– ARTICLE –

EMBODIED SPACES, COSMOPOLITANISM AND CORPOREAL DIVERSITY

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ABSTRACT

Drawing on my experiences caring for my disabled son and views from the parenting/disability blogosphere, this article illustrates a second-person phenomenology of disability. Parents' lived experiences of disability and the embodied knowledge they acquire through intimate acts of caregiving provide important insights into the diversity of human embodiment and the Othering practices that foreclose our capacity to connect with and understand others. This article shows that the act and experience of caregiving opens new possibilities for engaging with the world and others. Through their participation in online communities, parents come together around their shared moral orientation to making the world more inclusive of human difference, generating cosmopolitan spaces of care.

Keywords: caregiving; embodiment; disability; phenomenology; activism

INTRODUCTION

Parents' experiences of caregiving offer second-person insights into disability, that is, insights into the inner lives of their children and a sense of how they experience the world around them. In this article, I draw on my experiences of caring for my atypical son and views drawn from the parenting/disability blogosphere to illuminate a second-person phenomenology of disability and related notions concerning corporeality, personhood, relationality, interdependency, affectivity, and moral cosmopolitanism. I include a consideration of perspective and the various ways we are sensorially enmeshed in the world. I also consider the ways in which atypical human beings become Other to those who take for granted the way they inhabit the world. The messy entanglements of bodies, practices, representations, senses, emotions and affects produce, and are produced in, overlapping and often conflicting spatialities and realities. Within

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the dynamic of these ephemeral spaces, embodied experiences and cultural constructions of impairment collide, often producing or revealing important embodied knowledge around caregiving. Online forums and blogs are drawn upon in this chapter as cosmopolitan spaces and communities that transcend national borders. These spaces bring caregivers and parents together, across geographic distance and other categories of difference, around their similar experiences of caregiving and shared commitments to an inclusive reality for all forms of embodiment.

PERSONHOOD AND CORPOREAL DIVERSITY

Conceptions of what it is to be human are important. Not only do they affect the ways we relate to others, but they influence our ideas of what constitutes a meaningful existence. This section interrogates the ableist assumptions often underpinning notions of personhood by highlighting different embodiments and the care relationships we are embroiled in.

Modernist notions of 'normal' are defined within the parameters of liberal individualism and its core principles, such as self-governance, autonomy, self-determination, and progress (Thompson 1997). Consequently, those who depart from such principles by virtue of perceived or corporeal differences are differentiated from the general population and cast as abnormal, subhuman. Those who are dependent on others for their daily care, therefore, unsettle core constituents of personhood framed and recognised on the basis of normative independence.

Underlying much of the anthropological research on parents' experiences raising atypical children is the notion that parents and intimate others can contribute to public understandings of corporeal difference and diversity through the intimate knowledges, emotions and values constructed through caregiving. Rapp and Ginsburg (2011) have considered the ways parents and intimate others have taken their insights garnered from caring for atypical children beyond the home to transform public understandings around 'life with difference' (p.383). Rapp and Ginsburg focus on 'cultural innovators' – parents who creatively go about reshaping schools, diagnostic categories and media representations to accommodate difference. These parents illustrate the possibilities for enacting change and setting about, what anthropologists Raspberry and Skinner (2007) call 'renorming the normal'.

In her ethnographic work with mothers of children with disabilities living in New York, Landsman (2009) documents the complex ways mothers reconstruct

motherhood and the meanings surrounding disability. Landsman sees the knowledge that mothers acquire through their caregiving practices as a rich resource for the general public's understanding of difference and personhood. She posits that through everyday acts of caring, mothers come to discover and establish their child's personhood (Landsman 2009, 211). By veering away from notions of personhood and 'normality' that venerate and confer worth according to principles of self-governance and autonomy, Landsman suggests that personhood is established through our relationships with others. This resonates strongly with Kittay's (2001) call for a social ontology based on an ethics of care and a recognition of our 'nested dependencies' and 'the distinctiveness of our particular human relations to others and of the world we fashion' (p.568).

Reflecting on his experiences caring for his wife, Kleinman (2010) says 'caregiving is among those usually hidden pro-social activities of everyday life keeping the world going' (p.18). Childrearing, facets of marriage, and the infirmities of old age, according to Kleinman, all involve asymmetrical relations and dependency, of various kinds, on other persons. As such, the aforementioned liberal predicates and conditions of personhood are insufficient because they do not adequately reflect dependency relations that pervade life, nor are they, as Kittay (2013, 4) emphatically states, 'conceptually commodious enough to encompass all'.

