground, new knowledge, new ways of creating, exploring, interfacing, and socialization. The success of The Lab has spawned fourteen replications throughout five Australian states, and the work of Ng, Schutt, and Corcoran contributes to the few research studies that have been done that "examined the social use of digital technologies by young people with autism." Of note is the participants' sense of belonging

and eagerness to participate and create—characteristics that are absent in clinical descriptions of Aspergers.

In *Signifying Disability And Exclusion: Tales From An 'Accidental Activist,'* Mary A. Burston's story is DSE-centric as it "contrasts medical, scientific, psychological understandings with social and experiential understandings of disability" (AERA, n.d.). Burston engages with the discourse of mothers as "…meddling… interfering… overprotective…" believing she has no resort other than to help her son make sense of, and confront a system that systematically blocks his requests to continue his education after a prolonged medical illness. Given that it was impossible for him to sit, stand, or travel, a request for access to online work appeared reasonable. However, fighting for access causes Burston to question the sincerity of the university's claims to inclusive practices and student diversity. She writes, "Fears of expulsion in the later stages of the degree brought into focus whether the core value of inclusivity and diversity promoted by the university were meaningful." Burston reframes her thinking from requests pertaining to accommodations into one of a disabled person's *rights* to an education. Furthermore, in an interesting twist, she contrasts society's general valuing of athletic bodies to its devaluing of disabled ones stating, "I raise the question of whether students with disability are treated *on the same basis* as elite student athletes." By doing so, she illuminates the reproduction of state hegemony in that certain bodies are preferable "physical specimens that reflect the nation's self-image," and argues persuasively for the need of everyday activists in the form of the disabled and their allies to advocate for inclusion.

Kim Davies's chapter *A Troubled Identity: Putting Butler To Work On The Comings And Goings Of Asperger's Syndrome* illustrates the following example of practicing DSE in theory as it "engages work that discerns the oppressive nature of essentialized/categorical/medicalized naming of disability in schools, policy, institutions, and the law while simultaneously recognizing the political power that may be found in collective and individual activism and pride through group-specific claims to disabled identities and positions" (AERA, n.d.). This proved to be a fascinating foray into troubling the paired concepts of Aspergers and ab/normal body by utilizing the theoretical work of Judith Butler to contemplate the performativity of disability and the ontological integrity of "disabled embodiment." All of this made more interesting because Asperger's Syndrome was recently removed from the DSM-5. Davies describes the discursive construction of Asperger's Syndrome being based on a mere 10 clinical case studies between Asperger's study in 1944 and Wing's 1981 resurrection of his original idea. The author deftly included the popularization of Asperger's within public media, illustrating this phenomenon with many examples including Mark Haddon's *The Curious Incident of the Dog in the Night Time* (Haddon, 2003), and the runaway success of *The Big Bang Theory* (Cendrowski, 2007-) on television. However, it is the clinical authorization by the American Psychological Association and its subsequent legitimization through the clinical process that makes Asperger's "real." Of particular interest was the description of a 5-year-old child being discursively constructed within a clinical

meeting, "… subjectified and now embodied a pervasive developmental disability, of unknown cause and uncertain, contentious 'cure.'" Of course, to complicate matters, the identity of Asperger's Syndrome have been adopted by "aspies" who assert they are a breed apart and cast themselves in affirmative ways that reject the DSM-5 description (see, for example, www.wrongplanet.net), and in the process cast aspersions about being "normal." The chapter does raise many important points, including the observation how the DSM-5's purposeful withdrawal of Asperger's Syndrome was strategic:

> Regardless of the rationale, it is a sociocultural significant move, especially given the industry and commerce—'scientific' and cultural—that Asperger's Syndrome has generated. Massive future profits have seemingly been sacrificed in order to reign in a diagnosis that seems to have taken on a life of its own.

The label of Asperger's, therefore, that initially shored up clinical authority proved troublesome when a more articulate Aspie community "spoke back" and troubled unquestioned notions of normalcy.