A popular online blogger known by the *nom de plume* Single Dad captures the value of caregiving and the importance of considering relationships when thinking about personhood when he writes:

> I am my daughter's primary, if not sole, caretaker. I am the only one who dresses her in the mornings and gets her ready for bed at night. I bathe her. I wipe her butt when I change her diaper. I hold her when she is seizing. I laugh and cry with her. She is my life. (2009a)

The intimacy born from the unrelenting responsibility and vigilance required of caring for children in need of constant supervision is of a unique experiential order. As Kelly (2005) has documented in her ethnographic work, parents not only become agents of their child's personhood to the wider world but interpreters and experiencers of impairment also. Similarly, in her ethnography on parents of children with autism, De Wolfe (2013) examines the multiple ways parents come to identify with autism through their multiple engagements with the autism label within particular spaces at different times; foregrounding both the shared and variable properties of parents' experiences around autism that give their lives meaning. De Wolfe illuminates the ways the autism label

is employed by parents to organise their experiences, for example, through storytelling, and the power labels wield in creating emotional bonds through a shared sense of what it means to be an autism parent. According to De Wolfe, these uniquely felt autism experiences serve as a platform for parents to come together around their similar experiences, engage in educative practices, and enhance the efficacy of their advocacy efforts. This resonates with my own interest in online support groups as cosmopolitan spaces where parents come together to share and discuss 'differences that matter' (Jenks 2005, 153).

A key assertion within cosmopolitanism rests on assumptions of a pan human universality that are analogous to liberal doctrines of personhood. Cosmopolitanism is predicated upon cultural openness and impartiality towards others, and assumes a global commonality beyond categorisations and identity politics. Kantian inspired cosmopolitan ideals, wherein persons are viewed as equal, moral, autonomous and rational constitute these shared capacities that inform understandings of a universal form of embodiment. However, the caregiving relationships described by Landsman, Kittay, De Wolfe, and Kleinman poignantly illuminate the reality of diverse embodiments and the importance of our affective ties and commitments to others. If we look at caregiving descriptively, then, in terms of what concrete caregiving entails and how it is experienced for families providing care, the embodied, situated, and emergent features of relational selfhood become central to understanding the significance of care and its articulation in moral life.

Despite the diversity of experience among caregivers, through concrete practices of care, cosmopolitan spaces may be produced around universal commonalities and a unified purpose. Participation in online communities, for example, may constitute a cosmopolitan project of a global moral conversation around the universal value of difference, the moral worlds constructed through dependency relations, and the ways moral agents in various socio-political contexts inadvertently contribute to ableism and oppression. Parents' collective efforts, from geographically distant places, enact a cosmopolitan agenda of creating a more inhabitable world inclusive of different forms of embodiment, and a sense of a 'global-network-as-community' (Wardle 2010, 385). These spaces are often used as a platform by carers to highlight the different way their children inhabit the world and act upon those around them through alternate forms of agency that emerge through embodied interaction.

Prejudices and negative attitudes toward non-normative ways of being are manifest and perpetuated through a number of social and cultural rituals, practices, discourses, and ideologies. Not only do they pose barriers to social

inclusion for those with impairments and, by extension, their families, but they may work to deepen the experiential chasm between parents' lived reality and social reality. Solomon (2014) suggests that perhaps the most insidious form of stress arising for parents raising an atypical child is 'the social isolation that can ensue when friends retreat, or when parents withdraw from their friends' pity or incomprehension' (p. 363). To illustrate how those with 'impairments' and their families encounter ableist attitudes and practices on a daily basis, I offer a few examples from my personal experiences.

During an election period quite recently an internet meme depicting Homer Simpson frozen in a spastically contorted manner with the caption 'Look Marge, I'm Australian Politics' propagated in social media networks over a period of weeks. Following this, American singer-songwriter 'Weird Al' Yankovic released a song called 'Word Crimes' (2014) which contains the lyrics, 'Saw your blog post, It's really fantastic, That was Sarcastic (Oh, psych!), 'Cause you write like a spastic'. These two examples capture the pervasive, insidious nature of ableist representations and stereotypes that work to produce and reproduce prejudices and unjust power relations by ridiculing or inciting disdain for those who occupy a different way of being. As disability studies scholar Tremain (2014) writes in response to Yankovic's lyrics, the 'motivational assumptions of the video are much more damaging than any one of the offensive words that he chose to use' (para. 3).

In addition, there are innumerable covert representations that objectify persons with disabilities by sensationalising their stories for the benefit of providing inspiration to the non-disabled majority. This is referred to by Young (2012) as 'inspiration porn'. Moreover, these kinds of representations inadvertently marginalise persons who are simply not able to conform to such inspiring corporeal standards.

For instance, on a recent current affairs program (Noonan 2012), a father and his young son who was born with quadriplegic cerebral palsy were featured. The story was framed around the medical profession's underestimations of a father's love and determination. An intense weekly schedule consisting of a variety of intensive therapies, orchestrated by the boy's devoted father, assist the boy in 'overcoming the odds' and standing for the first time. This milestone is followed by several more with the boy eventually learning to walk and talk.

Two years after the birth of my own son, this story (and its follow-up) wielded significant affective influence on my own experiences as a father, as I received calls and advice from well-meaning family members who had watched the

program, telling me of my son's potentialities and the possibilities born from some patience and tenacity. While this moving story captures a compelling bond between father and son, what troubles me most is how this story genre perpetuates a moral imperative to 'fix' one's child, and supports the idea that an individual's worth is contingent and predicated upon ideals and practices surrounding autonomy and conformity. But, in a more immediate sense, it was hurtful. It made me feel that by not adhering to this cultural script of 'overcoming the odds' I was a failure and had somehow failed my son. Perceptions like these are alienating and not only presume a homogeneity of disability but of people's experiences surrounding it.

In studies that address impairment, and in disability studies more broadly, little attention has been given to those whose ontological way of being precludes them from engaging with cultural apparatuses for translating their experiences of impairment and disability. I depart from normative realities that derive from the discourses of social institutions, or that are constructed on the basis of dominant typical modes of being, and offer an alternative explanation based on my interactions with my son and the interpretations of others' experiences. I begin by discussing two of the multiple ways bodies are enmeshed and interact with the world: neurological diversity and sensory enmeshment.

NEUROLOGICAL DIVERSITY

Within the domains of cognitive neuroscience and psychology, the social impairment associated with individuals diagnosed with autism spectrum conditions (ASC) is positioned within the mind (Baron-Cohen 2008). The neuro-typical majority are used as standards of comparison, to which those who are differently disposed are measured and subsequently pathologised as neuro-deviant. Treatment plans by various occupational specialists are often devised on the basis of correcting the social 'deficits' that individuals with autism express in their behaviour, an undertaking that is viewed by many in the neurodiversity movement as being steeped in the prejudices of neurological essentialism (Ortega and Choudhury 2011).

The neurodiversity movement has sought to redress these normative perspectives by asserting that all neuro-minorities are part of the vast spectrum of human diversity. In doing so, neurodiversity activists draw on the same language and strategies used by other civil rights activists and proponents of diversity that have been muted and peripheralised as the 'Other' due to regressive hegemonic understandings of the body and difference (Baker 2011). However, as Solomon (2014) notes, most activists within the neurodiversity movement

do not deny the importance of biology – hence, the neuro prefix – but seek to challenge the meanings assigned to biological differences (p. 281). This approach has been coined, 'neurocosmopolitanism' (Walker 2014) as the unified efforts of those within the neurodiversity movement aim to bring about more tolerant societies concerned with furthering the well-being of all members of the human community.

A neurological approach to understanding various dispositional affordances is an important one. As Oliver Sacks (1995) has illustrated through his work, alternate conditions of the brain tell us a lot about the nature and diversity of human perception and experience. Through caregiving for my son I have come to learn about his sensorial world and how this affects his experiences and actions in the world. Therefore, to complement understandings of altered selves and worlds, I turn to a somatic-oriented consideration of the sensorial worlds bodies inhabit.