In *Attending to the Potholes of Disability Scholarship,* Ben Whitburn's piece is a prime example of the DSE approach to research in that it "includes disabled people in theorizing about disability" (AERA, n.d.). His work can be characterized as both rich in metaphor and narratives. Whitburn also directly acknowledges the "formidable" work of reconceptualizing disability as human diversity rather than abnormality or aberration. Although he respectfully invokes Julie Allan's thoughts about DSE being an escape route from special education, he notes, "… 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 with potholes can only get you so far." The potholes he speaks of can also be seen as gaps, dangerous spots, pockets without solid matter. Regardless, they all are reasons to mend, fill in, overlay, complete, or simply build a new road from scratch.

Like several other authors in this volume, Whitburn's work features a strong autoethnographic strand in which he shares his experiences as a child and as an adult. For example, he values the teaching of Braille as special education service and brought him literary skills. Simultaneously, his time in mainstream classrooms exemplifies *exclusive* practices within what are, on the surface, inclusive situations. He notes, "Stories like mine … are useful. They signify change in the construction of knowledge and the possibilities for research, by offering evidence from the inside of social and political struggles." His relationship with his friend Jack, for example, highlights the absurdities and inadequacies of systems in which provisions are not thoroughly thought through. Although Jack could read Braille, and had a laptop with Braille reading software, he had not been taught computer skills.

Inclusion, Whitburn believes, is akin to cooking the traditional Spanish dish of paella in which mixed ingredients become amalgamated, simmer over time, thus generating a flavor and form that is, for the most part, quite organic. Whitburn

writes, "… while the mixing of diverse ingredients takes a little coaxing at times, the task is not nearly as monumental as we might think." I tend to concur, often asking myself: why have we made such a simple idea like inclusion become so difficult? After all, as Doug Biklen points out in *Including Samuel* (Habib, 2008), "Families do it all of the time." In his travels to Spain, Whitburn notes how the Spanish focused on the notion of equality for all, and were used to "… sharing everyday, mundane experiences of inclusion." In sum, the author argues for the need to address the potholes by filling them with actual substance because "superficial and symbolic actions alone will not advance any cause."

Julie White's *A Hidden Narrative: Reflections On A Poster About Young People With Health Conditions And Their Education* is chapter that is worth pondering because she struggled to make sense of indifference shown to the topic of health and disability compounded by its format as the only poster at the DSE conference. I would match this work with DSE "Cultivates interdisciplinary approaches to understanding the phenomenon of disability, e.g., interfacing with multicultural education, the humanities, social sciences, philosophy, cultural studies, etc." (AREA, n.d.) with the caveat that it is partly located in the field of rehabilitation, and arguably medicine. After careful consideration as to what should be in the poster and its painstaking assemblage (text, images, color, layout) the author felt underwhelmed at the response to it at the DSE conference noting, "our poster … stood alone and remained isolated at this conference." However, White saw beyond her disappointment and confusion to explore possibilities as to the audience's indifference.

The topic of the poster itself was children with health issues such as "…diabetes, organ transplants, stroke, Crohn's disease, scoliosis, anorexia nervosa, chronic fatigue syndrome and immune system disorders." White's main point was that students with health conditions were growing in number and needed to be included in disability discourses. In order to do this, they had to stand apart to be recognized—hence the topic, hence the poster. And yet … it did not achieve its intention of engaging conference participants. Why? White makes the astute observation that "Health related disability received little attention and can often be the afterthought or the odd one out, rather like the conference poster." She is, indeed, correct. There has been an underrepresentation of health related issues and disability within DSE, quite possibly to disability studies challenging of the medical model as the primary understanding of human difference. However, not to ignore that the *physically painful* manifestation of disability is important, as has been recognized by critical disability studies scholars such as Shakespeare and Watson (2001). There must be a balance within DSE; we cannot throw the proverbial baby out with the bath water. I believe there is room for specific medicalized disability issues while negotiating disability studies' general rejection of the medical model having the monopoly of understanding disability. After all, somebody experiencing pain is likely not interested in primarily seeing it as a social construct. White also asked, "whether the academic culture of the DSE conference was not accustomed to poster presentations?" This is largely true; very few DSE conferences have had posters. At the same time, she also wonders about

the content within the poster format, stating "… the poster lacks a story and it lacks a heart … the poster became a technical, rational, factual and dull communicative device." I posit that audience indifference was likely a confluence of several things: illness related disabilities of being (unfairly) taboo within the discipline of disability studies in DSE; the audience expectations of an ostensibly "clinical" topic within a formal format, and; inadvertently being positioned as the "outsider" lone poster. More importantly, White's chapter reveals a "pothole" within DSE that needs to be addressed in better ways than it has been to date.