SENSORY ENMESHMENT AND OTHER MODES OF BEING

According to Maurice Merleau-Ponty (1962) the body and that which it perceives could not be separated. In writing about our experiences of the world, Merleau-Ponty writes, 'it appears to us in so far as we are in the world through our body, and in so far as we perceive the world with our body. … the body is the natural self and, as it were, the subject of perception' (p. 184). In this sense, embodiedness provides individuals with a specific perspective on and way of being in the world. Therefore, ruptures in reciprocity and understanding between interactants are not only the result of neurological and social disjunctures but also involve bodies and physical environs. Thus, our differently embodied experiences and relation with others and the world derive from neural, corporeal, and environmental structures and processes.

Sensory information and the ways it is processed form the bedrock of our perceptions, behaviours and learning. They are constitutive of our connections, experiences, and understandings with others and the world. Sensory input; tactile (touch), vestibular (balance), proprioceptive (spatial positioning and movement), visual (sight), auditory (sound), olfactory (smell) and gustatory (taste), while dynamically interconnected, underpin the overlapping spatialities and realities that we inhabit. Examining the senses moves us closer to understanding how unique realities emerge from our sensorial enmeshment.

For example, atypical vestibular[2] processing produces a reality in accordance with the effects of certain movements and activities, and in congruence with

one's understandings and feelings associated with movement and gravity. Similarly, auditory senses attuned to an assortment of sounds, near and far, soft and loud (or somewhere in-between), may invoke certain responses and aversions that will determine how one comes to experience their surroundings, and thus influence what activities are suitable or perceptually manageable on a day to day basis. This invites us to think of multiple bodily modes of engagement. Specifically, the peculiarities of bodies and the different perceptual modalities from which the world is disclosed.

In his 1839 story *The Fall of the House of Usher,* Edgar Allan Poe describes the corporeal reality of his character, Roderick Usher. In doing so, Poe illustrates the ways our behaviour and temperament hinge upon our physical conformation and sensorial enmeshment in the material world, and the realities that emerge through these lived sensorial engagements. Thus, of Roderick Usher:

> He [Roderick] entered, at some length, in what he conceived to be the nature of his malady. It was, he said, a constitutional and a family evil, and one for which he despaired to find a remedy. … It displayed itself in a host of unnatural sensations. … He suffered much from a morbid acuteness of the senses; the most insipid food was alone endurable; he could wear only garments of certain texture; the odours of all flowers were oppressive; his eyes were tortured by even a faint light; and there were but peculiar sounds, and these from stringed instruments, which did not inspire him with horror. (Poe 2011,10)

Like Poe's Roderick, those with atypical sensory processing often report, or are observed to display, a host of sensory peculiarities. Those with the capacity to verbalise their feelings often describe their sensory peculiarities in cross-modal ways. For example, I recall one child describing an audio-tactile type of[3] synaesthesia where listening to his mother sing produced the sensation of pins prickling his flesh from the inside out. As such, the sensory world of coffee machines, lawn mowers, chatter, laughing, light, shade and colour, sounds from the radio and TV, various textures, smells, tastes, and movements comingle in various ways, producing different embodied sensations and understandings of the world.

For instance, my son cannot handle crowded or mildly busy public spaces. It is impossible to eat out or to even have cup of coffee while in his presence. His audio hypersensitivity coupled with any kind of dynamic social activity set him in to, what can only be described as, panic. This state of being is manifest in his writhing and wiggling, as he attempts in vain to overcome the disruption and

restore some equilibrium. Discussing her own sensory atypicalities, Temple Grandin (2011) has likened her sensitivity to loud noise to the pain one might feel when a dentist's drill hits a nerve. She elaborates, 'I still dislike places with confusing noise, such as shopping malls. High-pitched continuous noises such as bathroom vent fans or hair dryers are annoying … certain frequencies cannot be shut out' (Grandin 1992, 106).

In contrast, beach visits offer a vastly different sensory experience for my son. He will sit contentedly on the sandy shore as small waves break over his legs. I feel as though he would be quite happy to sit there the entire day, gently paddling the shallow surf with his hands and squeaking intermittently, in what is an expression of unbridled and immense joy. It would appear that the wide-open space, the sun's warmth, the cool ocean water, and the gentle and rhythmic hum of the surf provide him with solace and calm, a place to be.

In summary, our corporeality provides an important context for understanding our sensory perceptual experiences and modes of engagement with the world. Furthermore, our corporeality provides a common constitution and a shared horizon that structures our experiences of the world. The common fact of our corporeality, however, should not limit recognition of unique ontological ways of being predicated upon neuro-psychological and physiological distinctions. This is a particularly important approach when attempting to understand the phenomenologies of those who are non-verbal or non-communicative. While these particular sensorial experiences are not always communicable by those with atypical sensory processing, parents' and primary caregivers can offer an access point to understanding atypical ways of being from the knowledge that is generated through their embodied acts of caregiving.

THE RELATIONAL EXPERIENCES OF PARENTS

Kelly (2005) writes about impairment as an emergent property of the inter-subjective and intercorporeal worlds those with impairments inhabit. The first years of adapting to this new reality are arguably the most daunting for parents. This can often be an overwhelming and stressful time, as parents learn how to deal emotionally with the discordance between what they imagined parenthood would be like and the reality they are faced with. This entrance into an alternative reality for parents is described by Single Dad. Discussing the hardships and marital tensions that emerge as a result of parenting a severely impaired child he writes, 'we come to the situation with no experience, no basis of reality … both spouses are thrown into … a life-changing monumental situation' (Single Dad 2014a).

For parents, nurturing and representing a child considered 'abnormal', physically or behaviourally, can lead to profound realisations of the concerted efforts required to push the pliable boundaries of certain social spaces in order to accommodate one's child. Landsman (2009) and De Wolfe (2013) have both discussed the tensions that arise from interactions between parents and various institutions. These tensions can be seen to wax and wane as parents learn to navigate the social spaces controlled and maintained by diagnostic procedures, therapies, regimens, stigmas, etc. (De Wolfe 2013, 12). Over time, parents may find some semblance of equilibrium in their lives as they become more familiar with what their child needs[4] and how to navigate certain social spaces. For some, the sheer unpredictability of their child's behaviour and practical needs will make securing such a footing that much harder to achieve.

Those who do experience this grounding sometimes find themselves in a favourable position to take the embodied knowledge they have accrued through caregiving beyond the home to challenge commonly held cultural perceptions around 'normalcy' and humanity. These activist efforts by parents and intimate others have proven to be efficacious in changing legislation and policy, reforming the material and relational spaces where diverging realities intersect, improving service provisioning, and reformulating understandings in both public and medical/scientific worlds. I now share a few of my own and other parents' stories to illustrate not just what parents come to know through caregiving, but, also, how they come to know.

EMBODIED KNOWLEDGE AND EXPERIENCES OF CAREGIVING

Online communities offer a shared space where repertoires are located. Through online collaborative engagements, parents are afforded the opportunity to tell their stories, exchange information, discuss problems, negotiate meanings, and share various strategies related to parenting and caregiving (Lave and Wenger 1991). For instance, it was through my participation in an online community that I learnt how to taper off my son's anti-seizure medication. Contrary to the generalised and lax recommendations offered by his neurologist, the online community provided useful bits of advice and a careful strategy for reducing his dosage, while minimising the adverse side effects associated with the drug. In this particular instance, the primacy of medical scientific knowledge was subverted in favour of the knowledge and strategies learned by parents from carrying out the day-to-day tasks of caregiving. The particularities around caregiving that arise within local worlds intersect with a global community of parents and bring forth cosmopolitan caregiving practices.

Online communities offer a salient medium for socially engaging and connecting with one's horizontal community. These emergent cosmopolitan spaces are characterised by members' collaboration, mutuality, respect, a concern for social justice, and personal growth. Through these context-specific practices, caregivers are linked to cultural Others by way of shared experiential and existential experiences. They exemplify spaces of cultural convergence where intercultural connections are made around the intimate and particular experiences of one's life. These can be described as moral communities (Komito 2010) that are strengthened through parents' emotional and ideological commitment to creating a reality that validates and advances the rights and well-being of all kinds of embodiments. As Gerard Delante (2009, 88) notes, cosmopolitanism 'resides in social mechanisms and dynamics that can exist in any society at any time in history where world openness has resonance'.

Building relationships with parents – who may be from different settings but feel united by the commonality of their experiences – can aid in warding off the negative feelings arising through experiences of societal alienation and disconnection. Therefore, these groups offer not only an important forum for having one's experiences as a parent validated, but for countering the hegemony of ableism and validating the alternative embodiments of one's children. Furthermore, participation in these communities may provide an important outlet to anonymously express the joys and grievances surrounding caregiving that those in one's local world may not understand.