In *Thinking About Schooling Through Dis/ability: A DisHuman Approach,* Dan Goodley and Katherine Runswick-Cole's work evokes several examples of DSE in practice because it "Recognizes the embodied/aesthetic experiences of people whose lives/selves are made meaningful as disabled, as well as troubles the school and societal discourses that position such experiences as 'othered' to an assumed normate," and, "Disabled students are supported in the development of a positive disability identity" (AERA, n.d.). *Dishuman* is an initially odd sounding and intriguing concept articulated "… to explore how disabled children's lives are enabled and limited by their construction as simultaneously both 'different from' and 'the same as' other children." The authors counter the fact that within research, children's lives have been told in ways that cast them in an unfavorable light. The use of "dis" in front of many established categories calls the normativity of these very categories into question. For example, "DisChild" emphasizes the ability while "attending to the presence of disability and the opportunities that creates for rethinking." This chapter is an outgrowth of Goodley and Runswick-Cole's previous work in which they champion "… the possibilities for disabilities to trouble, re-shape and re-fashion traditional conceptions of the human (to 'dis' typical understandings of personhood) while simultaneously asserting disabled people's humanity (to assert normative, often traditional, understandings of personhood)" (Goodley & Runswick-Cole, 2014, p. 1). In this particular piece, they utilize insightful and informative descriptions of classrooms replete with vignettes and examples of typical occurrences, all the while troubling the usually unarticulated norm.

Goodley and Runswick-Cole question the premise of inclusion as the ability to perform in certain ways noting, "To be included, you have to match up to standards of achievement and behavior expected of the 'majority.'" However, the authors see the value of focusing on children who do not fit the mold, as such children challenge schools to examine their current practices that are often, simply put, discriminatory. The authors write, "One way we might think of disabled children's impact on educational contexts is in terms of their disruptive potential. Disabled children often demand places such as schools to rethink their priorities, their usual modes of operation and their cultural foundations." In sum, they note that being DisHuman, being DisChild, "Being 'same, but different' offers up a challenge to school communities to respond." Ultimately, I find their work quite intriguing as they call attention to longstanding problems in new ways, with an emphasis on *community* in resolving these problems.

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G(R)O(W)ING FORWARD GLOBALLY

This "Afterword" chapter ended up quite longer than I originally intended because it was hard not to do justice to each of these distinct works that contribute to the growing body of DSE literature around the world. In many ways, these writings are examples of continuing and expanding the issues raised within DSE books such as *Disability and the Politics of Education: An International Reader* (Gabel & Danforth, 2008) and South Asia and Disability Studies (Rao & Kalyanpur, 2015), and articles such as *Cripping the Curriculum through Academic Activism: Global Exchanges to Reframe Disability and Education* (Connor & Gabel, 2013). While interest in and use of DSE is growing globally, it is important to be explicit about what it means so that audiences can begin to see there are other options to conceptualize, frame, and respond to real life issues related to education and disability, options that are outside of the default of special education. In particular, the authors from Bangladesh and Nigeria, perhaps new to DSE, conveyed the tenets and sentiments of DSE, including both researchers casting inclusive education as a social responsibility. However, we must continue to mention, explain, and/or describe what DSE is to *potential readers,* otherwise we risk what happened to us in the US, namely DSE was becoming co-opted by special education—thereby defeating its initial purpose of being an independent entity.

A major theme running throughout much of the research in this volume is that no matter where in the world, there is often philosophical agreement that inclusion is generally the right thing to do—yet is hindered by inadequate conditions, overstretched teachers, lack of financial support, and entrenched ableist values and beliefs. My closing thought is a simple one. Let us remain working together across borders as we continue to learn from each another in a common effort moving forward to dismantle barriers, reduce prejudice, and create systems of education that are fair to everyone.

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