Writing about how he will never witness the milestones and accomplishments that often accompany normative parenthood, Single Dad (2014b) laments:

> It hits you out of nowhere. You think all will be ok, at this point you can handle anything. Bullshit. Like an unexpected left hook, life just crashes. . . . I will never die having seen my child get a diploma. Lots of people die in that situation. It was not my plan. Not my hope. Not my dream. I will never walk my daughter down the isle [*sic*]. Never be proud of her accomplishment.

In the same blog he continues, 'And no, it's not about . . . not loving what I have, what they are, and if you think that is what is about, well fuck you too' (Single Dad 2014b). Rather than suggesting that caregiving is experienced as a burden or a joyless endeavour, these experiential accounts point to the kaleidoscope of emotions that arise through multiple interwoven forces, and their part in the production and reproduction of embodied knowledge.

Drawing on his own embodied experiences of caregiving, Kleinman (2009) writes about the strength and determination required of those responsible for assisting others in their daily practical activities. He writes, 'It can divide the self. It can bring out family conflicts. It can separate out those who care from those who can't or won't handle it. It is very difficult' (p. 292). Kleinman's account not only foregrounds some of the experiential conditions that make caregiving difficult, but illuminates the under-recognised human conditions of dependency and interdependency. Recognising our web of connections with others, and the value of caregiving to society speaks to our shared human emotions, affective connections, needs and aspirations, and so to the humanitarian aspects of cosmopolitan activism. Furthermore, in capturing the complexes of emotions and difficulties born from caregiving, Kleinman is writing about how experiences that puncture our illusion of order and control often bring an understanding of what matters most to us, such as our intimate relations with others.

Attending to these embodied experiences of caregiving helps shed light on how caring knowledge, practices, habits, and sentiments are cultivated and contoured. Recounting a morning in her kitchen at breakfast with her atypical daughter, Kittay (2001) poetically describes the dance between their bodies that ensues as she negotiates a kiss, one of the many sensuous moments that she emphatically states fills her life with meaning and pleasure (p. 567). Kittay (2002, 239) writes:

> What makes life worth living or what makes a life a good life; what makes relationships ethical, what personhood is; how to understand beauty, anomaly, function, capacity; joy; what justice and equality are. I have always, to some extent or other, seen philosophy as refracted through my experience with Sesha.

Parents who come to find themselves nurturing a child who, as disability scholar Asch (1998, 77) describes, 'departs from what is understood to be species typical', may find deep resonance in the critical anthropological ethos 'we can be other than what we are' (Hage 2011, 11). Through these caregiving experiences an affective stock of embodied knowledge accumulates, enhancing one's empathetic imagination and capacity to care for and about others (Hamington 2004). This is certainly evident among those parents who make brave sacrifices for their children and reorient their lives towards making a more accommodating world. Narratives of personal transformation figure strongly in the stories parents tell about their experiences raising children with disabilities and are a prominent theme in the relevant scholarship (for a review, see, Knight 2013). What is less often focused on, however, is the ways affective spaces shared with others con-

tribute to our flux of experiences over time. The interactive spaces that I move through with my son are inseparable from the range of emotions that colour my experiences caregiving. The next section will attempt to demonstrate this, with reference to my own experiences and the interactions that have given my reality their particularity.

AFFECTIVE SPACES OF CAREGIVING

Ontological invalidations are perpetuated and reified through a number of exclusionary and discriminatory attitudes and practices manifest in forms from the more overt, to the subtle and subtextual. I suggest that these moments in time work to deepen the experiential chasm parents feel between lived reality and social reality; one predicated on parents' ongoing experiences and the knowledge, beliefs, and values that emerge through the embodied acts of caregiving, set against the struggles for inclusion and acceptance in a context that perpetuates practices and values based upon one dominant mode of being.

Social devaluations of a child's embodied difference may be experienced by parents in the form of what Goffman (2009) calls 'courtesy stigma'[5], or more directly as a personal slight or indignity because of the strong closeness parents establish with their child through the emotional and practical dimensions of caregiving. Arguably, these demoralising moments are most acutely felt when a child's corporeality or behaviour fails to meet normative expectations and, therefore, becomes the subject of detached interest or scorn.

For example, some time ago I visited the post office with my son. In the centre of that noisy room he clamped his hands down over his ears and began squealing loudly. A lady waiting in line ahead of us glanced back at him, clicked her tongue, and then moved her hands over her own ears. She remained that way until she was served and allowed to go on her way. The moment hung in the air with a weight so hefty that the moments stopped piling on top of one another.

Of course, to some, this fleeting moment may seem relatively benign, nonetheless, it served its purpose of making me feel uncomfortable and added to my anxiety about running errands in public with my son. It is one of many exclusionary measures adopted at an interactional level and directed towards those with impairments and their families to guard and maintain protocols surrounding bodily conduct, behaviour and communication in various social spaces. As Goffman (1963) has noted, these rules establish what can be expected in certain social contexts and therefore maintain social order.

Hughes (2007, 678) writes, 'Impairment is the vantage point from which disabled people see the world and how the world responds. Their intersubjective and inter-corporeal experience is marked, ubiquitously, by "felt" processes of socio-ontological invalidation'. Similarly, by association, parents' caregiving experiences may be marred by these sorts of invalidations. As Landsman (2009) has noted with impairment, the ways it is constructed, experienced and evaluated is always situated within a cultural context. The blogosphere is replete with stories from parents that attest to the isolation and rejection experienced through these social encounters and devaluations.

In a recent article, Sarris (2015) writes about the fear and discomfort that children with ASC elicit in strangers through their display of atypical behaviours, such as not responding to others, hitting, screaming, hand flapping, or hurting themselves. Citing sociologist David E. Gray – who has studied stigma experiences of parents with children diagnosed with ASC – Sarris draws attention to the unique quality of parents' experiences arising from parenting a child with ASC who often embodies a 'combination of pervasive disability and apparent physical normality' (Gray 1993, cited in Sarris 2015). As such, according to Sarris, the behaviour of those with ASC is often perceived as highly suspicious and uninformed.

Parents' first (and ongoing) experiences with these sorts of socio-ontological devaluations often unfold within medicalised spaces. Indeed, it is often through medical interactions that parents' embodied knowledge is assaulted or questioned through normalising ideologies. Accordingly, through medical knowledge's sway of power and legitimacy, and its naturalising and reductionistic tendencies, a child's relevance and idiosyncratic relationship to the world is often ostensibly called into doubt by medical practitioners and other specialists. Without parents' knowledge of a child, clinicians and specialists offer only streamlined treatment and management of a child based on distant and short clinical encounters.

Parents' 'felt' ontological invalidations of their children may not always spring from a particular kind of performance or explicit verbal interchange with medical specialists. Often, a range of muted signals and tacit understandings imbue our interactions with meaning and contour our experiences, as illustrated by one of my recent visits to the neurologist's office:

> Sitting in a chair opposite my son's neurologist always makes me
> feel uneasy. Although he has treated my son regularly since his first
> seizure almost four years ago, I still feel like a stranger sitting in his

> office; as though I'm in some sort of permanent transitory state. His demeanour is warm and his interactions with my son are almost grandfatherly, in fact, they make me beam. Yet, our own interactions, which usually assume the form and rhythm of a question and answer session, always feel static, uncomfortable and rehearsed. My son, sitting on my lap, watches him peripherally – his typical way of using his vision – and smiles big. It's contagious, I'm smiling and watching for the neurologist's   response. Then, after a brief moment of locked gazes, he asks, 'Is he talking at all yet?' I shake my head, completely caught off-guard. His face drops, 'Oh'. (Journal entry, April 2014)

In speaking of the 'reeling present' of affective intensities that animate the everyday, Stuart (2007, 1) writes about the value in paying attention to 'the forces that come into view as habit or shock, resonance or impact', and the often unanticipated thoughts and feelings they make possible. Affects pervade the everyday and the disparate scenes our lives are composed of, much like my depicted visit to the neurologist. They traverse and inhabit encounters and the spaces where something is happening, giving moments in time a layered texture and bringing to life rhythms and tensions, freedoms and constraints, resonances of opportunities lost and found (Stuart 2007). For me, this visit to the neurologist engendered a depressive lethargy that persisted for days. It is not an over-statement to suggest that the embodied sensations that emerge in affectively charged spaces wield immense influence over the ways atypical parenthood may be experienced over time.

By considering the affective intensities that traverse the disparate scenes of parents' lives we are better able to consider their continually shifting experiences that are turbulent and paradoxical, fleeting and enduring, and resistant to closure. This exposes the shortcomings of studies that try to unify parents' experiences into an experiential trajectory, highlighting the fluidity and contingency of parents' experiences and subjectivities.

Moreover, parents' experiences, as represented by online blogs and De Wolfe (2013) and Landsman's (2009) studies, hint at the interactive link between parents' interactions and their experienced realities. For example, realities that diverge from the normative order may emerge in relation to some interactions, such as when parents engage with other parents online or interact with their children's bodies during various daily routines. Conversely, normative notions and practices may impose constraints on interactions, such as when parents visit clinicians, limiting the possibility of experiencing different realities. In this way, cultural forces can be seen to pervade interactions, contouring the

particular qualities of parents' experiences. Notwithstanding, parents may also challenge cultural ideas through their interactions, and contribute to reinventing interactive spaces.

These interactions highlight the intercorporeal and intersubjective dimensions of impairment and parents' experiences. Locating parents' experiences and understandings of corporeal diversity between conflicting realities and spatialities both reminds us of the depth, complexity and fluidity of experience, and points to a chasm where knowledge, beliefs and practices are produced and reproduced through the struggles to reconcile seemingly incongruent ways of understanding impairment, and what it is to 'be' human.

CONCLUSION

As those in caregiving relationships so often clearly demonstrate, the liberal dictates of autonomous personhood are insufficient in accounting for those who occupy divergent ways of being and who are dependent on others for care. They overlook the variety of dependency relations in society, and the interdependence, closeness, values, and meanings that may arise through caregiving relationships. In this chapter I have examined the senses as a means to discuss other ontological modes of being by considering the multiple ways bodies are enmeshed in the world and the realties that are disclosed, produced, and Othered through these modes of being and engagement. I speak to the notion that the 'cosmos is composed of multiple perspectives residing in different kinds of bodies' (Pederson 2011, 62).

After all, the senses are, for all of us, the building blocks for experiencing and understanding the world around us. This challenges us to rethink the experienced realities our intersubjective gaze is bound up in, and to more thoughtfully consider the social spaces we occupy, and our practices within those spaces. This resonates with a cosmopolitan form of activism that recognises human unity by virtue of our differences.

Addressing parents' relational experiences of impairment not only provides insights into the contestations and negotiations that occur at the intersections of competing realities, but it also reveals detailed and complex embodied knowledge that is produced as an outcome of these experiential disjunctures. The knowledge acquired through caregiving is conceptual, practical and affective. These experiences are felt and responded to within psychological and emotional domains, while also being socially and politically contingent. Online communities are important cosmopolitan spaces that connect parents from

geographically diverse settings around their similar experiences of caregiving, and ward off feelings of societal isolation and disorientation. One could argue that it is the act and experience of caregiving itself that turns caregivers into moral cosmopolitans. It is this moral cosmopolitanism, established through caregiving and one's resonance with difference, that becomes a part of the shared experience and support that caregivers offer each other.

Notably, the knowledge that these experiences engender often productively unsettle dogmatic distinctions between mind/body, self/other, independency/dependency, and reality/appearance that work to perpetuate and sustain certain realities. It is often the case that the ambivalences and inconsistencies born from these overlapping and contested spatialities and realities assist in revealing what matters most, and the possibilities of more accommodating and commodious realities – even if they are only hinted at through the interstices of disruption and turbulence. Indeed, by straddling these conflicting realities I have come to learn what Solomon (2014, 700) describes as 'the terrifying joy of unbearable responsibility'.

NOTES

1   Aaron J. Jackson is a doctoral candidate at the University of Melbourne in Australia. His current work examines the experiences of parents in the U.S. who are raising children with disabilities.
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2   The vestibular, tactile and proprioceptive systems provide key information; giving meaning to what is seen by connecting visual information with movement and touch (Ayres, 2005).

3   Synasthesia is described by Olga Bogdashina (2003, 119) as an 'involuntary physical experience of a cross-modal association', i.e. the stimulation of one sensory modality *triggers* simultaneous experiences in *one* or more *other modalities*.

4   Separating the needs of one's child from one's own needs is not unproblematic. However, as Solomon (2014, 678) notes, even where parents of typical children are concerned there are instances of ego confusion; wherein the line between helping one's child realise their dreams and trapping them into realising your own are sometimes blurred.

5   According to Goffman (2009, 30), courtesy stigma may ensue by association; wherein an individual who is in a relationship with the stigmatised may be

treated by wider society in the same respect.

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